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 [1], long term care services [2], and integrated care [3]. 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 [4]. 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 [5]. 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 [6]. 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 [7,8]. Different approaches have been used worldwide [9-12], 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 [13], and needs substantial timely feedback and consensus by experts [14].

In this vein, in recent years there has been a growing demand for developing a standardised terminology in mental health care [15-18]. For instance, the WHO Assessment Instrument for Mental

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Health Services (WHO AIMS) has provided some definitions of different elements of mental health systems, including indicators of mental health services [19], and a number of mental health policy-related glossaries have been published [20]. 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) [21], the European Network for Mental Health Service Evaluation (ENMESH) [22], the Roadmap for Mental Health Research in Europe (ROAMER) [23], and the Description and Evaluation of Services and Directories in Europe for Long-Term Care (DESDE-LTC) [24,25]. 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) [26], the EuroREACH project to improve access to and use of healthcare data and to enhance cross-country comparisons of health system performance [27], and the BRidging Information and Data Generation for Evidence-based Health policy and research project (BRIDGE Health) [28].

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 [24].

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 [9]. This equivalence of meaning is not necessarily obtainable through translation. Conceptual equivalence also requires intimate knowledge of context and culture [29]. 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 [30,31].

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 [32] 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 (http://www.refinementproject.eu/results.php).

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) [33]. 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) [34]. It included papers, reports, technical notes or other documents produced and published by governmental

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agencies, academic institutions, professional associations, organizations and groups [35]. 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 [2,36-37], 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) [24,25] 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) [10], the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS) glossary [19] 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 [38]. 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 [29].

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 (www.refinementproject.eu/REFINEMENT_Glossary.pdf). 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 [24,25], 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 [39].

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 [33]. 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 [40]. 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 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 [41]. Straßmayr and colleagues

[42] 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 [43-44], 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 [28] 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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