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The REFINEMENT glossary of terms: An international terminology for mental health systems assessment

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TITLE PAGE

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The REFINEMENT glossary of terms: An international terminology for mental health systems assessment

ABSTRACT

Comparing mental health systems across countries is difficult because of the lack of an agreed upon terminology covering services and related financing issues. Within the European Union-project REFINEMENT, international mental health care experts applied an innovative mixed "top-down" and "bottom-up" approach following a multistep design thinking strategy to compile a glossary on mental health systems, using local services as pilots. The final REFINEMENT glossary consisted of 432 terms related to service provision, service utilisation, quality of care and financing. The aim of this study was to describe the iterative process and methodology of developing this glossary.

KEYWORDS

Mental health systems; international comparison; psychiatry; glossary; international terminology.

BACKGROUND

International comparisons have become a key issue in health services research in complex areas such as health systems (Cacace et al. 2013), long term care services (Salvador-Carulla et al. 2013), and integrated care (Wodchis et al. 2015). A common consensus-based terminology is necessary for making meaningful international comparisons to aid in improving health, strengthening health systems and providing essential health for all (WHO 2007). Comparability is also relevant in order to assess transferability of the evidence-base for health policies and practice among countries. European health researchers are therefore constantly engaged in bridging gaps and fostering understanding between health specialists from many different cultures and languages by developing standardized terminologies. This is in line with the World Health Assembly's resolution adopted in 2008 (WHA 2008). Previous examples in the field of medicine and life sciences include the SNOMED CT (Systematized Nomenclature of Medicine Clinical Terms). Launched in 1975, this is now the most comprehensive, multilingual clinical healthcare terminology in the world (Schulz et al. 2009). It was a joint development between the British National Health Service (NHS) and the College of American Pathologists (CAP). This initiative was followed by the development of the International Health Terminology Standards Development Organisation (IHTSDO), also known as "SNOMED International", to produce an international common clinical language for healthcare.

Arriving at a consensus-based terminology for mental health care is particularly challenging. Mental health services have changed dramatically in recent decades with the development of a wide array of new types of services moving the focus of care from hospital to the community (Chow and Priebe 2016; Fakhoury and Priebe 2002). Different approaches have been used worldwide (Priebe et al. 2008; Becker and Kilian 2006; Johnson et al. 2000; Johnson et al. 1998), and comparing and studying mental health services across countries and health care systems has become challenging, not the least because of the lack of an agreed upon terminology covering service provision, service utilisation, quality of care and financing. The definition of concepts and terms in mental health care is

highly complex and changes over time (Proctor et al. 2011), and needs substantial timely feedback and consensus by experts (ECT 1998).

In this vein, in recent years there has been a growing demand for developing a standardised terminology in mental health care (Bramesfeld et al. 2016; Killaspy et al. 2016; Muijen 2012; WHO 2004). For instance, the WHO Assessment Instrument for Mental Health Services (WHO AIMS) has provided some definitions of different elements of mental health systems, including indicators of mental health services (WHO 2005), and a number of mental health policy-related glossaries have been published (Spaeth-Rublee et al. 2010). Several recent European projects and initiatives have provided grounds for a consensus-based terminology on mental health care. These include, among others, the Mental Health Economics European Network (MHEEN) (Knapp and McDaid 2007), the European Network for Mental Health Service Evaluation (ENMESH) (2017), the Roadmap for Mental Health Research in Europe (ROAMER) (Haro et al. 2014), and the Description and Evaluation of Services and Directories in Europe for Long-Term Care (DESDE-LTC) (Salvador-Carulla et al. 2013; Salvador-Carulla et al. 2011). Other similar projects aimed at health in general have noted the importance of achieving a more common terminology, such as the European Health Care Outcomes, Performance and Efficiency project (EuroHOPE) (2017), the EuroREACH project to improve access to and use of healthcare data and to enhance cross-country comparisons of health system performance (2017), and the BRidging Information and Data Generation for Evidence-based Health policy and research project (BRIDGE Health) (2017).

Yet despite these initiatives, harmonized terminology for planning, resourcing, management, financing and delivery of mental health services has not been produced. This lack of commonly agreed terminology in the literature is largely due to several factors: (1) the complexities of mental health care systems that hamper international comparison; (2) the difficulty of agreeing upon comparable units of analysis at macro- (countries, regions), meso- (catchment areas) and micro-levels (individual service types); and (3) the wide variability in the terminology of services and programmes even in the same geographical area, and the low usability of listings of services by their

mere names alone (e.g. “day hospital”, “day centre”, “social club”), since the service names do not necessarily reflect the actual activity performed in the setting (Salvador-Carulla et al. 2011).

The quest for a common terminology then faces the difficulty of establishing cross-societal equivalence of concepts and names of services as they may have different meanings in different countries. So, in order to compare a service or a structure across countries it is then necessary to have confidence that their components and properties can be compared and do indeed indicate something equivalent (Johnson et al. 1998). This equivalence of meaning is not necessarily obtainable through translation. Conceptual equivalence also requires intimate knowledge of context and culture (Salvador-Carulla et al. 2015). Finally, concerning mental health care financing issues, standardized terminology is needed in order to compare different financing systems and their potential effect on quality of care (Toth 2016; Wendt, 2009).

In order to fill the above described gaps, within the European Union-funded project REFINEMENT, we developed a glossary of terms covering mental health care services, their utilisation and quality, and related financing issues. This study describes the process and methodology used to develop this glossary aimed at (1) producing a comparable terminology for countries with different cultures, languages, health and social care systems, and (2) deriving recommendations for future work in similar fields.

Method

The REFINEMENT project

This study was part of the European Commission Seventh Framework Programme ([FP7/2007-2013] [FP7/2007-2011]) REFINEMENT project (REsearch on FINancing systems’ Effect on the Quality of MENTal health care – project number 261459, www.refinementproject.eu), where the provision, pathways of care, quality and financing of mental health care were to be compared across eight European countries (Austria, England, Finland, France, Italy, Norway, Romania and Spain), and involving the use of eight languages (English, Finnish, French, German, Italian, Norwegian, Romanian

and Spanish). The study included the analysis of national and local data in eight catchment areas: Industrieviertel (Federal State of Lower Austria); Hampshire including Portsmouth and Southampton Unitary Authorities (England); HUS - The Hospital District of Helsinki and Uusimaa (Finland); the Loiret Department, hosting seven sectors of psychiatry of the Georges Daumézon hospital (France); Verona Mental health Department (Italy); Sør-Trøndelag (Norway); Jud Suceava (Romania); and Girona Health District (Spain).

The REFINEMENT project ran for three years (from 2011 to 2013) and its final output was the REFINEMENT DECISION SUPPORT TOOLKIT (REFINEMENT Group 2014a) including four tools, a manual with guidelines on how to use the tools, and the REFINEMENT glossary comprising all the English-language terms and definitions from the tools and the manual. The four REFINEMENT tools were: (1) REMAST (REFINEMENT Mapping Services Tool) for collecting information on services and their geographical distribution; (2) REPATO (REFINEMENT Pathways Tool) for collecting information describing the typical and most common pathways of care for people with mental health needs in the adult population; (3) REQUALIT (REFINEMENT Quality of care Tool) for collecting information on the performance and outcomes of care for people with mental health needs; and (4) FINCENTO (Financing & Incentive Tool) for collecting information on regulations, funding and payment mechanisms. All original tools are available online (REFINEMENT Group 2014b).

The REFINEMENT glossary

An experienced team of 67 members with two different profiles, i.e. 12 researchers (list available in APPENDIX A) and 55 field workers (i.e. staff who applied the REFINEMENT tools, collecting and collating data from local services providing mental health care), from different backgrounds (health economics, mental health services research, health planning, health decision and policy making, sociology, modelling and statistical analysis, geography, public health, psychiatry, psychology, nursing and social care) from the eight REFINEMENT countries were brought together and led by the

coordinator of the REFINEMENT project, the University of Verona (Italy), under the specific responsibility of the first author of this paper (IM).

In order to produce the REFINEMENT glossary, the team was asked to collect, list and define terms corresponding to four groups of mental health care terminology: service provision (group A), service utilisation (group B), quality of care (group C) and financing (group D). The team opted for a collaborative method, trying to move to a common definition which could satisfy all other colleagues, and then discussing and voting (if needed) on the optimum definitions. More precisely, the team engaged in an iterative design thinking process lasting 36 months. Design thinking is a problem-solving strategy driven by a repetition of three major steps as shown in Figure 1: brainstorming (step 1), prototyping based on pragmatism (step 2), and selection of best elements (step 3) (Bernstein 2011). Following this multistep strategy, the commonly used "top-down" approach of creating and revising glossaries through the theoretical work of expert committees was combined with a "bottom-up" approach consisting of experiences gained through "on the ground" field work in the eight partner countries.

<Insert Figure 1 about here>

The three steps in the construction of the REFINEMENT glossary

All three steps to build the glossary were conducted by means of face-to-face discussion by partners in project meetings, conference calls and e-mails. During the iterative brainstorming phases of step 1, the 12 researchers in the team completed preliminary "top down" listings of terms from existing glossaries identified through a scoping review on mental health service provision and utilisation (groups A and B). In addition, preliminary definitions and related indicators were provided for each of the identified terms. A scoping review methodology was used in order to pragmatically map the key terms and concepts to include in the glossary. When listing such terms, the 12 researchers also provided preliminary definitions and related indicators. Search terms and the search strategy were developed and discussed among the 12 researchers. The researcher leading on the development of

the glossary (IM) reviewed examples of the literature and refined the selection of studies. Multiple databases were searched for published literature (i.e. Medline via Pubmed, Google Scholar, the Cochrane Library, PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, and SocINDEX), complemented by searches on key organization websites and snowballing with hand searching of references lists. Quantitative, qualitative research and grey literature were included. Grey literature was deemed useful since it provided information from expert practice knowledge ("top down" approach) and expert experience knowledge ("bottom up" approach) (Salvador-Carulla et al. 2014). It included papers, reports, technical notes or other documents produced and published by governmental agencies, academic institutions, professional associations, organizations and groups (Lukersmith et al.2016). Thus, by means of meetings and regular exchange by e-mail and phone calls, a unique common scoping review was performed under the coordination of IM.

Step 2, defined by the design thinking strategy as "prototyping based on pragmatism", involved all 67 team members and consisted of the identification of additional terms and definitions to integrate into the REFINEMENT glossary. At this stage, terms on quality of care and financing in particular were identified (groups C and D). A "bottom-up" approach was used through feedback from the use of preliminary versions of the REFINEMENT tools in the eight local health areas of the participating countries. Researchers collected ground level feedback from all 55 field workers by means of short written reports in the form of a three-column table. The first column reported the term in both English and local language, the second column contained suggestions for term definition in both English and local language, and the third column reported any additional commentary in local language concerning the real, pragmatic use of the term. While the final glossary was to be produced in English, translations and back-translations of terms and concepts had to take place in the eight partner countries with eight different languages. Researchers from the team centralized all reports received from field workers at the regional and national levels and merged them in a unique harmonized document containing a single table with all inputs in English language only. Researchers

were then asked to send the final harmonized document to the glossary coordinator (IM) who collated and compared all tables.

Step 3 consisted of the selection of the most relevant terms retrieved from the collation, analysis, comparison and summary of tables from step 2 for both intermediate and final versions of the REFINEMENT glossary. Each researcher was asked to select and comment on the most important and frequently recurring terms and their respective definitions in tables from step 2. The lists were then sent to IM who was in charge of producing a "total list" of terms by counting the occurrences of all the words (excluding connectors such as "and", auxiliaries, prepositions such as "of" etc.) in a unique text file containing all REFINEMENT tools as they existed at this stage of the project. The lists of the most frequently recurring words in each table received from other researchers were cross-checked and compared with the "total list" through the use of the word frequency counter of a text editor.

Finally, researchers were asked to check for applicability, acceptability, practicality and relevance of the final REFINEMENT glossary. In order to do so, an *ad hoc* 19-items feasibility checklist with a mix of 4- and 5-point Likert scales, yes-no questions and open text-fields was used. The feasibility checklist was adapted from existing feasibility instruments (Salvador-Carulla et al. 2013; Zeilinger et al. 2011; Salvador-Carulla and Gonzalez-Caballero 2010), and included six sections: socio-demographic questions (4 items), questions on applicability (4 items), acceptability (3 items), practicality (2 items), and relevance (4 items), plus a final comments section (2 items). The feasibility checklist is available in APPENDIX B.

All three steps included discussions, review of documents and feedback to the coordinator and approval following the design thinking iterative process. In case of doubt, field workers were furtherly contacted for *ad hoc* consultations by mail or phone.

It was then eventually decided to keep the group of 12 researchers together beyond the end of the project: under IM's leadership, this team would constantly collect new information and answer requests of addition of terms on an annual basis.

Results

Evidence from implementation of the design thinking process to construct the REFINEMENT glossary

For step 1 (months 1 to 20), the 12 researchers in the glossary team were involved in brainstorming sessions during eight meetings: 5 REFINEMENT Steering Committees, 2 Workpackages Meetings, and 1 Dissemination Day (see APPENDIX C). The scoping review was performed through an iterative process involving the exclusion, selection of studies and data extractions. A total of 15 sources were identified and are reported in a Reference list (see APPENDIX D), representing the result of the common scoping review of step 1. The main identified source was the DESDE-LTC instrument (Description and Evaluation of Services and Directories in Europe for Long Term Care) (Salvador-Carulla et al. 2013; Salvador-Carulla et al. 2011) which provides detailed descriptions for coding services for long term care from all relevant sectors (i.e. health and social care, education, employment, drugs, housing and the legal sector). Terms from the DESDE-LTC tool were retrieved to cover types of care other than long term care in order to identify and classify hospitals, mental health care centres, primary health care centres and other services that are relevant for mental health care (including general health services which often provide mental health care such as primary care doctors). Further sources were the ESMS instrument (European Service Mapping Schedule) (Johnson et al. 2000), the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS) glossary (WHO 2005) which has been applied mainly in low and middle income countries, but nonetheless provided some interesting inputs for a general definition of psychiatric services, and the WHO Terminology Information System glossary (WHO 2017). Based on both the brainstorming sessions and the scoping review, the output of step 1 was a first list of 350 terms mainly concerning service provision and utilisation (groups A and B).

During step 2 (months 6-30), through the use of the four REFINEMENT tools on the ground, field workers suggested the inclusion of 50 new terms and definitions, mainly for the topics of quality of care and financing (groups C and D), bringing the number of terms up to 400. The use of the REFINEMENT tools allowed for a practical test involving an intensive process of data collection and

reporting in all partner countries. This resulted in multiple feedbacks. This iterative process involved the development of the REFINEMENT tools, the selection of terms from the tools, the field test of the tools themselves, and the consequent harmonisation of the terms according to the field test. The terms included in the glossary were actually corresponding to the final four REFINEMENT tools: group A for REMAST, group B for REPATO, group C for REQUALIT, and group D for FINCENTO (Salvador-Carulla et al. 2016).

During step 3 (months 20-36), all 67 members of the REFINEMENT glossary team worked on cross-country harmonisation, refining of definitions, and adding terms and new definitions for all four terminology groups of the REFINEMENT glossary. At this stage, the "total list" produced by IM included 464 terms.

Iteratively, the 12 researchers identified 132 synonyms. For instance, "Evidence Based Care" is a main term that has two synonyms: "Evidence Based Medicine" and "Evidence Based Practice". The "total list" containing now 332 main terms and 132 synonyms was circulated among all 67 REFINEMENT glossary team members. The invitation to comment on the list was sent with the aim of examining the relevance of the terms included to the project, the choice and arrangement of words and phrases for each term, and the identification of terms not included in the list. Key and potentially ambiguous terms were also discussed. Unique and approved definitions which could satisfy all eight REFINEMENT country partners were obtained by discussing and voting on the most precise definitions. All critical terms where consensus was not reached were further discussed during meetings (step 1). Several terms needed extended discussions to reach a final agreed upon definition due to ambiguity and significant semantic variability across different countries. This group of ambiguous words included key terms in health care research. By way of example, in Table 1 the final definitions of three terms, "Hospital", "Residential Care" and "Service" which were problematic during the collection and analyses of the REFINEMENT data, are provided.

<Insert Table 1 about here>

The 12 researchers were also asked to do detailed editorial work on the terms and definitions of the glossary. One English mother-tongue member of the researchers' team checked the quality and appropriateness of the language of the glossary. This editorial stage was introduced to assure, in an iterative fashion, that the glossary included all terms and concepts selected for the purposes of the REFINEMENT project.

After the end of the REFINEMENT project, with the finalisation of the data collection and analyses (month 36), the 12 researchers completed an *ad hoc* feasibility checklist. The REFINEMENT glossary fulfilled the criteria for feasibility on all four factors (applicability, acceptability, practicality and relevance). Ratings were best to good, where 1 = "best/highest" and 5 = "worst/lowest judgment". Applicability obtained an arithmetic mean of 1.62; the acceptability average rating was 1.72; the arithmetic mean of practicality was 1.67; and the relevance average rating was 1.71. Overall, the glossary was regarded as very useful for understanding mental health service provision, utilisation, quality of care and financing.

The final REFINEMENT glossary was produced after further consultation with the project participants. In this final phase the number of terms was reduced to 426.

After the completion of the study two additional key terms were suggested by one external reviewer: "case management" and "assertive outreach" with its synonym "complex care team". Definitions of these two terms (plus the new synonym) were discussed by the core group and added to the glossary of terms after reaching consensus by the core group. Three additional synonyms of "integrated care", i.e. "care coordination", "case coordination" and "collaborative care" were also added, bringing the final number of terms to 432.

The structure of the final REFINEMENT glossary

The final output of this iterative process, the REFINEMENT glossary, is available for consultation online (REFINEMENT Group 2014c). The REFINEMENT glossary is 70 pages long, containing all 432 terms: 296 main terms with full definitions and 136 synonyms. All terms are presented in

alphabetical order. The corresponding REFINEMENT tools when all of the 432 terms appear are reported with the following acronyms in brackets: RM for REMAST; RP for REPATO; RQ for REQUALIT; and F for FINCENTO. When terms and definitions were derived from the DESDE-LTC instrument (Salvador-Carulla et al. 2013; Salvador-Carulla et al. 2011), which is part of the REMAST tool, the combined acronym RM-DESDE-LTC is used. In addition to the acronym for each respective REFINEMENT tool, a short plain text describes the related field of interest: Service Provision (group A), Service Utilisation (group B), Quality of Care (group C) and Financing (group D).

Figure 2 shows the proportion of terms per mental health care terminology group.

<Insert Figure 2 about here>

At the end of the glossary, the sources used for definitions are cited. A detailed view of the glossary structure is shown in Figure 3.

<Insert Figure 3 about here>

DISCUSSION

Each country in the world has its own peculiarities in its general health care and mental health care systems. In order to produce valid information on systems of health care, it is essential to compare like-with-like, using the same units of analysis and a common terminology. To the best of our knowledge there is no internationally agreed upon glossary on the financing and delivery of mental health services that existed prior to the start of the REFINEMENT project, either in Europe or further afield. Eight partner countries, selected to represent a broad spectrum of differing systems of health and mental health care, from mainly tax funded (e.g. Italy) to mainly insurance funded (e.g. Austria) systems, participated in the project. These countries cover different European regions including Western and Eastern Countries, as well as Northern Europe, Continental-Middle Europe, Mediterranean Countries, and the UK. Similarly, this study includes countries within different economic zones of the European Union, affiliated countries within the European Economic

Area (Norway), OECD (Organisation for Economic Co-operation and Development) countries plus one Middle Income Country (Romania).

Early in the project it became apparent that one of the main obstacles to working together was the ambiguity and the lack of a common understanding of terms and concepts as defined in existing glossaries, both concerning health care in general and mental health care in particular. It soon turned out that concepts, terms and their definitions in such existing glossaries were insufficient in terms of exactness and lack of comparability, and that a new operational and pragmatic glossary was necessary. The REFINEMENT glossary had to incorporate experience obtained "on the ground" in different partner countries by testing different versions of the components of the REFINEMENT toolkit, i.e. by involving the field workers in a "bottom-up" approach in addition to the classical "top-down" approach using existing glossaries. Similar developments involving field workers are taking place in the domain of implementation research (Goodyear-Smith 2016).

The emphasis of this paper has been on describing in detail the process of developing this glossary, in order to demonstrate the advantages and new insights derived from a combined "top-down" and "bottom-up" approach incorporating experiences, testing and piloting "in the trenches". This approach provided "real life" answers "on the go", which were required in order to apply the REFINEMENT tools and progress on the project. The flexible and dynamic nature of both the glossary and its building process, and the fact that it was developed by an extensive international consortium related to an EU project allowed for further inclusion of relevant terms, and refinement and update of the existing definitions: this is a clear advantage of a "real life" instrument which can be constantly improved by researchers in contact with field workers.

The use of design thinking as a problem-solving strategy proved to have a significant positive impact on the way we developed the REFINEMENT glossary (Bernstein 2011). By gaining an understanding on how the different mental health care systems work within each REFINEMENT country, the glossary was created accordingly. The method here presented has to be highlighted as an innovative

contribution providing a significant step forward in improving consensus and the knowledge-base for conducting research in this area.

Furthermore, while starting from existing concepts and definitions, the necessity to make them work in actually comparing eight different health care systems "on the ground" and to develop and apply tools for such comparisons, helped to identify terminological variability, gaps and opaqueness in concepts and terms. The REFINEMENT glossary also had a practical rationale, being used to answer to questions on defining terms and concepts that popped up continuously when testing interim drafts of the tools in each partner country.

The format of a EU Research Framework project where the European added value of cooperation is crucial, helped to perform the "on the ground approach", and to foster "learning by doing", similar to the well-known but rarely used "Plan-Do-Study-Act (PDSA)" approach (Taylor et al. 2013). Regular conference calls and face-to-face meetings were essential for the hand-in-hand development of the REFINEMENT toolkit and the glossary. Kiivet and colleagues (2013) have stressed the importance of such prolonged face-to-face cooperation in their project (EuroHOPE) on studying diabetes by analysing routine health care databases with different content and structure in different countries. Straßmayr and colleagues (2016) have documented similar experiences in the EU FP7 project CEPHOS-LINK (Comparative Effectiveness Research on Psychiatric Hospitalisation by Record Linkage of Large Administrative Data Sets), where psychiatric rehospitalisation rates were to be compared across six European countries, but where a lack of comparability of existing routine data turned out to be a major obstacle, due to very different routines of definitions and reporting of health service utilisation data.

The step by step approach to glossary construction for mental health care is set out here in order to allow for potential replicability and adaptation for cross country comparisons in other specific areas of health systems analysis. In general, we tried to prove that a glossary of terms is relevant for: improving the knowledge base on a topic; developing assessment tools (to collect data); providing

common ground for data analysis and interpretation; and developing implementation tools such as guidelines.

Limitations

Firstly, the main limitation of this glossary is that it is only definitively applicable for Europe. However, we have included a wide array of different European countries, both middle income and high income countries, with different societal models, and economic levels. It may therefore only require limited adaptation to be used in many high income countries, but this needs to be tested. Further studies will be needed to adapt it to other world regions, taking into account cultural and health systems characteristics and diversity.

A second issue is how an English glossary might positively influence national routines and perspectives usually formulated in local languages, and thus contribute to increasing not only comparability between countries but also to obtaining research results which can be implemented in the country specific health care planning and policy activities. In this project, the resources were limited and did not allow for the development of a multi-lingual glossary. This should be the next step, in order to improve communication in the discussion of health care concepts and terms and their application in health care planning and policy, and the inclusion of non-English speaking players.

Thirdly, a glossary of terms, however comprehensive, is never complete as the meaning of terms varies and new terms are incorporated as the health care systems evolve. In any case this glossary allows for incorporation of new terms. Fourth, harmonization and developing of semantic interoperability with IHTSDO-SNOMED International will be needed in the near future. Further metric testing of this glossary and similar tools will be beneficial with new feasibility analysis by other groups as well.

Conclusion

This study aimed to describe the project specific process of developing a glossary of terms as a possible exemplar for future similar endeavours. While it has become apparent to health care planners and policy makers that one of the main obstacles to assessing health care systems in a reasonable and comparable way is the lack of terminological and conceptual comparability across different health care systems (Salvador-Carulla et al. 2010; Minksy and Llyod, 1996), no good solutions are yet available to improve this situation. A related recent project of the Health and Consumer Directorate of the European Commission is the BRIDGEHEALTH project (2017) which intends to overcome discrepancies in terms and concept to improve comparability of health care indicators across countries. We suggest that this and similar endeavours could profit from the combined “top down” and “bottom up” approach used in REFINEMENT, i.e. repeatedly carrying out data collection in different countries in order to obtain and incorporate feedback in an iterative way to foster the development of glossaries for international comparisons in the health care field.

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Table 1. Examples of controversial terms

HOSPITAL (RM, RQ; Services Type)
In England it is common for most specialist ambulatory and inpatient care services for physical health problems and some specialist services for mental health needs to be delivered in what are known as 'Hospitals'. When analysing the actual structure to which the term 'Hospital' refers to in England, it is clear instead that it refers to secondary care services. In Austria, for such ambulatory care is usually provided outside of 'Hospitals' by single handed specialists in their own private practices. This means that in Austria 'Hospital Care' means just 'Inpatient Care' or 'Residential Hospital Care' [17]. For example, a definition of the term 'Hospital' was only partially reached after 15 years within the European Service Mapping Schedule (ESMS) project [30]. In the original ESMS 'Hospital' was a first level branch descriptor and it referred to those facilities which were registered as hospitals on national listings. From an ontological point of view this was rather unsatisfactory but it allowed for to progress in the development of the system. 'Hospital' is actually a legal term that defines a health meso-organisation (i.e. a care organisation which includes several services within the same location) registered as such in an official listing at national or regional level. This register has legal implications for quality standards and budgeting etc. However the same type of facility may be registered as 'Hospital' in one region of Spain (i.e. Catalonia) and not in a neighbouring one (i.e. Valencia). On the contrary very different organisations with different financial arrangements may be registered as 'Hospitals' in the same region. Therefore the use of the term 'hospital' in WHO-AIMS and also in the System of Health Accounts (SHA 2.0) published by the OECD [31] is debatable. A definition of hospital is provided in the DESDE-LTC glossary and in ESMS-2: 'Hospitals are meso-organisations with a legal recognition in most countries. This legal recognition can be used as the basis for identifying hospital services (registered hospitals). Exceptions are units that have fewer than 20 beds and/or no 24 hour physician resident cover (these should be classified as non-hospital facilities even if they have the legal status of hospitals) –ESMS-2-. In those countries where there is no legal basis for deciding what are hospital services and what are not and where doubt exists, services should be classified as hospital services if they have 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'. When clustering the main types of health care that are categorised in the DESDE-LTC, facilities where the patient stay overnight and where there is a physician on duty 24 hours per day appear on the same branch of this coding tool. We had a problem in the distinction between 'on duty' and 'on call', for instance. In the final REFINEMENT glossary "Hospital Care" was discarded, whereas specific terms like "Hospital in-patient treatment care" and "Hospital" were included.

RESIDENTIAL CARE (RM-DESDE-LTC, RP, RQ; Care and Treatment)
Residential settings have been named internationally in several ways over time, including board homes, intermediate facilities, wards-in-the-community, supervised hostels and apartments [32]. The enormous number of synonyms for the same concept, such as residential care, can sometimes be misleading and generate controversy when comparing different countries' mental health and community care systems.

SERVICE (RM-DESDE-LTC; Services Type)
Umbrella term that encompasses many different units of analysis in service research. At the micro-organisation level of care delivery it describes a combined and coordinated set of inputs (including structure, staff and organization) that can be provided to different user groups under a common domain (e.g. child care), to improve individual or population health, to diagnose or improve the course of a health condition and/or its related functioning.

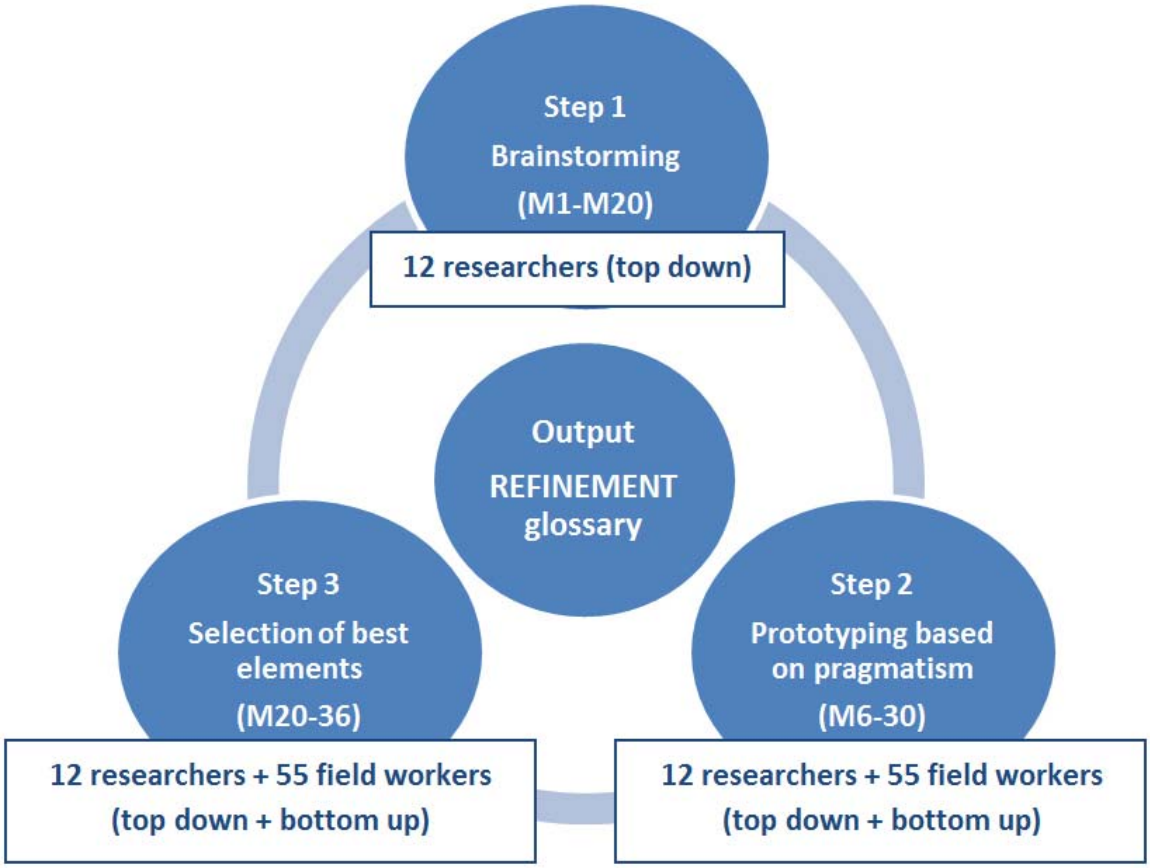

Figure 1. The three steps of the design thinking process to build the REFINEMENT glossary

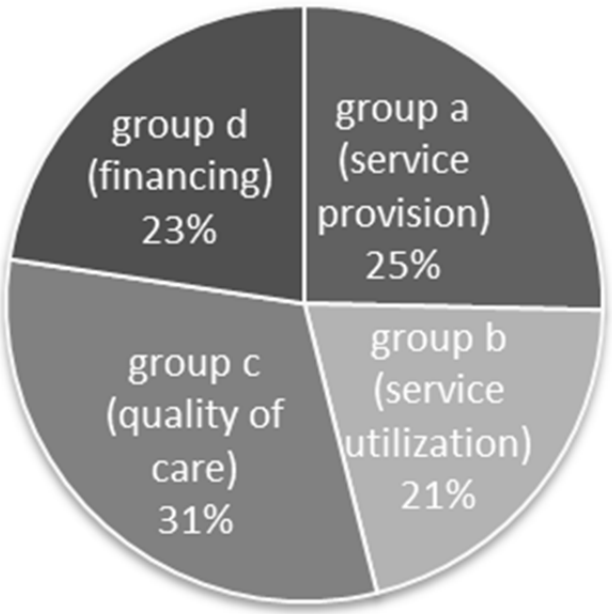

Figure 2. Proportion of terms per mental health care terminology group.

E

Early Detection (RM, RQ; Care and Treatment):

See **Early Intervention**.

Early Intervention (RM, RQ; Care and Treatment):

A process of assessment and therapy provided to young people to prevent developmental disability, delay or detect psychosis.

Effectiveness (RQ; Quality of Care):

The extent to which any service or intervention achieves its intended outcomes in routine settings. If a service is deemed to be effective it has been shown to achieve its intended outcomes.

Efficiency (RQ; Quality of Care):

The capacity to produce the maximum output for a given input to any action or service or given the amount of outputs how to reduce the inputs needed, e.g. including the provision of a service to treat mental health disorders.

Emergency Care (F, RQ, RP; Care and Treatment):

See **Emergency Mental Health Care**.

Emergency Mental Health Care (F, RQ, RP; Care and Treatment):

All those services (e.g. delivered in a psychiatric hospital, psychiatric ward, or **emergency room** (see definition); mobile crisis intervention teams) which provide immediate treatment to both voluntary and involuntary patients 24 hours a day, 7 days a week. In many countries (e.g. Norway, the UK), the general emergency services are also likely to provide emergency services for people with mental health disorders, including for immediate treatment after deliberate self-harm or other suicidal acts. These are typically the first point of entry-which refer the patient to specific/acute psychiatric services.

Emergency Mental Health Treatment (F, RQ, RP; Care and Treatment):

See **Emergency Mental Health Care**.

Figure 3. Detail of the REFINEMENT glossary structure.

APPENDIX A

REFINEMENT GLOSSARY TEAM (12 researchers)

Italy:

- Francesco Amaddeo (Università di Verona - UNIVR) - PhD, psychiatrist and Professor
- Ilaria Montagni (UNIVR) - PhD, health communication and terminology expert
- Valeria Donisi (UNIVR) – PhD, psychologist

Austria:

- Heinz Katschnig (Ludwig Boltzmann Institut für Sozialpsychiatrie - LBG) - PhD, psychiatrist and Professor
- Gisela Hagmair (LBG) - sociolinguistic and research assistant
- Christa Straßmayr (LBG) – sociologist and research manager

England:

- David McDaid (London School of Economics - LSE) – PhD, health economist and Associate Professor
- Tihana Matosevic (LSE) - PhD, health economist

Spain:

- Mencia Ruiz (Psicost) - PhD, psychologist
- José Alberto Salinas (Psicost) - PhD, geographer
- Luis Salvador-Carulla (Psicost/ Australian National University) - MD, PhD, psychiatrist

Norway:

- Jorid Kalseth (Sintef) - PhD, health senior researcher

APPENDIX B

FEASIBILITY CHECKLIST

The aim of this survey is to collect data on the usability of the REFINEMENT Glossary in order to assess its adequacy for its use in practice. This survey is built up around questions to four feasibility constructs: acceptability, applicability, practicality and relevance.

Please go through all questions and answer by stating what your personal opinion is. If you wish to add further comments in response to any question, please write in the textfield. Every question is obligatory. Should you wish not to answer to a specific question, please click “no answer”.

For any possible questions related to this questionnaire, please contact Ilaria Montagni:

ilaria.montagni@u-bordeaux.fr

Filling out this questionnaire will not take more than 10 minutes.

Thank you in advance for your support!

Adapted from

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

A. Sociodemographic Questions		
A.1	Country in which you work within the REFINEMENT project	Austria Finland France Italy Norway Romania Spain England
A.2	Sex	Male/female
A.3	Current profession	
A.4	Do you have experience with other glossaries in the field of mental health? (e.g. WHO-AIMS, DESDE-LTC,…)	Yes No

Please go through the questions below and answer by stating your personal opinion. Thank you!

B. APPLICABILITY **This section assesses the usability of the REFINEMENT Glossary**		
B.1	In your opinion, are the definitions provided by the Glossary useful?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
B.2	In your opinion, are the definitions useful for further processing? If so, please state in which subject areas in the comment field	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
B.3	From your point of view, does the Glossary cover important dimensions?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
B.4	In your opinion, is it necessary to have expert knowledge to understand the Glossary?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:

C. ACCEPTABILITY **This section assesses the easiness with which a user or professional can use the Glossary (user-friendliness)**		
C.1	Are the terms provided in the Glossary understandable to you?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
C.2	Do you think the quantity of specific terms included in the Glossary is appropriate?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
C.3	From your point of view, are the definitions understandable to you?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:

D. PRACTICALITY **This section assesses the degree to which the Glossary can be applied in practice and the level of training required to use the instrument**		
D.1	From your point of view, is the complexity of content (wording and definitions) appropriate?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
D.2	From your point of view, is the Glossary useful in relation to the time and efforts employed in using it?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:

E.RELEVANCE

This section assesses the usefulness of the Glossary

E.1	From your point of view, is the objective of the Glossary evident?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
E.2	In your opinion, are all sections of the Glossary important?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
E.3	From your point of view, does the Glossary serve to allow for a standardised description of the terms used in the Refinement toolkit?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:
E.4	From your point of view, does the Glossary provide useful information for other areas of health care apart from mental health care?	Yes, a lot ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 no, not at all The question is not clear to me ☐ No answer Further comments:

F. FINAL COMMENTS
F.1. Please grade the dimensions of feasibility according to your judgment of their importance (1=most important, 4=least important) Applicability: Acceptability: Practicality: Relevance:
F.2. Are there any basic domains for measuring feasibility missing in this survey? If so please write in the textfield yes no the question is not clear to me no answer

APPENDIX C

REFINEMENT MEETINGS

Scheduling of the REFINEMENT meetings where the structure and content of the REFINEMENT glossary were discussed.

- II REFINEMENT Steering Committee, 9th - 10th March 2011, Jerez.
- III REFINEMENT Steering Committee, 5th September 2011, Verona.
- IV REFINEMENT Steering Committee and General Assembly, 13th - 14th - 15th February 2012, Vienna.
- V REFINEMENT Steering Committee and General Assembly, 14th - 15th June 2012, Helsinki.
- WPs Meeting, 20th - 21st - 22nd September 2012, London.
- WPs Meeting, 3rd - 4th October 2012, London.
- VI REFINEMENT Steering Committee and General Assembly, 25th - 26th-27th 2013, Paris.
- VII REFINEMENT Dissemination day, Steering Committee and General Assembly, 28th - 29th – 30th November 2013.

APPENDIX D

The sources of the REFINEMENT glossary

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