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PhD THESIS

Mental Health in Europe: the need for a common language, standard classification criteria and official communication.

Four studies about communication in Mental Health.

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INTRODUCTION

> “*Ignorance is always more costly than knowledge;*
> *research is essential even in difficult economic times*”
> (Kleinman, 1995).

Among the main objectives of the European Commission's current strategy “Together for Health: A Strategic Approach for the EU 2008-2013” (resolution of 9 October 2008) there is the need to produce and distribute health knowledge. The basic process through which health knowledge is made available and reachable to professionals as well as to general public is “communication”.

Recent years have seen a great evolution and development in Information and Communication Technologies (ICT) concerning health. ICT actually play a strong role in all contests of knowledge and are considered to be essential for ensuring a competitive and sustainable future for the new generations of Europe, as stated by the Commission in its overall strategic objective of prosperity (2008). The Green Paper “Improving the mental health of the population: Towards a strategy on mental health for the European Union” (2005) reports in fact that Information society and Media policy have to support the development of ICT-based tools for use in prevention, diagnosis and care.

In this vein, communicating scientific findings in the domain of health in general and of mental health in particular is crucial. Such a communication process involves both researchers and general audience (including peers, medical staff, policymakers, journalists and general public) and it is actually the main job of scientists today. Effective communication of mental health research can protect the public from being misled and from any form of stigmatization, overthrow previous misinformed beliefs, influence public policy and lead to further progress and clinical applications.

This thesis invites to reflect upon the role of communication and its different facets in mental health research trying to answer the following question: which communication strategies should be adopted in mental health and for which challenges?

The way research results are communicated has a strong impact on the patients' mental health and recourse to treatment. Here we report 4 studies aimed at identifying the real determinants of mental health information provision and seeking.

In Chapter I we describe the importance of communicating the results of the research in mental health taking into consideration all the above-mentioned parties, from researchers themselves to general public, with a focus on the current theories of Translational Research. Communication is at the heart of psychiatry and it can be defined as an assessable and measurable phenomenon but with unclear significance especially when referring to mental health. For this reason, a background on communication theories is also given.

Chapter II analyses the role of communication in international contexts. Research has an international nature and mental health data and information should be comparable across countries in order to be scientifically valid. Two studies (**STUDY** 1 and **STUDY 2**) issued from the European project REFINEMENT are reported as clarifying examples.

Chapter III describes in depth the role the Internet is playing today in providing both information and support for mental health care. Two studies (**STUDY 3** and **STUDY 4**) underline the impact online resources have on teenagers (using the website www.filsantejeunes.com) and university students (from the e-MentH project), thus focusing on the communication about mental health through new media.

Throughout Chapter II and Chapter III, the four studies (**paragraphs 2.2**, **2.3**, **3.2** and **3.3**) are presented as key examples of the role communication plays in mental health research.

Finally, the general conclusions report the limits and strengths of this multi-faceted study and its possible future developments.

CHAPTER 1

THE ROLE OF COMMUNICATION IN MENTAL HEALTH

1.1 Communicating the results of the research in Mental Health

Communication is the basic process through which knowledge (i.e. the acquaintance with information and data on specific subjects) is made available and reachable to professionals as well as to general public. In particular, health communication is the central social process in the provision of health care delivery and the promotion of public health (Kreps, 1988); in other words it is the acquaintance with information and data on general health issues. A further specified type of health communication is mental health communication (**Figure 1**) concerning the divulgation of all information and data related to mental health: research projects, investigation results, general news, improved techniques and treatments, activities etc.

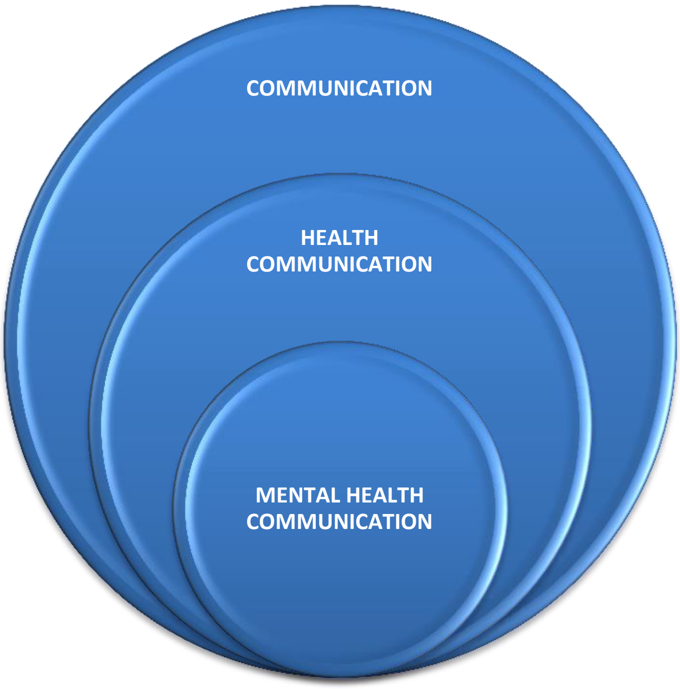

Figure 1. Mental Health Communication is a subgroup of Communication

Knowledge is then the basic element of the communication process and it is released in the form of "messages" usually by health institutions, official entities or societies. Messages can be based on rough statistical data, health/medical data, evidence-based data or descriptive data. Especially statistical data play a fundamental role in mental health research since they allow the production of indicators to check, for instance, the quality of services or provision of care. This is valid namely for all epidemiological studies and research.

The actors involved in the communication process who produce and acquire knowledge on mental health are the following:

1) Researchers: all researchers interested in mental health but also in the communication of mental health information, from different disciplines and working in different universities, centers, hospitals etc..
2) Media partners: journalists responsible for the concept, production and diffusion of information for press, television, radio and the Internet.
3) Policymakers: all administrative staff involved in the production, financing and development of mental health research and promotion. This category includes the Ministry of Health, the Public Health authorities, NGOs etc.
4) Medical staff: all professionals providing health care to people in need (physicians, psychologists, nurses, occupational therapists, social workers, etc.).
5) General public: not only patients, but also caregivers and people curious about or interested in mental health issues.

These actors can play an interchangeable role in the communication of mental health knowledge since they can be the active communicators ("senders") or the recipients ("receivers") of the communication act. Beside the senders, the receivers, and the messages, the fourth component of the communication process are the "channels" (Munodawafa D., 2008) as showed in **Figure 2**. The channels of communication are different and well developed today: journals, internet, TV, scientific publications, book, movies, propagandas etc.

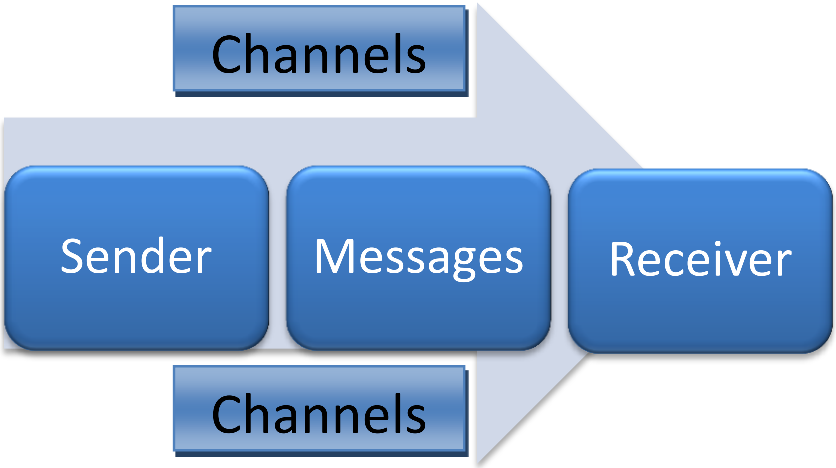

Figure 2. The process and the actors of the Communication activity

The communication of messages is successful if the right channels are used according to the different receivers and senders. Today this process is also facilitated by new technological instruments like search engines specialized in health issues, portals and file folders. Consequently, given the increasing importance of all mass media in general and of modern communication tools in particular, nowadays it is essential to analyze the role of communication techniques in the mental health sector, i.e. the best ways to organize and share information, to accede to pertaining data and to capitalize knowledge in this specific domain.

The theme of "mental health" is differently treated not only in relation to the involved actors (both receivers and senders) but also according to the employed channels. Knowledge of mental health is delivered and acquired in different manners by written media in comparison with audio-video tools for example. Each type of media (from journals to radio, from television to internet, from cinema to fliers) is a business on its own with its objectives.

Here we provide a research-based overview of mental health communication balancing theory with practical advice and examples from specific studies and project. Mainly we discuss the results of four studies from two projects: REFINEMENT and e-MentH. These two projects will be described in detail in the present thesis but we can already state that they both compare epidemiological data on mental health services and tools in different European countries. The comparisons and dissemination of these data constitute a clear example of how communication plays a fundamental role in mental health research. Other studies and examples will be presented in separate paragraphs and boxes in order to provide further demonstrations on the importance of a review of the communication techniques applied to the mental health field of research.

Considerations and analyses on broader health communication have been recently carried out. As reported in **Box 1**, there are research units specialized in health communication. Mental health communication is now emerging as a new interesting domain of research, especially with the impact new media and technologies have in treating mental health disorders.

Then mental health communication is here analyzed as a part of the whole communication domain and also throughout the lenses of translational research. Furthermore, examples of communication studies report the relationships between the different actors of the mental health communication: researchers, media partners, policymakers, medical staff and general public.

Communication is an invisible input aimed at implementation of research in mental health care, i.e putting research results into practice.

THE CANADIAN EXAMPLE: THE GROUPE DE RECHERCHE MÉDIAS ET SANTÉ (GRMS) AND THE 6 PUBLIC HEALTH INFORMATION CENTERS

The *Groupe de recherche Médias et santé* (GRMS) is based in the University of Québec in Montréal (UQAM) and it encourages collaboration between researchers, media partners/communicators and health staff. This group acts as a catalyst of knowledge and information and one of its main aims is to allow journalists to get this information to diffuse them later to the general public. The GRMS conceives its work as a dynamic process, well planned, continuous and interactive with the main aims of developing an exchange and support environment for the partners of the group for a mutual enrichment; developing a culture of cooperation and co-construction of knowledge between universities and hospitals/centers of care, optimizing the attitudes of the partners and of their workplaces about the reception and use of scientific resources, and developing the attitudes of researchers face to reality and worries about provision of care.

In order to fulfill these objectives, the GRMS calls for some network strategies to exchange and implement transfer and diffusion of information. The creation of a network allows the flow of information between individuals and their organizations. This network is based on three specific tools: partners meetings, mediator role of the GRMS and common organization of seminars and congresses. These tools rely on technical instruments like the GRMS official website, official Facebook page, researchers' blogs, monthly reports, papers, articles etc.

In Canada another interesting example of the way communication strategies affect health knowledge is given by 6 Centers aimed at sharing information about public health. These centers have been created by the Health Canadian authorities especially for medical staff and policymakers. These centers underline the importance of a central resource for the application of knowledge and the decision-making: for this purpose they publish reports, create networks, organize education and

Box 1.

Theory of communication

The definition of theory of communication (or communication theory) is borrowed directly from the research world of mathematics and physics and firstly referred to the study of the transmission of information through a channel from one sender to one receiver (Shannon, 1948). The theories and analyses by Shannon and Weaver (1949) were secondly applied to other disciplines like sociology and psychology. It is only after the work of Craig (1999), however, that the theory of communication became the general discipline studying the principles of transmitting information and the methods by which it is delivered. According to Craig, different models of communication can be applied by communicators according to the treated subjects and concerned actors. The theory of communication needs to be strictly related to the practices of communication and the dialogue between theorists of communication and real actors of the communication is fundamental for understanding which are the best models to be applied.

In the fields of general health and mental health the theory of communication is the study of how successfully transmit information for better healthy choices. Communication is a transactional process and in a health context it is an important part of health promotion work. According to Minardi and Reily (1997) communication is an essential, instrumental and purposeful process. The communication transaction is one of sharing information using a set of common rules (Northouse and Northouse, 1998). The application of theory to practice in interventions cannot be ignored then and in order to promote health successfully, health promoters should design all interventions using theoretical concepts for successful health promotion campaigns (Corcoran, 2007). All this constitutes the core of the theory of communication applied to the health field.

Translational research

Translational Research studies the way scientists and researchers communicate to policy makers their discoveries and results. More precisely, translational research focuses on how to transform scientific theories and discoveries into practical applications, especially from an economical point of view. Novel discoveries must in fact be rapidly disseminated without any barrier: information needs to be easily passed on to policy makers and medical staff for best practices employment and development. It goes without saying that translational research is actually one of the hottest key topics of medicine in general and of psychiatry in particular (Lee et al., 2009). As for mental health, services researchers have developed specific principles and methods which are different from other research approaches. In 2000, the National Institute of Mental Health called for translational research paradigms and standards (Corrigan et al., 2003). In this vein, the analysis of golden standards in both mental health services and online information is essential for service providers, administrators, and policy makers whose overwhelming task is to identify and implement intervention strategies that meet the needs of the diverse population of people with mental health problems. In other words, standards are fundamental for translational research to be productive in terms of psychiatric medical care. Furthermore, translational research also provides a common set of terms and methods that basic and applied researchers can use to communicate about collaborations (Widiger, 2005; Zvolensky *et al.*, 2001).

Finally, limited financial resources, escalating mental health related costs, and opportunities for capitalizing on advances in health information technologies have brought the theme of efficiency to the forefront of mental health services research and clinical practice (Donisi *et al.*, 2011; Lagomasino *et al.*, 2010). Translational research tries to propose solutions to these economical problems, analyzing the current provision of mental health care and services and theorizing new models for best practices.

1.2a Communication between researchers and media partners

High quality media partners and especially journalists must awaken public opinion to all issues related to mental health care and the patients' rights. The scope of medical journalism is to convey mental health research findings to general audience avoiding jargon and overly technical language. Journalists’ writing and speaking should be clear and concise, taking the level of understanding of their audience into consideration. For such a reason journalists should receive enough effective training for producing reference points for scientific trust. In this sense, researchers should help journalists by sharing their professionalism and experiences. Research suggests that the general public relies on the popular media as a primary source of information about mental illness. Unfortunately, newspaper articles rarely reflect the common realities of mental illness phenomenology, course, and outcome (Whitley and Berry, 2013). By contrast, media can strongly influence public opinion and social policy on mental health issues.

The exchange between researchers and journalists should produce then clearer and more accessible medical press addressed to both experts (specific press) and general public (mainstream press). Specific press usually reports the financing sources of projects in order to provide clear and unbiased information. On the other hand, mainstream press plays a different role since doctors and health staff can directly communicate with general public and give voice to their personal, but at the same time professional, point of view.

The outcomes of health communication could be improved by leveraging the synergistic contributions of the continuum of specific and mainstream press (Napoli, 2001). An example of such collaboration is the Rosalynn Carter Fellowships For Mental Health Journalism, i.e. stipends to journalists from the United States, Romania and Columbia to report on topics related to mental health or mental illness. This initiative is aimed at increasing accurate reporting on mental health issues and decreasing incorrect, stereotypical information. Journalists are helped to produce high-quality work that reflects an understanding of mental health issues through exposure to well-established resources in the field. Similar initiatives could definitively improve the quality of information about mental health thus avoiding any type of stigmatization.

Researchers and policymakers should collaborate with journalists for producing appropriate and correct information for both medical staff and general public.

1.2b Communication between researchers and policymakers

Policymakers are policy analysts and researchers working within governments, insurance funds and regional health authorities, but also practicing hospital managers interested in the policy environment within which they work. The communication between mental health researchers and policymakers is then a process involving two different categories of research experts.

European national policymakers broadly agree on the core objectives that their health care systems should pursue, e.g. universal access for all citizens, effective care for better health outcomes, efficient use of resources, high-quality services and responsiveness to patient concerns (Mckee and Healy, 2002). However the methods and financing for reaching these common objectives vary, especially as far as policies and politics in general are concerned. The approaches to institutional arrangements in the health sector are different in most of the European countries which are historically characterized by heterogeneous cultures and political experiences. Such a diversity of health systems all based on the same values and aimed at the same core objectives has lead policymakers to discuss about the best organization strategies and policy priorities. Especially with the XX century reforms that have revolutionized (or at least tried to do so) the health care systems in Europe, policymakers concerns have increased. Against a common European background the necessity of comparable arrangements has emerged together with the need to overcome the existing institutional divergences in countries which should, in theory, share the same European guidelines. For this reason, the European Commission published in 2010 a guide on "Communicating research for evidence-based policymaking". Cross-national health policies are then necessary and they are even more urgent when referring to a very sensitive domain such as the mental health one (Amaddeo and Tansella, 2007; Grigoletti *et al*., 2010).

Throughout the panel of experts of "The European Observatory on Health Care Systems" the World Health Organization tries to serve as a bridge between pure academic research and the needs of policymakers, thus applying in practice the principles of the translational research.

In mental health, an important area of research should be the evaluation research (or evaluative research or program evaluation research) aimed at exploring programs to determine if they are having the intended effect on the population. First of all, the evaluation research determines whether or not a specific program is necessary throughout the collection of data and the communication of such results. Only necessary programs should then be implemented. This means that policymakers should also invest in evaluation research in order to select only those programs which can have good repercussions on the population.

Health policy must be based on the best scientific evidence derived from sound data and information, and relevant research. The European Commission must answer calls for better information and more transparent policymaking even through a clear communication strategy among researchers, policymakers and stakeholders. Thus also allow the protection of Public Health and the regulation of Health expenditures.

At Community level an interface between policy and research should be implemented convening Community and national authorities, academic institutions and stakeholders. This interface is needed to give advice on relevant mental health indicators for the EU, the monitoring of mental health, and on priorities for research activities at the EU-level. Through its recommendations researchers would then find the most effective ways to identify research priorities according to policymaking needs and vice versa.

For such a reason there exist in some European countries (see an example in **Box 2**) some research groups within Universities and Research Centers specialized in the economic evaluation of mental health care. They analyze all factors affecting the economy for care like,

for instance, the technology advances and the early intervention services. The actual scarcity of the resources compared to the high demand of patients obliges policymakers and financing entities to make choices. Research is then essential to guide politicians' decision making for the well-being of the entire society. For such a reason it is fundamental to bridge the gap between research and policy.

<u>THE IOP CEMPH EXAMPLE: RESEARCH AND POLICYMAKING</u>

The research "Centre for the Economics of Mental and Physical Health (CEMPH)" is lead by Professor Paul McCrone and two deputy directors - Professor Sarah Byford and Dr Anita Patel - of the Institute of Psychiatry (IoP) of the King's College, London. It consists of a team of health economists with experience and expertise in designing and conducting high quality economic evaluations of healthcare interventions, modeling studies and cost analyses. The results of the CEMPH work contribute to policymaking and healthcare practice in England and abroad, and promote the use of rigorous evaluation techniques through a program of teaching and training.

The Centre was established in 1993 and initially focused on mental health, but now it works in all areas of health care.

Box 2.

McCrone and colleagues (2012) defined "society" as a combination of different actors: healthcare sector, insurance companies, health and social care sector, patient and family, other agencies. All these actors must be informed of the relevant research activities.

Economic evaluation research produces specific models to be applied for better outcomes. However these models should be properly communicated to policymakers and political decision makers. In Europe such communication process takes place in different ways according to the different countries. For example in England, as it is the case of the Centre for the Economics of Mental and Physical Health (CEMPH) (see **Box 2**), economic evaluation in the mental health sector is directly commissioned by national authorities and entities, like the National Institute of Health (NHI).

The National Institute for Health and Care Excellence (NICE) reports are also the basis for economic evaluations in the English health sector. In other countries, research results are published in journals (of different degrees of quality and scientific soundness) aimed at diffusing the activities and reports of scientific groups. However it is not automatic that policymakers can get to know and read such documents and make official decisions on the basis of published results. **Box 3** summarizes the main projects and activities concerning the financing of research for mental health while **Box 4** focuses on the Italian healthcare system.

Economic evaluation is the fundamental process through which the costs of the provision of care (in all its different forms) are compared with their effects in terms of health improvement and/or resource savings (Amaddeo et al., 1999). Thanks to this rational economic evaluation policymakers can decide how to allocate funding for both mental health provision of care and research.

The REFINEMENT project described in **Chapter 2** is a clear example of the importance of the communication between researchers and policymakers. Analogously, the two studies about the use of the Internet for mental health information and support seeking (e-MentH project, described in **Chapter 3**) are relevant because policymakers must also take note of the role the Internet is gaining in help-seeking behaviors.

FINANCING THE RESEARCH FOR MENTAL HEALTH: A GENERAL OVERVIEW

Mental health expenditure represents one of the largest items in the total public spending of all countries in the World. In European Union countries its costs are substantial, accounting for 9% of total health care costs on average (OECD Policy Brief, 2008). It is then useful to evaluate the current status of mental health services in order to allocate resources in a more effective way and to develop a funding system that can support the pathways of care of frequent users of these services. The Mental Health Policy and Service Guidance Package by the World Health Organization (2003) has clearly stated that mental health innovation proposals and initiatives should be financed throughout funds specifically allocated to evaluate and demonstrate all the types of changes recommended by policies and best practice models.

An exhaustive survey on the investments made in research on mental disorders by both government and nonprofit nongovernmental organizations in France, the United Kingdom and the United States was conducted for the years 2007-2008 (Chevreul *et al.*, 2012). From this survey it emerged that funding support for mental health research is still inadequate. A previous informal survey (WHO 2008) of European countries by the World Health Organization had reported that funding for mental health research ranged from 4% (Czech Republic) to 18.5% (Ireland) of total health research expenditure. However, in the three countries taken into account by Chevreul and colleagues (2012), some initiatives for financing mental health research were identified. In the US, a strategic plan for research on mental health was developed by the National Institute of Mental Health (NIMH) with the aim to promote research in mental health that can indeed result in health benefits for patients. In the UK, there is now an active campaign supported by high profile celebrities to counter the pervading culture of stigma and to increase funding for mental health research (http://www.researchmentalhealth.org.uk). In France, a new scientific foundation, FondaMental, created by the Ministry of Research and dedicated to mental health, was set up in 2007 with the goal of raising funds for mental health research (http://www.fondation-fondamental.org). In the case of these three nations, but also as a general statement, the structure of funding for research on mental disorders varies by country, although the state or social health insurance seems to be the principal source for mental health research. Estimates from this study are close enough to confirm that the proportion of health research budgets that is spent on mental health research is low, given the burden of disease and also given the potential return on investment.

Box 3.

FINANCING THE RESEARCH FOR MENTAL HEALTH: THE ITALIAN SITUATION

From the deinstitutionalization to the present days, Italian mental health care financing has evolved in line with both national plans and the actual European directives (Amaddeo, Grigoletti and Montagni, 2014). In accordance with the Piano Sanitario Nazionale (National Health Plan) also the Regional programs and health plans take into consideration the importance of the strategic role of communication of mental health research results. For example, the Piano Sanitario Regionale (PSR) of the Friuli Venezia Giulia region of the years 2010-2012 mentions among its main investment areas the "development of communication and integration technologies aiding the access of citizens to the provision of continuous care".

The 2010 PSR of the Emilia Romagna region contains an entire chapter where the following issues are underlined: citizens' participation and satisfaction, health services evaluation, utility and trustworthiness of the information on scientific health. Also in the 2009-2011 PSR of the Lazio region, among the instruments of the regional government to promote the appropriateness of the health services the following issues are proposed: the empowerment of the citizen and of the community, media information campaigns, innovative forms of health education for the general population and for the single user. The 2008-2010 PSR of the Puglia region states that the coherent and efficacious communication is the right strategy to develop in order to guarantee the effectiveness of the prevention and promotion actions about health.

The majority of the Italian regions and autonomous provinces demonstrate however a high interest in all themes related to the promotion of health, but with a scarce reference to national strategies (Relazione sullo Stato Sanitario del Paese 2009-2010, Ministero della Salute).

From an international point of view, the 2008-2013 "Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases" defined communication and information as

Box 4.

1.2c Communication between researchers and medical staff

Dialogue between theory and practice is a must in research, whatever the field but especially in all health related domains. Researchers represent the theoretical actors of this dialogue, while medical staff (practitioners, nurses, social workers, psychologists etc.) represents the practical actors. To promote a cross-sectional cooperation between these two actors of the mental health research dialogue, in 2004 the EU-Platform on Mental Health was launched and involved medical experts, staff and researchers of the health sector. The Platform was conceived to produce proper information systems which had to be well coordinated and organized through systematic observation and surveillance tools.

With the same objective, the so-called *sociétés savantes* (La Santé de l'Homme, 2010) are associations made of experts, researchers and professional staff who compare and present the results of their researches and projects throughout different media: reviews, journals, conferences, seminars, lectures and other scientific meetings. These associations profoundly influence the universe of the Public Health thus proposing a collective and inter-professional overthinking of theories and practices.

In general medical activities, researchers and medical staff should be engaged in a mutual learning process. Researchers should give the medical staff a sense of ownership in the research process. On the other hand medical staff should relate to the lives of patients by using their experiential knowledge. In the context of collaborative working, this would help shape better guidelines for research (Nierse, 2011). Moreover medical staff is essential in providing researchers with all data concerning patients and treatments. Doctors, nurses, health caregivers in general are the main source of information for researchers whose theories, *viceversa*, are of unquestionable help for medical practices.

Finally, it is important also to understand that the dialogue between researcher and medical staff can be biased by private objectives. Research results and information can be communicated also by lobbies whose aim is to influence both stakeholders and public opinion. This is true especially for some pharmaceutical realities and entrepreneurs. The State should then check the information provided by lobbies and guarantee a real health democracy.

1.2d Communication between researchers and general public

Popular science is meant to be intended by any general audience and official scientific communication by experts is thus essential to provide accurate quality information about delicate fields of research like that of mental health care. Mental health communication is then fundamental since it spreads knowledge in the practical life of individuals and organizations, thus influencing personal and common decisions and changing specific behaviors throughout the dissemination of messages from experts to the general public. These messages are based on decades of scientific research on diseases and their treatment. All research results are initially not intended for general public and for such a reason it is necessary to work hard on their selection and adaptation to make them accessible and diffuse them to the general public.

Moreover, the increase in mental health information sources and in information itself makes it hard - but imperative - to organize the way such information is spread from the world of science to that of common people. There already exist several communication strategies based on traditional health behavior models. ‘Classic’ theories/models of health behavior include: the Health Belief Model, the Theory of Reasoned Action, the Transtheoretical Model, Learning and Conditioning, Social Learning Theory, Decision-making Theory and Diffusion of Innovations (for reviews see Ferguson, 1998, and the Institute of Medicine’s report on Health and Behavior, 2001b).

In this sense, institutional communication about mental health plays a strategic role in the relationship between all National Health Systems and the citizens. One of the main objectives of institutional communication for health is the empowerment of citizens, as stated by the World Health Organization in several official documents (Wallerstein, 2006; WHO Regional

Office for Europe, 2009a; WHO Regional Office for Europe, 2010). The WHO is following the guidelines on empowerment of The Ottawa Charter for Health Promotion (1986) affirming that access to information is a necessary condition for individuals to make choices, participating to health issues and then playing an active role in achieving one's fullest health potential. Patients have the right of being informed about the results in the mental health research in order to prevent and/or cure any mental disease. Empowered citizens can better understand and choose, build their own way of life, be the protagonists of their welfare and responsibly interact with the services provided by any National Health System.

When empowered, patients can play an active role in research in line with the "Public Engagement with Science and Technology" (PEST) model. Different strategies by which patients can be involved in research include consultation, control and collaboration. The active involvement of patients as research partners can add value to a research strategy, especially when research partners and professional researchers engage in a dialogue that is open, inclusive and deliberative. Issues for discussion include the possibility of 'over-involvement', the research profile and training of research partners and whether participation of patients is restricted to certain types of research (Nierse, 2011).

One of the most outstanding examples of the positive results of the collaboration between general public and researchers is the "Community-based participatory research (CBPR)" model. The CBPR methodology presents an alternative to traditional population-based biomedical research practices by encouraging active and equal partnerships between community members and academic investigators (O'Fallon and Dearry, 2002). Moreover, the CBPR has emerged in the last decades as a transformative research paradigm that bridges the gap between science and practice through community engagement and social action to increase health equity. The CBPR expands the potential for the translational sciences to develop, implement, and disseminate effective interventions across diverse communities through strategies to redress power imbalances; facilitate mutual benefit among community and academic partners; and promote reciprocal knowledge translation, incorporating community theories into the research (Wallerstein and Duran, 2010).

Communication in mental health passes also throughout patients’ associations. Not real experts, but in any case more informed than general public, patients and their families and caregivers can collect, produce and diffuse knowledge about health. All this contributes to a sort of communication democracy in the mental health field.

Last but not least, the Internet and the media in general are today determinant tools in empowering citizens and increasing their knowledge about mental health issues. Lemire and colleagues (2007) reported that patients use the Internet for health information seeking according to the following three paradigms:

1) the professional paradigm - patients use the Internet to complete and better understand the information provided by their doctor

2) the democratic paradigm - patients help each other throughout social networks and discussion boards where their share their experience

3) the consumeristic paradigm - patients use the Internet to get informed and to compare different knowledge for decision making about their health.

Chapter 3 analyzes in details the central role the Internet has nowadays in the provision of information and advice about mental health. The interactive proprieties of the Internet underline how effective communication can be with specific publics and the Internet seems actually more efficacious than other media to diffuse mental health information and change the general public behaviors and attitudes towards mental health issues. Official communication is in any case necessary to raise public awareness about mental health and mental disorders since such issues are becoming the most researched topics on the web.

COMMUNICATION AND STIGMA

Social psychology and sociology have underlined the importance of the role played by mass media in the knowledge acquisition on different themes in different important sectors of the population, and messages by media are especially one of the most important information sources for mental health. However, such messages are often negative or wrong: there is some confusion among different types of illnesses and troubles, the language used is somehow stigmatizing and stereotypes are often employed. Media can then represent unfortunately also a powerful instrument of stigmatization. It is then necessary to promote information and reports offering a balanced and positive opinion of people with severe mental illnesses.

Information tools should then be developed and applied in order to communicate about mental health without stigmatizing. Any communication project should be carried out after a correct analysis of the actors' own representations and stereotypes of mental ill people.

Stigma is a barrier to recognition and treatment of mental illnesses and bridging this gap means understanding that it is a problem of knowledge, i.e. ignorance. Communication is the right way to fight against this ignorance (Thornicroft, 2006).

Box 5.

CHAPTER 2

COMMUNICATING ABOUT MENTAL HEALTH IN DIFFERENT NATIONS, LANGUAGES AND CULTURES

2.1 Communication about mental health in Europe

Europe is very diverse with each country's health care system reflecting its unique culture and history (McKee and Jackobson, 2000). Comparability of health care services is very difficult and even more complicated also because of the language barriers. Research has an international nature which should overcome any language difficulty, and communication experts should contribute to facilitate any exchange in research for mental health. A further challenge in comparing European services is presented by the diversity of health systems themselves, which may be in different stages of development: some systems may be in their initial stages of development while others may be more developed (Funk *et al.*, 2003). General health services are very difficult to compare across different territories even in the same country, but there is the strong need for international comparison to assess health care reforms which could also facilitate patient mobility.

The scenario is the unfortunately the same for mental health care with the provision of mental health services varying tremendously across the WHO European Region. Although several countries have similar service structures, particularly in the more institutionalized part of the Region, even these countries show considerable variation in the number of beds, admissions and community care developments such as crisis services and units in district general hospitals. Services in the EU15 countries appear to be so differentiated that any comparison is haphazard. Associated with the differentiation is the growing complexity of mental health services (WHO 2005). Moreover, the availability of data across countries is generally very good for some types of data (structure and activity) and problematic for others (opening times and quality of care, for instance).

Given these difficulties in analyzing the way mental health research is conducted in Europe, official organisms and entities like the European Commission, the World Health Organization, the Organisation for Economic Co-operation and Development (OECD) and other national research units - both governmental and nonprofit nongovernmental - have constantly produced research projects and activities in the world and in Europe in particular.

The Declaration and the Mental Health Action Plan for Europe defined in 2005 the scope of mental health policy and practice and proposed a series of actions to create a comprehensive mental health system. Countries accepted responsibility to support the implementation of measures, and the WHO Regional Office for Europe was requested to take the necessary steps to fully support the development and implementation of mental health policy. In line with this plan, the Seventh Framework Programme (FP7) and the following Eight Framework Programme (FP8) are seeing the development of several projects reuniting different European countries for providing a comparative and comprehensive overview of the mental health services and systems of care (e.g. the REFINEMENT project described in **paragraph 2.4**).

What has emerged so far is the presence still of some significant inequalities between and also within Member States since the status of mental health reflects diversity between countries, their situations, traditions and cultures. It is really hard to propose simple conclusions or solutions, but the general scope is to make cooperation among Member State feasible. Any strategy for a European Mental Health improvement should then be based on the creation of a framework for exchange and cooperation between Member States, and the increase of the coherence of actions in different policy sectors. In this sense one of the main purposes of the Commission for a EU-strategy for mental health is to “develop a mental health information, research and knowledge system for the EU” (2005).

European research groups produce different models about, for instance, the financing of mental health care. Given the heterogeneous nature of the health care systems in Europe, such models can be applied only to specific nations and, sometimes, even specific local contexts. It is difficult somehow to uniform the models to be applied on a European scale, thus transferring a model from one nation to the other, i.e. from a health care system to the other.

That of mental health cross-country comparisons for a better provision of care and services in Europe is a key question which has triggered a series of studies, instrument and projects. In fact there is a lack of agreement on which measures should be used in mental health as robust ones that permit meaningful comparisons across providers, systems or geographic areas (Hermann et al., 2006). The initiatives undertaken differ widely among countries reflecting differences in the organization of health care systems, in national health policy priorities and in data sources available and consider different levels at which quality of care can be described and classified producing different frameworks of analysis of the quality.

Against this background, a method of standardization of provided services is necessary. In a globalized world, the need for international standards simply makes sense: science must be clearly comprehensible for all kinds of audience from different cultures, languages and socio-economic conditions. In other words, in order to turn the scientific results into better account and then put under the spotlight the cultural products of the academic research, it is essential to reconcile the world of science with the society.

2.2 Definition of mental health standards

DEFINITION OF STANDARD FROM THE EUROPEAN COMMITTEE FOR STANDARDIZATION

A standard (French: norme, German: Norm) is a publication that provides rules, guidelines or characteristics for activities or their results, for common and repeated use. Standards are created by bringing together all interested parties including manufacturers, users, consumers and regulators of a particular material, product, process or service. Everyone benefits from standardisation through increased product safety and quality as well as lower transaction costs and prices.

A European Standard (EN) is a standard that has been adopted by one of the three recognized European Standardisation Organisations (ESOs): CEN, CENELEC or ETSI. It is produced by all interested parties through a transparent, open and consensus based process.

Box 6.

According to the definition provided in **Box 6** standards are all those procedures of quality assurance which are necessary to elaborate the translation and correction of the items of an instrument to be applied in several countries. In other words, standards are means for reducing cultural bias and eliminating differences at the micro-level for better international comparisons. Throughout a common coding system, standards overcome terminology problems and enable comparisons of local/national data to generate informed evidence. Standardization can be then defined as the totality of international classification systems applied across all stages of data production, storage and report, with the final objective of increasing data comparability.

The problem of standardization is urgent in the very complex and delicate field of mental health provision of care where standards are needed to both inform and provide new knowledge to areas in which action could be beneficial and also offer examples of excellence that could assist other countries in their development (WHO 2005). Standards should be aspirational for all professions engaged in the provision of mental health services, in order to ensure the best possible outcomes for people with mental health conditions.

Within the standards for mental health, there are the Practice Standards intended to outline the knowledge, skills and attitudes required when psychiatrists, nurses, social workers, psychologists and occupational therapists work in a mental health service. In this sense, standards are necessary in care providing since they represent valuable guidelines in ensuring that clinicians provide high-quality up-to-date evidence-based care and that the public and users of services know what standards of care should be offered.

Among the main comparative instruments clinicians have at their disposal there exist some measurement tools that accurately capture symptoms of mental troubles, i.e. common language and standard criteria for the classification of mental disorders. Nowadays it is still difficult to categorize all psychiatric illnesses and syndromes. However, it is necessary to formulate broader categories which could represent standard definitions in all countries, without any localization. It is also imperative to develop a worldwide consensus on the descriptive categories of psychiatric troubles, throughout the development of ontology of psychiatry (Charlet et al., 2006). With this aim, the Diagnostic and Statistical Manual of Mental Disorders (DSM) is published by the American Psychiatric Association and used in the USA and in other world countries including Europe by clinicians, researchers, psychiatric drug regulation agencies, health insurance companies, pharmaceutical companies, and policy makers.

Similarly, the WHO’s International Classification of Diseases (ICD) is used to classify diseases and other health problems, and it has become the international standard diagnostic classification for epidemiological and health management purposes. ICD-10 is the latest version (an updated ICD-11 is currently under development). However, because of its impact in shaping national information systems, update to new versions of ICD involves issues such as staff training, adaptations to new definitions and changes to funding schemes that make it onerous for countries. As a result many countries still rely on ICD-9 for data codification.

Therefore the use of different versions of ICD across countries is a real issue in specifying the indicators for international comparison.

International care standards for one of the most socially excluded groups of people – i.e. people experiencing some kinds of mental health problems - are essential because of the large increase in mental health troubles incidence (Salvador-Carulla et al., 2010). Official standards should then be developed by stakeholders and desk researchers for a better provision of mental health care. Unfortunately, there are limits and challenges in defining mental health standards: first of all the definition and production of such mental health standards depend on the collection of comparative data on the state and progress of mental health and mental health services in member states. Such a collection has proven to be a real challenge, since essential information is not always available, and if information is available, it is not always known whether data are standardized and consistent across member states, since countries had rarely agreed on definitions. In fact, concepts, quality of data, collection methods and the structure and delivery of services vary from country to country, even within the European boundaries. Secondly, as for care providing, the challenge is that, whereas developing and publishing guidelines is relatively straightforward, ensuring that clinicians comply with those guidelines is much harder.

To conclude, the need for standards in the mental health domain falls in the larger context of Translational Research, i.e. the way scientists and researchers communicate to policy makers their discoveries and results. More precisely, translational research studies how to transform scientific theories and discoveries into practical applications. Novel discoveries must in fact be rapidly disseminated without any barrier: information needs to be easily passed on to policy makers and medical staff for best practices employment and development. It goes without saying that translational research is actually one of the hottest key topics of medicine in general and psychiatry in particular (Lee et al., 2009). In order to provide efficient and effective mental health services, services researchers have in fact developed principles and methods that distinguish it from other research approaches. In 2000, the National Institute of Mental Health called for translational research paradigms and standards (Corrigan et al., 2003). In this vein, the analysis of golden standards in both mental health services and online information is essential for service providers, administrators, and policy makers whose overwhelming task is to identify and implement intervention strategies that meet the needs of the diverse population of people with mental health problems. In other words, standards are fundamental for translational research to be productive in terms of psychiatric medical care. Notwithstanding the difficulty of comparing data, standardization is always an advantage in research.

2.3 European standards for mental health

The request of comparable data is continuously increasing in Europe with several challenging surveys and analyses concerning different countries.

First of all, there exists an official European organization for health standards: the CEN-CENELEC Advisory Board for Healthcare Standards (ABHS). It was originally created as a CEN-only body by the CEN Technical Board - the policy-making body - in December 2005 to replace the CEN Healthcare Forum (CHeF). One of the principal aims of standardization in Healthcare, and therefore of ABHS, is to ensure a high degree of patient safety and to support public health objectives whilst breaking down international barriers to trade. ABHS benefits from participation by the whole European healthcare sector. The CEN-CENELEC Advisory Board for Healthcare Standards (ABHS) is involved in all current issues affecting healthcare standardization, for instance, the relationship between European and international healthcare standardization and eHealth standardization activities. Since its first meeting in March 2006, ABHS has set up several Task Forces in these key areas of the healthcare sector, notably:

- Task Force 1 - eHealth to look into the needs and possibilities of coordination and cooperation in eHealth
- Task Force 7 - Promotion to consider ways to promote ABHS and standardization in general.
- Task Force 12 - Communication and education to promote ways to better communicate with European Healthcare stakeholders on Healthcare standardization matters.

Specifically for mental health care, international, national and local indicators/registers/files etc. are applied for comparing the mental health care systems of the different European countries. Among the most important and recent works aimed at bridging the gap of different mental health systems all around Europe, we can mention the following: the European Services Mapping Schedule (ESMS), the Description and Evaluation of Services and Directories in Europe (DESDE) and the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS). A first attempt had also been made in the European EPSILON study (Johnson et al., 2000) in respect solely of specialist services for people with schizophrenia. The existence of these different studies on services codification and of their attached tools shows the great interest research has in trying to standardize the description of services (de Jong, 2000) to aid in such comparisons. In this vein the REFINEMENT project described in **paragraph 2.4** answers the necessity to standardize the description of services to aid their comparisons in present days.

Simultaneously, In March 2007 the DEMoB.inc project (Development of a European Measure of Best Practice for People with Long Term Mental Illness in Institutional Care) coordinated by the UCL of London received foundations from the European Union to contribute to the development of the following policy tools: the first internationally agreed guidance on key measures of institutional care for people with long-term mental illness, which can inform European standards and policy; furnishing of policy-makers with valuable information about the economic and clinical effectiveness of institutional care, and the promotion of human rights; identification of resource gaps and areas of concern that can inform future healthcare policy. Throughout data collection and scientific literature reviews, the DEMoB.inc project has been underlining in its 3 working and researching years the need for an instrument to assess standards of care in European institutions, which incorporates assessment of the institution’s promotion of recovery and human rights, as well as the interventions used and their value for money. All this with the major aim to help set basic standards of mental health care across Europe. Throughout the combination of the Delphi approach and an international literature review, DEMoB.inc made a useful contribution to the task of providing a mean for an individual service to evaluate its own practice and enabling a comparison of practices across institutions and countries in ways that are valid and meaningful to those involved as well as rooted in an empirical evidence base (Turton et al., 2010).

Finally two mental health indicator projects, the MHMDS (Mental Health Minimum Data Set, 2012-2013) and the MINDFUL (Mental health Information and Determinants for the European Level, 2006), devise European Union standards according to which mental health information systems are being harmonized. These two projects are based on a fundamental assumption: although the amount of practice guidelines in the mental health care field has increased substantially over the past decades, the extent of agreed standards is less. To capture the quality of the mental health care process, measurements rely more on the organizational dimensions of the health care delivery process, such as timeliness, continuity of care and inter-professional communication. Weaker standardization of diagnostic and therapeutic practices are acknowledged as relevant issues partly explaining the comparative shortage of systematic information and well established coding and reporting practices.

All these instruments show that, notwithstanding their structural differences, mental health care systems in Europe converge to the same need for an improvement in the quality of mental health services.

2.4 The REFINEMENT Project: a key example of Mental Health research in Europe

The REFINEMENT (REsearch on FINancing systems' Effect on the quality of MENTal health care) project arises from the necessity to compare the different and elaborate systems of both financing and performance assessment of Mental Health care in Europe (Smith, 2009) throughout a standardized definition of their services. The project is financed for 3 years by the European Commission within the 7th Framework Programme (code 261459) and started in January 2011, lead by the Psychiatry Register, Economics & Geography of Mental Health team coordinated by Professor Francesco Amaddeo from the University of Verona. It is conducting the first ever comparative and comprehensive overview of links between the financing of Mental Health care in Europe and the outcomes of Mental Health services thanks to an experienced team of Mental Health service researchers, public health specialists and health economists. The project covers, in terms of funding models and interfaces with social care services, a representative range of health care systems across Europe. These systems are at very different stages in their development - especially after the shift from institution to community based care (Thornicroft and Tansella, 2009) - ranging from heavily hospital reliant systems in Romania through different balances between community and institutional care found in countries including Austria, the UK and Norway to the highly community centered system of Italy. For such a reason, the nine partner countries of the project represent a significant example of the variegated Mental Health care and financing systems in Europe. These nine countries are: Italy (University of Verona - project coordinator), Austria (Ludwig Boltzmann Gesellschaft), UK (London School of Economics and Political Science), Finland

(Terveyden ja Hyvinvoinnin Laitos), Spain (Asociacion Cientifica Psicost), Norway (Stiftelsen Sintef), Estonia (University of Tartu), France (Université Paris XII – Val de Marne) and Romania (Institutul de Prognoza Economica).

In order to reach its aims, the REFINEMENT is organized in 9 work packages: three mandatory work-packages on management (WP1), evaluation (WP2) and dissemination (WP3) and six technical work-packages concerned with the analysis of the financing of health and social care systems (WP4), functional and dysfunctional financial incentives (WP5), the mapping services for Mental Health care (WP6), the pathways of care (WP7), the quality of Mental Health care and met/unmet needs (WP8) and, finally, the building of the best practice models of Mental Health care financing (WP9). In this sense, tools are being developed to map and describe the peculiarities of Mental Health care financing systems (methods of revenue collection, pooling of funds, allocation to service purchasers and mechanisms for the payment of service providers) in a comparable way across the nine partner countries.

The present thesis is focused on the results of WP6 (**STUDY 1**) and the Glossary (**STUDY 2**) covering all the WPs.

Figure 3. The REFINEMENT logo

2.4.1 STUDY 1 - The REMAST tool for the REFINEMENT project: an example of classification and standards for mental health services in Europe

Background

The present thesis is especially focused on the results of the WP6 which answers the necessity to standardize the description of services to aid their comparisons. In order to analyze the different financing and care systems and their correlated outcomes, it is actually necessary to ensure that researchers, service planners and policy makers in different regions, countries and at the European level, compare ‘like with like’ and adequately use the data from different services systems. Past studies and project have already tried to compare in a standardized way different mental health services (De Jong, 2000; De Jong et al., 1995). For example, the European Psychiatric Care Assessment Team (EPCAT) developed the European Service Mapping Schedule (ESMS) to describe Mental Health services for the population of a catchment area provided by public sector health and social service agencies, voluntary sector and private sector providers (Johnson et al., 2000). This instrument classifies provision in a “service mapping tree” on the basis of operationalised definitions of Mental Health services and it also documents the associated levels of services provision in order to compare services in catchment areas across different countries (Becker et al., 2002). A further development of this approach has been the creation of a new instrument called ‘Description and Evaluation of Services and Directories in Europe’ (DESDE) which also includes long term care and disability services and which is now used in sixteen European countries (Salvador-Carulla et al., 2006). What has been missing from these service mapping instruments to date – including the WHO’s Assessment Instrument for Mental Health Services (WHO-AIMS) (WHO, 2005) - has been a common comparison of primary care, general health and social care services that may be used to support people with Mental Health needs. For such a reason, the REFINEMENT project has developed its own tool (the REMAST, with its revised version REMAST 2.0) applying a multilevel description which has only previously been made in the

European EPSILON study in respect solely of specialists services for people with schizophrenia (Becker et al., 2002).

Finally, in order to provide a further visually comparative description of the services, the REFINEMENT project also analyzes the spatial dimension of Mental Health care delivered by health and social services by means of Geographical Information System (GIS); to date such a type of studies have only been conducted on single services at a local level (Curtis, 2007).

Given the huge amount of information retrieved, specific and ad hoc analyses were performed to provide new insights on the following two topics: geolocalization of psychiatric hospital-based acute services (1) and spatial accessibility to psychiatric mobile services (2) in the REFINEMENT countries.

As for topic 1, in recent years there has been an evident decrease in the provision of mental health care by hospital-based acute services. Hospitals still play an important role within the mental health care system accounting for a substantial proportion of the health care budget. In comparison with the work by Priebe and colleagues (2008), the REFINEMENT project presented new insights also in poorest European countries like Estonia and Romania. Moreover it provided updated information about other European countries.

As for topic 2, provision of mobile services is an essential feature of psychiatric care and crisis interventions teams represent an important element of the whole mental health system (Allen, 1999). Quick and adequate interventions in emergency situations are fundamental to assist psychiatric patients in critical clinical conditions and should prevent any further mental health deterioration or risk in acute patients. Especially in geographical areas which are poor in mental health structures, mobile teams can be of decisive help. When necessary, mobile teams can provide cost-effective psychiatric emergency services that are favorably perceived by consumers and police officers (Scott, 2000).

Data collected within the European REFINEMENT project were used to describe the distribution and utilization of both these types of mental health care services. The geographical areas where these services are distributed were then analysed and represented in ad hoc maps.

Materials and Methods

The REFINEMENT MApping Services Tool (REMAST) is one of the three legacy products of the REFINEMENT project intended to be used also by other countries and regions seeking to undertake analysis of their mental health systems, and also for future adaptation for the analysis of the relationship between financing systems and health care outcomes. The REMAST tool was built using the experience of previous developed and validated international instruments like the European Services Mapping Schedule (ESMS) and the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS). However, the separate instrument included in the REMAST on which the majority of the analyses are based, is the Description and Evaluation of Services and Directories in Europe for Long Term Care (DESDE-LTC). This instrument classifies provision in a “service mapping tree” (**Figure 4**) on the basis of operationalized definitions of mental health services. The DESDE-LTC coding system has been enriched by complementary information collected with the SERVICES INVENTORY. Another important tool constituting the REMAST is the Verona SES Index. Data collected through the DESDE-LTC, the SERVICES INVENTORY and the Verona SES Index have been utilized also for the creation of specific maps to describe the spatial context of all mapped services. These maps have been the first step towards the creation of an Atlas of Mental Health Care. All components of the REMAST tool are described in detail in **Table 1**. After a preliminary collection of the data, a new lighter version of the tool was produced: the REMAST 2.0. This shorter version contained less items for an easier application on several countries with different mental health care systems, thus allowing quicker and more reliable data comparisons.

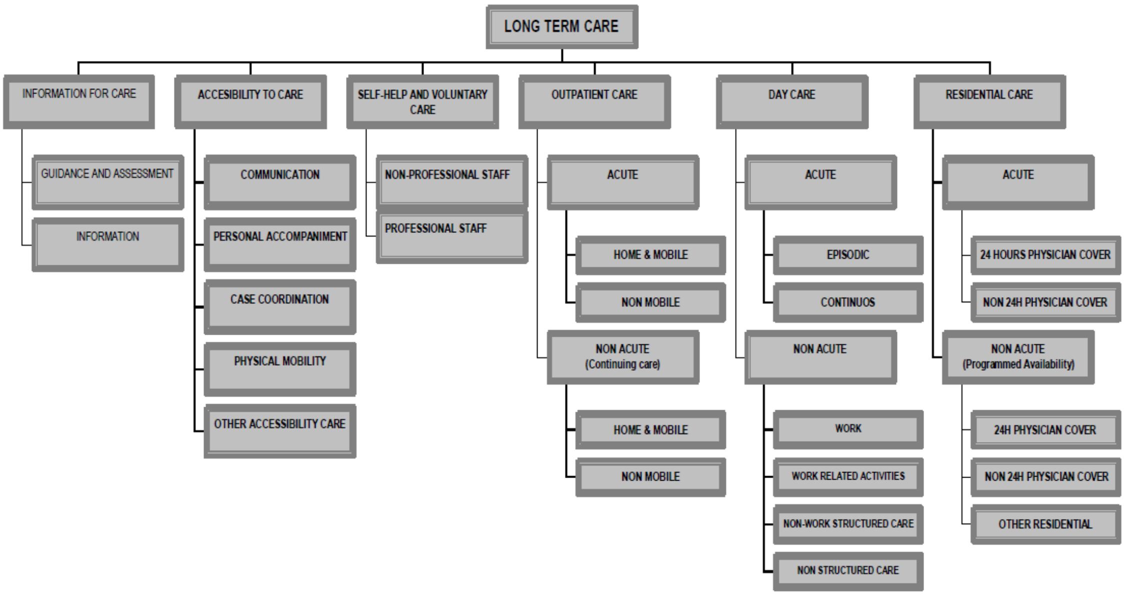

Figure 4. DESDE-LTC mapping tree

REFINEMENT maps were created through GIS, used to analyze mental health care need, access, and utilization. This instrument especially underlines the disparities in accessing services among population groups and it is a structured system for the assessment of mental health care needs (McLafferty, 2003). GIS adoption was possible thanks to the access to integrated spatial data on the 6 countries' (Italy, Spain, England, Norway, Finland, France) mental health services utilization and information about the populations living in the services area. The spatial organization of services is given by their number, sizes, types and location. GIS was used to allocate patients from postcode areas to census blocks to allow comparison of register data for those areas. Geographical access to mental health services was measured here according to an area-based approach (Cromley and McLafferty, 2002).

REMAST	
SERVICES INVENTORY	It allows comparisons between Study Areas regarding the structure, staff, opening time, funding system, range and level of provision of services. Data were collected by interrogations of different administrative databases and/or interviewing heads of units, services, health districts and private sector providers. Study population: public and private mental health services, aimed at caring for adult people (+18 years old) with mental disorders and their families. Inclusion Criteria: services providing Health and Social Care to people with a psychiatric disorder who are at least 18 years old (no upper age limit is applied). All services which treat individuals with F0- and/or F1- and/or F7- diagnosis or elderly people or forensic patients amongst others (F2-F6) will be included. All relevant non-specialist and general services in the health and social care system should be included in the mapping. Exclusion criteria: The following types of services were excluded: 1) all services especially dedicated to the treatment of individuals with F0- and/or F1- and/or F7-diagnoses (as per ICD-10), 2) all services especially dedicated to the treatment of the elderly, unless they provide services especially for people with mental disorders (again, except services as per 1), 3) forensic services, 4) services exclusively for child and adolescent disorders.
DESDE-LTC	"Description and Evaluation of Services and Directories in Europe for long-term care" (DESDE-LTC) is an instrument for the standardized description and classification of services for Long Term Care (LTC) in Europe. Coding branches are: ACCESSIBILITY TO CARE CODING BRANCH (A), INFORMATION SERVICES FOR CARE CODING BRANCH (I), SELF-HELP AND VOLUNTARY CARE CODING BRANCH (S), RESIDENTIAL CARE CODING BRANCH (R), DAY CARE CODING BRANCH (D) and OUTPATIENT CARE CODING BRANCH (O). DESDE-LTC is designed for comparison across geographical areas. Therefore, boundaries of health, social care and local administrative areas should be taken into consideration. Classification of health care geographical areas are: H0: Pan-national level, H1: National level, H2: Regional level, H3: Maximum administrative territorial specific health care area, H4: Basic administrative territorial area of specialized mental health, and H5: Minimum local health administrative areas.
MENTAL HEALTH SERVICES: POLICIES AND DESCRIPTION	Policies and general descriptions of the health and social services that provide care to mentally ill in the 9 REFINEMENT countries have been described separately in details. Then, a comparison of the more relevant differences between countries has been prepared and available data for each country will are summarized according the following topics: mental health policy, mental health plan, monitoring and training on human rights, mental health services, human resources, activities of user/consumer associations, family associations and other ngos and patient mobility.
VERONA SES INDEX	The variables considered in this INDEX relate to: Family composition: Single-parent families; Individuals divorced or widowed; Employment: Workers employed in Industry; Workers employed in Services; Unemployment rate; Education: Individuals with Tertiary qualification on people aged 15 or older; Household size: Average number of people per household; Households made up by 1 person; Households made up by 5 or more people; Age composition: Ageing index; Dependency ratio; Individuals below 5 years old; Others: Rented accommodation; Population density; Immigrants.
ATLAS OF MENTAL HEALTH CARE	The Atlas consists of 3 main sections: geographic analyses linking socio-demographic characteristics and services delivered in the study areas; locational analyses of mental health treatments and services delivery (including social services and private affiliated physicians); spatial accessibility analyses of the health and social care for mental health.

Table 1. Instruments and sections composing the REMAST

The collection of the data

After the REMAST test phase, collection of the data was conducted from February 2012 to March 2012. From April 2012 to early November 2012, data had been checked, refined and then analyzed. All data had been gathered in either an ad hoc Access file or an Excel file or a specific website (http://rpc.spsichiatria.univr.it/REFINEMENT_sif/) from different sources: Mental Health Information Systems (e.g. social insurance and administrative databases, psychiatric case registers); datasets from institutes for statistics; Social Care questionnaires adapted from Health Care ones; interviews to both medical and administrative staff; previous reports; and official and reliable websites. All mapped services have been associated to a DESDE-LTC code for a better comparison within the 9 partner countries, thus aiming at the standardization of the services descriptions through mapping trees.

Tables, graphics, boxes, maps and descriptive paragraphs were prepared to show in detail these data for the mapping and description of the structure of mental health care services, including primary, general and specialist health care services and social care services all concerning mental health. This detailed description was employed to illustrate both the spatial distribution and the socio-economic environment of such services in selected Macro and Study Areas in our countries for a total of 9 Macro Areas and 9 Study Areas (**Table 2**). Each Study Area had a population between 200,000 and 1,500,000 inhabitants and it preferably covered a health district or a municipality (or had other specified administrative boundaries) served by a defined range of health services. The Macro Area (for Italy the Veneto Region) had to include the Study Area (for Italy the ULSS 20 Area) and it had a population between 1,500.000 and 10,000,000 inhabitants: this could be identified as a NUTS1 or NUTS2 (see the Nomenclature of Territorial Units for Statistics). The reason to collect data in parallel for the Study Area and for the Macro Area was to statistically obtain information on how different and far the characteristics of the Study Area are from a Macro Area of reference. This allowed to understand if the Study Area was representative of the macro level where it was included or how much and in which direction it was different from the Macro Area.

COUNTRY	STUDY AREA	NUTS classification	POPULATION (> 18 years)	Land Area (km²)
AUSTRIA	**Industrieviertel**	**AT127 + AT122 (without the Lilienfeld district, ID 314)**	**445,748**	**3,921**
ENGLAND	**Hampshire** **(including Portsmouth and Southampton Unitary Authorities)**	**All NUTS-3 UKJ31, UKJ32, UKJ33**	**1,364,799**	**3,769**
ESTONIA	**Tallin municipality**	**EE0 (NUTS 3)**	**328,783**	**158**
FINLAND	**Helsinki and Uusimaa Hospital District**	**approx. FI181**	**1,206,446**	**8,751**
FRANCE	**7 sectors of psychiatry of the Georges Daumézon hospital in the département "Loiret" of the region "Centre"**	**FR246**	**422,853**	**5,626**
ITALY	**ULSS20 - Verona**	**ITD31**	**393,402**	**1,061**
NORWAY	**Sør-Trøndelag**	**NO061**	**225,081**	**18,856**
ROMANIA	**Jud Suceava**	**RO215**	**484,212**	**8,553**
SPAIN	**Girona Area**	**ES512**	**599,473**	**5,585**

Table 2. Study Areas of the REFINEMENT project countries

The data collection procedure was as follows: first of all, a list of all services providing care for the mentally ill from 18 years old living in the study area was prepared. This data collection was carried out through the review of service catalogs and databases, as well as contacting services' managers or team leaders. The listed services were allocated to one (or more) of six DESDE-LTC branches (A, I, S, R, D, O) and fully codified following criteria defined in section B of DESDE-LTC. For a more detailed listing of local services and a description of their characteristics a separate form was completed in section D (service inventory) of the DESDE-LTC. These forms include: Service basic information (e.g., name, type of service), Location and Geographical information about the service (e.g., service of reference, service area), Useful info and contacts (e.g., local definition of the service, sector), Service data (e.g., opening days, opening hours, staffing, system management, economic information, legal system, user profile, number of users, number of contacts or admissions, number of day in hospital or residential structure, number of available beds or places, links with other services), Evaluator information (name and contacts, observations), and Presentation of the DESDE-LTC data in graphical/table format adapted the style proposed by Salvador-Carulla et al. (2012).

Results

Data were analyzed using STATA software, version 11.2. Statistical analyses of the data were conducted throughout four stages:

1. Firstly, it was necessary to conduct a screening of each analyzed variable, thus identifying possible coding errors as well as missing data and outliers.
2. Secondly, it was necessary to make some changes in the variables and to recode them. The possibility of creating synthetic variables to summarize the set of variables of both the staff and the type of payment was also taken into account. For this purpose, multivariate methods that allow the summarization of information were used.
3. Thirdly, once established the groups of codes of interest, the following descriptive statistical analyses were applied: frequency distribution for categorical variables, and mean values as representative parameters in each analyzed context for numeric variables. In each case, the graphics settings for each type of data were used.
4. Finally, crosstabs were used in order to obtain conditional distributions for categorical variables.

Hospital-based acute services

According to the DESDE-LTC classification, all hospital-based acute services categorized as MD-R1 and MD-R2 were included, where MD stands for services specifically addressed to mental health care and R stands for Residential services. All mapped services were in fact firstly classified as either MD (Mental Disorder) or MG (Generic Medical Users) according to the type of care provided. The distinction between MD and MG was considered also for mobile services (see following section).

The codes R1 and R2 refer to acute facilities where users are admitted because of a crisis, a deterioration of their physical or mental state, behavior or social functioning which is related to their health condition (Salvador-Carulla et al., 2011). In these services admissions are usually available within 24 hours and users usually retain their own accommodation during the admission. All R1 and R2 services belong to a hospital setting and a 24-hour physician cover is provided. More specifically, R1 services provide continuous surveillance for 24 hours a day and special isolation measures can be applied. Users are admitted in these facilities because they are considered to be too dangerous to themselves or others to be managed adequately in non-secure facilities, or because of a specific legal judgment which states that for reasons of safety they must be admitted to these particular facilities rather than to the local generic facilities. R2 services have the same characteristics of R1 facilities but their users usually retain their own accommodation during the admission. Moreover, R2 facilities provide regular care (medium intensity) of surveillance and/or security for in-patient admission. For example, hospital units where routinely admissions from a specific catchment area included are coded as R2, as well as acute units from general hospitals, psychiatric hospitals and other specialist hospitals.

For both R1 and R2 facilities, the following data were collected: service basic information (e.g., name, type of service); location and geographical information about the service (e.g., service of reference, service area); useful info and contacts (e.g., local definition of the service, sector); service data (e.g., opening days, opening hours, staffing, system management, economic information, legal system, user profile, number of users, number of contacts or admissions, number of day in hospital or residential structure, number of available beds or places, links with other services); and evaluator information (name and contacts, observations). Forensic services were excluded from the mapping.

In order to provide a clear picture of the availability and efficiency of hospital services for mental health care, mental health beds were counted. These are beds maintained for continuous use by patients with mental disorders. The summary data in **Table 3** show descriptive statistics related to beds availability in acute hospital services (corresponding to DESDE codes R1 and R2) in each country. In detail, the highest number of acute hospital services was reported in Finland (n=22) while in Spain only 1 hospital service was mapped. The highest bed rate per 100,000 adult inhabitants was registered in France (63.38) whereas the lowest one in Spain (7.01). Beds rates are similar instead across the Study Areas of Austria, England, Finland and Norway. Data for Estonia were not reported and for such reason this country was excluded from the final analyses. Acute beds were mapped for both units/wards and institutions, thus including also non-acute beds as part of the same hospital/institution. This may influence how the system works and hence bed rates, AloS etc.

Study Area	**Acute hospital services (R1, R2)**		
	Number of services	**Total number of beds**	**Beds rate per 100,000 inhabitants**
Verona Mental health Department (Italy)	4	55	13.98
Industrieviertel (Austria)	2	104	23.33
Girona Area (Spain)	1	42	7.01
Hampshire (England)*	17	360	26.38
Helsinki and Uusimaa Hospital District (Finland)	22	324	26.86
Sør-Trøndelag (Norway)	3	64	28.43
Loiret Departement (France)	9	268	63.38
Jud Suceava (Romania)	4	215	44.40

Table 3. Hospital beds for acute patients: numbers and rates

Secondly, data on staff number and working hours were collected, by considering firstly the single professional figures (doctors, psychologists, nurses, social workers, occupational therapists and other health workers) and then by grouping them in 4 multi-professional teams (Team 1 = Doctor+ Psychologist + Nurse + Social Worker or Occupational Therapist; Team 2 = Doctor + Nurse; Team 3 = Doctor + Psychologist + Nurse; Team 4 = Doctor + Psychologist + Social Worker or Occupational Therapist). The summary data in **Table 4** show the percentages of professionals employed in psychiatric hospital-based acute services. Data on staff were collected using Full Time Equivalents (FTE). FTE is a unit to measure the amount of the workforce per unit of time, thus allowing comparisons across services or systems with different average numbers of weekly working hours per employee. FTE at the individual level is often used to measure a worker's involvement in a project, while, in an organization, it may be used to track cost reductions. A FTE of 1 refers to a full-time worker, while a FTE of 0.5 signals a half-time worker.

Study Area	**Doc**	**Psyc**	**Nurses**	**SW**	**OT**	**Other**	**Nr of obs**	**Doc + Psyc + Nurse + SW or OT**	**Doc + Nurse**	**Doc+ Psyc+ Nurse**	**Doc + Psyc + SW or OT**
Verona Mental health Department (Italy)	14.77	4.50	56.41	2.70	0	21.62	4	2	0	2	0
Industrieviertel (Austria)	20.97	1.94	68.16	1.55	3.88	3.50	2	2	0	0	0
Girona Area (Spain)	35.71	3.57	53.57	0	0	7.14	1	0	0	1	0
Hampshire (England)	8.02	4.22	76.63	2.11	5.88	3.13	17	17	0	0	0
Helsinki and Uusimaa Hospital District (Finland)	8.50	3.90	50.70	4.37	2.61	29.92	22	20	0	0	0
Sør-Trøndelag (Norway)	14.35	8.06	60.71	0.54	1.08	15.27	3	2	0	0	0
Loiret Departement (France)	7.53	0.98	53.73	2.29	0.02	35.44	9	7	0	0	0
Jud Suceava (Romania)	15.87	6.35	68.25	6.35	3.17	0	4	3	0	1	0

Table 4. Professional staff in acute hospital care (percentages of FTE)

Finally, geographical information about these services were collected through a Geographical Information System (GIS) in order to describe the density of hospital services in the Study

Area and verify their distances from other mental health services and from the most inhabited areas.

	Density of acute hospital units for 1000 square Km (n services/ LAND AREA (Km^2)*1000	**Mean travel time from acute hospital unit to population (minutes)**	**Travel time between acute hospital unit (minutes)**			**Percentage of people living within 10, 20, 30, >30 minutes from acute hospital unit**			
			min	mean	max	**10**	**20**	**30**	**>30**
Verona Mental health Department (Italy)	3.77	17	7	17	23	76%	15%	6.5%	2.5%
Industrieviertel (Austria)	0.51	30	30	30	30	52.5%	31%	12%	4.5%
Girona Area (Spain)	0.18	35	not applicable, 1 acute hospital unit	not applicable, 1 acute hospital unit	not applicable, 1 acute hospital unit	19.5	12.1	26.6	41.8
Hampshire (England)	4.51	28	0.07	25	51	63.7	17.2	18.4	0.59
Helsinki and Uusimaa Hospital District (Finland)	2.51	40	1	43	114	52%	34,5%	10%	3.5%
Sør-Trøndelag (Norway)	0.16	112	0.7	9	14	54%	11%	4%	31%
Loiret Departement (France)	1.6	38	5	9	13	50%	14%	9%	27%
Jud Suceava (Romania)	0.47	59	15	43	73	33.1%	27.6%	22.32%	17%

Table 5. Geographical variables of the hospital-based acute services

As for the density of acute hospital units for 1000 square Km it is interesting to note that the Norwegian Study Area is 18 times bigger than the Italian one, thus showing an evident difference in the distribution of the services in these two Study Areas.

Mobile services

Out of the 9 countries included in the REFINEMENT project, three (Austria, Estonia, Romania) were excluded from these analyses since they did not provide the information on the mobile services because they were not publicly available. Mobile services were identified by a specific code, according to the DESDE-LTC. The codes O1, O2, 05, and O6 and O7 referred to all mobile services, with the codes O1 and O2 referring specifically to acute services, and O5 and O6 to non-acute ones and O7 to low intensity mobile services. The

DESDE-LTC instrument defines mobile services as those facilities where user contacts occur 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 50% of contacts should take place away from the premises where the service is based. Moreover, according to the DESD-LTC definitions, acute mobile services are those facilities where users are regularly admitted because of a crisis (deterioration in physical or mental state, behavior or social functioning which is related to his or her condition) for alleviating this deterioration. The admission to the acute program is usually available within 72 hours. Non-acute mobile services are all the other mobile services not meeting these criteria.

A total of 184 mobile services were mapped: 114 mental health oriented services (Mental Disorder - MD) and 70 services for general health (Medicine General - MG) (see **Table 6**), according to the distinction provided by the DESDE-LTC instrument. In all countries but Norway and France, mobile services were mostly MD instead of MG. In England, Finland and Spain no MG services were mapped. However, missing rates were not reported since not in all countries it was possible to identify available services. For instance, in the sole Norwegian Study Area, in two municipalities (Osen and Midtre-Gauldal), services could not be mapped and were thus not included in the global analyses.

Table 6 also reports the staff composition for each type of service (either MD or MG or all services) in terms of percentages on the total workforce with nurses, social workers and other workers being the most employed in all types of mobile services. Other workers are all those health workers whose job is not classified as "doctors", "psychologists", "nurses", "social workers" or "occupational therapists". For instance, voluntary staff is included in this percentage. On the total workforce, the highest percentage of nurses is reported in Finland (70.74%). Interestingly, occupational therapists are the least employed type of staff in all countries: they are employed only in England (8%), Norway (1.16%) and France (3.64%).

Study Areas	**Nr of services**		**Staff**											
			DOC		**PSYCH**		**NURSES**		**SW**		**OT**		**OTHER**	
	MD	**MG**	**MD**	**MG**	**MD**	**MG**	**MD**	**MG**	**MD**	**MG**	**MD**	**MG**	**MD**	**MG**
Verona Mental health Department (Italy)	**8**	**3**	**21.54**	**0**	**0.36**	**2.53**	**38.01**	**0**	**7.67**	**2.53**	**0**	**0**	**32.43**	**94.95**
Total	**11**		**1.14**		**2.41**		**2.02**		**2.80**		**0**		**91.63**	
Girona Area (Spain)	**1**	**0**	**0**	**X**	**0**	**X**	**0**	**X**	**25.00**	**X**	**0**	**X**	**75.00**	**X**
Total	**1**		**0**		**0**		**0**		**25.00**		**0**		**75.00**	
Hampshire (England)	**60**	**0**	**10.76**	**X**	**12.79**	**X**	**34.02**	**X**	**19.18**	**X**	**8.00**	**X**	**15.26**	**X**
Total	**60**		**10.76**		**12.79**		**34.02**		**19.18**		**8.00**		**15.26**	
Helsinki and Uusimaa Hospital District (Finland)	**9**	**0**	**9.88**	**X**	**1.94**	**X**	**70.74**	**X**	**7.75**	**X**	**0**	**X**	**9.69**	**X**
Total	**9**		**9.88**		**1.94**		**70.74**		**7.75**		**0**		**9.69**	
Sør-Trøndelag (Norway)	**34**	**56**	**2.32**	**X**	**4.69**	**X**	**18.94**	**X**	**25.61**	**X**	**1.16**	**X**	**47.29**	**X**
Total	**90**		**2.32**		**4.69**		**18.94**		**25.61**		**1.16**		**47.29**	
Loiret Departement (France)	**2**	**11**	**2.59**	**1.16**	**0**	**6.11**	**72.12**	**16.93**	**6.00**	**2.71**	**0**	**4.84**	**19.29**	**68.26**
Total	**13**		**1.51**		**4.60**		**30.59**		**3.52**		**3.64**		**56.14**	

Table 6. Number of Mobile Services and Staff employed

As for the number of opening days and hours (**Table 7**), the averages have been calculated considering all services (e.g. for Verona 6.375 is the average of opening days per week of all 8 MD services, 6.33 for all 3 MG services and 6.36 for both MD and MG services). The final columns report population ratios, i.e. the sum of the opening hours across services divided by the total adult population, and multiplied by 100,000.

Refinement Study Areas	Number of services		Opening days and hours					
			AVERAGE DAYS		AVERAGE HOURS		HOURS PER 100,000 POPULATION	
	MD	MG	MD	MG	MD	MG	MD	MG
Verona Mental health Department (Italy)	8	3	6.375	6.33	76.50	117.00	155.57	59.48
Total	11		6.36		84.60		215.05	
Girona Area (Spain)	1	0	5.00	X	14.00	X	2.34	0
Total	1		5.00		14.00		2.34	
Hampshire [1] (England)	60	0	5.47	X	66.93	X	284.44	0
Total	60		5.47		66.93		284.44	
Helsinki and Uusimaa Hospital District (Finland)	9	0	5.00	X	40.00	X	29.84	0
Total	9		5.00		40.00		29.84	
Sør-Trøndelag (Norway)	34	56	5.35	6.25	56.13	119.15	773.10	2964.49
Total	90		5.93		96.70		3737.59	
Loiret Departement [2] (France)	2	11	X	6.25	X	52.625	X	99.56
Total	13		6.25		52.625		99.56	

Table 7. Opening days and hours of Mobile Services

Study area	Artificial surfaces	Agricultural areas	Forest and semi natural areas	Wetlands	Water bodies
Verona Mental health Department (Italy)	9.53%	66.31%	18.01%		6.15%
Girona Area (Spain)	4.25%	28.83%	66.23%	0.13%	0.57%
Hampshire (England)	13.53%	68.62%	16.70%	0.41%	0.74%
Helsinki and Uusimaa Hospital District (Finland)	9.33%	25.75%	57.87%	0.60%	6.44%
Sør-Trøndelag (Norway)	0.64%	7.30%	71.60%	15.33%	5.13%
Loiret Departement (France)	5.20%	67.94%	26.04%	0.02%	0.81%

Table 8. CORINE Land Cover 2006 in the REFINEMENT study areas

Discussion

The current status of hospital-based acute services and mobile services for mental health care was reviewed in 9 European countries by use of data compiled by international mental health experts and economists and from published country profiles. Although the data might not be fully accurate, they are the most recent and updated ones available.

A strength of these analyses is in fact that it finally provided harmonized data from 9 different countries, including Estonia and Romania whose registers are sometimes difficult to retrieve and France where recent and updated information had been missing for a decade (Priebe et al., 2008). In this sense, the study provided a wide panorama of both Western and Eastern Europe as for the provision of mental health care. Largely primary sources were used, and reported data were accurately analyzed by a team of experts three times.

A limitation of the study is that data on admissions, contacts and users were partially collected and not reliable. To the best of our knowledge, these data are difficult to be obtained for most countries especially for crucial aspects like contacts and involuntary admissions. Moreover it is essential to underline the fact that the number of services is not a sufficient indicator of the quality of the service itself. In other words, only one service within a delimited Study Area could be more effective than more services of the same type. To have some relevant information in terms of quality, other data (as, for instance, number of users) should be considered alongside number of services. However, this work can be seen as a first step towards the political challenge to arrange consistent and reliable mental health data collection across European countries.

As for topic 1 (hospital-based acute services) the REFINEMENT description of these specific psychiatric services and the insight into the current European mental health systems could directly help researchers, medical staff and policymakers to understand the actual extent of the provision of mental health care for acute patients. If economic, political and sociocultural variations among countries are taken into account, the present multi-site study represents a useful tool for a reform of a common European mental health care system.

Access to high-quality psychiatric care is associated with socio-economic differences. It is thus particularly important, in terms of equity, to guarantee homogeneity of costs and provision of mental health care across Europe (Knapp et al., 2006). Care institutions in general and hospital in particular are expensive and it is important to provide routine descriptions of these services in order to check their effectiveness.

REFINEMENT data confirm that acute psychiatric services in hospitals are still active and further research should help to understand how provision of institutionalized mental health care in different countries will have to change in order to have more homogenous and comparable mental health systems across Europe. Although community care has a better effect than hospital-based treatments on the outcome and quality of life of individuals with chronic mental disorders (Jacob et al., 2007), hospitals are still a core part of mental health care and their use should be constantly monitored, especially from an economic point of view.

As for topic 2 (access to mobile services), results showed that people are spread differently and not homogenously all over the 6 REFINEMENT countries with mobile services. Moreover they differ along many dimensions like the sociodemographic and socioeconomic composition of population: age, gender and socio-economic status. These differences increase when comparing countries even if they all belong to the European Union, with the comparisons being made among different areas in relation to populations within the same country. In this sense the contrast among different countries becomes more evident. When reporting the number of mobile services, it was important to underline the fact that this datum should be weighted on the number of users (both potential and real) and the employed staff. For this reason the results of the statistical analyses here reported were corroborated by the maps which explain the distribution of all services in each Study Area and the consequential coverage of mobile services.

Conclusions

In line with the importance of mental health for European countries and the objectives of the 'Europe 2020' strategy, the REFINEMENT project produced relevant and valid comparable data on mental health hospital-based acute services and mobile services in 9 European countries. Comparability of data was in fact low before the REFINEMENT project which retrieved its data trying to follow the European Commission's directives to ensure harmonized and comprehensive health data collection.

The REMAST tool allowed both a vertical (national, regional and local like for the Study and Macro Areas) and a horizontal (international) comparison with the aims of producing homogenous results. Comparable statistical analyses and spatial units provided a clear picture of the European mental health systems.

Through the description of the spatial organization of the mental health services mapped within the REFINEMENT project, the relationship between the geographical distribution of the services and their outcomes and access was analyzed for better exploring how the delivery of mental health care can be improved. Mental health services locations could be better planned after this geographical evaluation together with a spatial decision support for mental health care delivery. This work aimed then at providing a spatial decision support for a better planning of mental health services locations.

2.4.2 STUDY 2 - The REFINEMENT Glossary: an example of a multilingual tool

Background

Health information is expected to reach the people who need it in the languages they can understand (WHO, 2007). With this aim dictionaries and glossaries are officially provided in order to make health information more equitable and effective. For example, the Regional Office for the Eastern Mediterranean of the World Health Organization is engaged in bridging gaps and fostering understanding between people of different cultures and languages. It considers multilingual communication as an essential tool for improving health, strengthening health systems and providing essential health for all. Official definitions for health care are then provided through multilingual glossaries like the one by www.euro.who.int.

The quest for a common terminology faces the difficulty of cross-societal equivalence of concepts: services and structures for example may have different meanings in different countries. So, in order to compare a service or a structure across countries it is necessary to have confidence that their components and proprieties can be compared and indicate something equivalent (Rose, 1991). Such an equivalence of meaning is not necessarily obtainable through translation. Conceptual equivalence also requires intimate knowledge of context and culture (Hantrais and Ager, 1985; Hantrais and Mangen, 1996). A detailed consultation process to ensure robust concepts, and linguistic and measurement equivalence is therefore a vital element of the cross-national research process (Iyengar, 1993).

Glossaries in general and health glossaries in particular are distinguished between ontological glossaries and operational ones. In the ontological glossary, different meanings, cultural differences, relations and synonyms and semantically similar terms (also called "synset") have to be described in detail. In the operational glossary it is instead important to get a common language which is useful for a project (like in the REFINEMENT case) and which is agreed across the different partners (the REFINEMENT partners). For example, in the psychiatric research area, operational glossaries are more used and one example is the Diagnostic and Statistical Manual of Mental Disorders (DSM) one approved by the American Psychiatric Association (DSM-5, 2013). An ontological glossary helps to sort out all different meanings and cultural differences of the employed terms. In other words, it is useful to develop the conceptual map and the related ontological glossary of the area of international health financing. This is very important and needed, but actually beyond the scope of the REFINEMENT project. However, to the present days, previous comparative projects on mental health involving different European countries have encourred in the difficulty of using a common terminology but only a few (e.g. DESDE-LTC by Salvador-Carulla et al., 2013) have produced an either public or internal glossary about mental health services.

The REFINEMENT project produced its own final glossary, i.e. a pragmatic and consistent tool to define mental health care services. Here the methodology and construction of this systematic structured glossary of mental health (provision of care, services, financing) are described.

Materials and Methods

The REFINEMENT project developed from its very beginning a glossary of all terms used to identify the provision and services of mental health care across Europe. When preparing the glossary, a preliminary discussion was whether its first aim was to be useful for the sole REFINEMENT project or whether it could also be addressed to later users from countries other than the REFINEMENT ones. If the first option could make things apparently easier by making the REFINEMENT group choose terms and definitions on which only the REFINEMENT partners had to agree, the second option offered the chance to produce a linguistic tool of help for any future project on the psychiatric domain especially related to costs and services (both health and social ones) concerning mental health care. The answer to this dilemma was to prioritize usability for the project rather than global validity when conflicts may appear, and to try to reach only operational definitions of highly complex terms such as "Public/Private" or "Urban/Rural" where a final solution could be difficult.

As for the methodology adopted to produce the glossary, firstly all the meanings in English had to be agreed upon. During the different phases of the project (preparation of the tools, collection and analyses of the data etc.) different definitions and translations were presented in order to start clarifying the meaning of each term and to find an agreement on its definition. In fact, the glossary was not conceived as a "melting pot" of terms or as a "cut&paste" of definitions from several dictionaries, but it was the result of a deep linguistic (and practical/scientific as well) discussion on the terms used in the REFINEMENT tools.

The glossary of mental health service terminology was developed to qualify and describe the terms contained in the REFINEMENT Study Areas. The glossary (see **Appendix**) standardized the language of classification, thereby improving the accuracy of categorization according to the classification and improving communication in the sector (Wood and Pennebaker, 2004).

It goes without saying that the glossary itself started as a developing one in the sense that it changed (and not only grew) with the progress of the project itself.

The staged process

The glossary of terminology consisted of a six-stage process conducted over a 36-month period. These stages were as follows.

Stage 1: The Draft of the Glossary

At the beginning of the REFINEMENT project, for the collection of national data of the first tools applied (e.g. REMAST, see **paragraph 2.4.1**) it was necessary to agree on common basic definitions of mental health services. A preliminary “Draft of the Glossary” was prepared by the REFINEMENT team of the University of Verona. The draft contained the main terms and nouns mostly recurring in both the REMAST tool and the REFINEMENT project official document. For each term (mostly related to mental health services), definitions were provided from pre-existing dictionaries and glossaries. This initial Draft of the Glossary was then developed from a review of the classification literature, including taxonomic principles. Among the different sources, the team of the University of Verona recurred to the Who-Aims glossary directly referring to developing countries but giving in any case some interesting inputs for a general definition of psychiatric services.

Stage 2: The Operational Glossary

The initial Draft of the Glossary was reviewed by all other REFINEMENT partner countries. They completed it by assessing the internal and face validity, credibility, and representativeness of the initial glossary of terminology and by specifying modifications. Each definition was amended by each country according to their health and social care system. At this stage, all terms included in the REFINEMENT glossary were discussed as for their use and synonyms, paying a particular attention on their definitions since synonyms do not actually always refer to the same concept, but they tend to partly overlap (for instance "Pay for Performance" is not the same as "Pay by Results"). A first "Operational Glossary" was made by adding new terms and changing them as the tools were developed. The definitions were taken from different official sources (existing glossaries, national and international documents etc.). Especially starting from the WHO glossary (WHO Terminology Information System [online glossary] http://www.who.int/health-systems-performance/docs/glossary.htm) definitions were completed and compared with those provided by dictionaries and encyclopedias. References were reported for more specific terms.

Stage 3: The REFINEMENT PANEL List of terms

A REFINEMENT PANEL was created for the sole glossary. It was composed of one person for each of the 5 REFINEMENT tools (i.e. REMAST, FINCENTO A, FINCENTO B, REPATO, REQUALIT), the coordinator of the project and the responsible of the glossary. People in charge of each tool selected the most important and recurring terms of their tool and sent their own list to the responsible of the glossary. The lists of terms from the 5 tools were crossed and compared with a total list of all REFINEMENT tools produced by the responsible of the glossary through an algorithm. This total list was made by mechanically counting the occurrences of the words in a unique .TXT file containing all REFINEMENT tools. **Figure 5** shows and example of the results of the algorithm, with the most recurrent words and the list in alphabetical order.

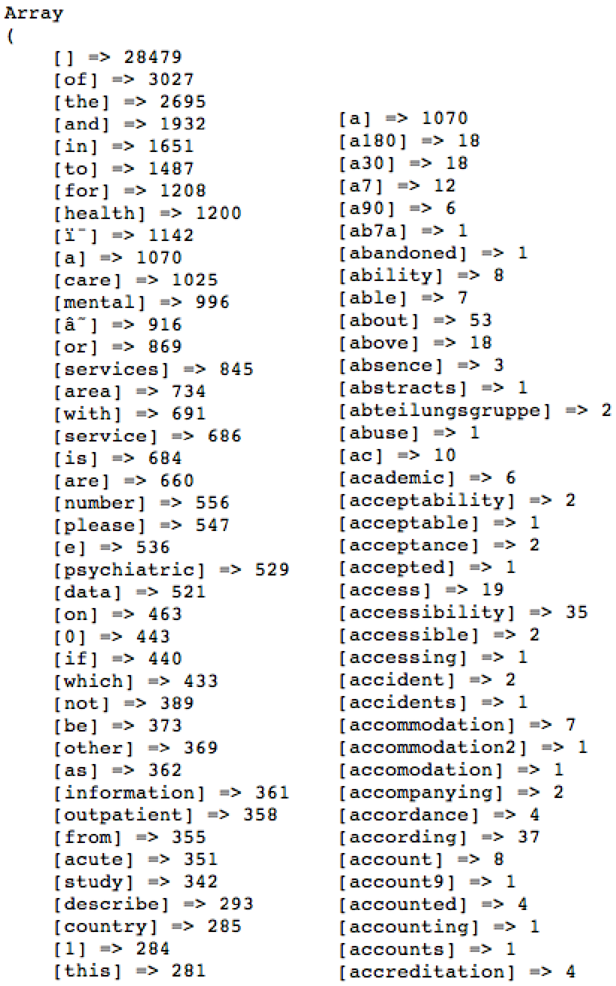

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Figure 5.

The REFINEMENT PANEL for the glossary produced then a unique list by comparing the lists coming from each tool with the general list from the algorithm. The list was circulated among partners after the approval of the coordinator of the project.

Stage 4: The REFINEMENT PANEL Glossary

Once the REFINEMENT PANEL list amended and finalized, the responsible of the glossary retrieved all the definitions for the approved terms from the Operational Glossary. Also existing glossaries, official resources, literature and previous work done for the REFINEMENT tools were consulted. This new glossary was then circulated among the REFINEMENT PANEL members. The definitions were checked also by other REFINEMENT members not necessarily composing the PANEL but belonging to different fields (economics, psychiatry, statistics…) and coming from different countries. Feedbacks, comments and information from these partners were taken into account to produce a final specific dictionary of sole terms referring to mental health services due at the end of the project. Unique and approved definitions which could satisfy all nine REFINEMENT partners were obtained by discussing and voting (if needed) the most precise definitions. All critical terms where consensus was not reached were further discussed during meetings.

Stage 5: The final REFINEMENT Glossary

The REFINEMENT PANEL collected all comments and revised the REFINEMENT PANEL Glossary accordingly. Especially for the economic section of the REFINEMENT project (WP4 and WP5) concerning financing and incentive terms, the inclusion of specific words and their definition was clarified only after the data collection. The glossary was in fact re-read on the basis of already collected data. With the end of the REFINEMENT project and the finalization of the data analyses the REFINEMENT PANEL assessed the validity and realiability of the defintions provided. The final REFINEMENT Glossary was then produced (see **APPENDIX**).

Some exemples of controversial terms

In **Box 6** and **Box 7** we provide two clear examples of English terms which appeared to be problematic during the collection and analyses of the REFINEMENT data.

<u>‘PUBLIC’ OR ‘PRIVATE’</u>

Within the Refinement Glossary we did not want to define the terms "Public" and "Private" in general. We just needed instead a common agreement on a series of financing related terms such as "Public and Private health expenditure", "Public and Private funding", "Public and Private management", "Public and private ownership", "Public and private delivery" and so on. In fact, "Public" and "Private" are not just words: there are concepts behind them and such concepts are different depending on the context (legal and factual) in which they are used. The tools for financing and incentives (WP4 and WP5) showed many different meanings attached to "Public" and "Private": of course there is a trivial meaning which one can find in any dictionary, but this is not useful for the project, which had to go into detail and variations of use (especially also across countries). So, we had to come up with more specific definitions (and synonyms) of these two terms/concepts for the development of this toolkit. To the best of our knowledge, in health economics public expenditure refers to all costs eventually paid by the State and related Governmental agencies after pooling and budgeting. Therefore "Public Mental Health Expenditure" refers to the part of the total mental health expenditure incurred by the government (this includes also payment to private providers working under agreement with the Governmental agencies, and reimbursement to users after out-of pocket expenses). A different case is when the State rules that any worker –or citizen over a given income- should have a private insurance which is paid by to a private company either by the worker and/or the company. In this case this amount does not enter in the process of public financing (revenue collection, pooling, budgeting and expenditure) and the State just plays a regulatory function. Of course there are huge differences between countries that work under a universal coverage schema fully reimbursed by the state (Spain until 2011), the German system, the Chilean system (where high income citizens should contract a private insurance level 1), Canada or the health reform system in the US.

Box 6.

‘HOSPITAL CARE

What is exactly a ‘Hospital Care’? In England any specialized ambulatory and in-patient care takes place in a structure which is called ‘Hospital’. When analyzing the actual structure to which the term ‘Hospital’ refers to in England, it is clear instead that it refers to a secondary care service. In Austria, such an ambulatory care is even forbidden in ‘Hospitals’ since it legally belongs to those singlehanded specialists who run their private bureaus. This means that in Austria ‘Hospital Care’ means just ‘In-patient Care’ or ‘Residential Hospital’ (as suggested by the DESDE, 2013). For example, a definition of the term ‘Hospital’ was only partially reached at EPCAT/ESMS after 15 years. In the original ESMS ‘Hospital’ was a first level branch descriptor and it referred to those facilities which were registered as hospitals in the national listings. From an ontology point of view this was rather unsatisfactory but it allowed to progress in the development of the system. ‘Hospital’ is actually a legal term that defines a health meso-organisation registered as such in the official listing at country or at regional level. This register has legal implications for quality standards, budgeting etc. However the same type of facility may be registered as ‘Hospital’ in a region of Spain (i.e. Catalonia) and not in a neighboring one (i.e. Valencia). On the contrary very different organizations with different financial arrangements may be registered as ‘Hospitals’ in the same region. The use of this term in WHO-AIMS and also in SHA 2.0 is debatable. For example ‘Psychiatric Hospitals’ are a type of ‘Target- specific hospitals’ and not an isolated category different from any other specific ‘Hospital’. A definition of hospital is provided in the DESDE-LTC glossary and in ESMS-2:

Hospitals are meso-organizations 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. ‘

In order to cluster main types of care DESDE-LTC classifies in the same main branch those facilities where the patient stay overnight and where there is a physician 24-hours on duty. We had a problem in the distinction between on duty and on call, for instance. In the next version on call may be also included when this service is provided with high frequency – at least several times a week.

Box 7.

Conclusions

Glossaries are fundamental to provide adequate translations of the terms employed in providing mental health care in services all over Europe. The standardization of the definitions constitutes the best way to ensure a common language across countries.

The REFINEMENT glossary is then one of the tools developed by the REFINEMENT group to assist policy-makers in developing best practice models for mental health care financing. With this aim it is meant to provide terms and definitions applicable to all countries.

In Mental Health provision of care in Europe there is an undoubted lack of standardization of definitions of terms across countries and also in the way in which the definitions are interpreted. Some terms have different meanings or different specificities of meaning in, and even within, different countries e.g., ‘public’ or ‘private’and ‘hospital care’. Although there was consensus that this lack of precision should not prove an insurmountable difficulty or prevent the systematic gathering and interpretation of meaningful information, it was decided that focus groups to clarify definitions should be conducted within the project to minimize the risk posed. There was further agreement that an important aspect of the whole exercise was to compile an internal glossary of terms and definitions and their different meanings across different countries.

The REFINEMENT glossary could eventually be used to support the development of an international nomenclature and classification system for mental health policy formulation.

There is no agreed international, and namely, European framework for mental health service delivery terminology. This glossary offers the first step to agreeing on the standard concepts and definitions used to describe services.

CHAPTER 3

MENTAL HEALTH AND INTERNET

3.1 Mental health information and support in the Internet

The use of the Internet as a mental health communication tool is still an almost unexplored field of research. However there is a growing interest in investigating how the Web can help medical staff to prevent mental diseases and promote mental wellbeing. Such an interest is directly originated by the popularity of the Internet as a tool to research mental health information and by the diffusion potential of the Internet. Mental health communication mediated by the Internet is supposed to have great potential to promote desired behavior changes through mass customization, interactivity and convenience (Neuhauser and Kreps, 2003).

An entire review, the "Journal of Medical Internet Research" is fully dedicated to this new way of being informed of one's health and wellbeing. Moreover, this growing interest is also shown by threads in forums, chat groups or blogrolls. Medicine and health are key subjects in the Internet from both the supply and the deman points of view. They are in fact among the first reasons why people consult the Internet. In the last few decades, the Internet has invaded the health domain in general and that of mental health in particular in two important aspects (Kivitis et al., 2009):

a) the process of the construction and circulation of knowledge,
b) the relations between health actors and practices.

As for the aspect a), the Internet has become a resource of public information about illnesses, provision of care, risk factors and professional services. It is a useful tool to spread health information in general and in particular it is playing a significant role in mental health information-seeking. Moreover, today it is a fundamental mean of communication having a deep impact on web-users' mental health and recourse to treatment.

For the future, the Internet is estimated to become the major source of information on health and welfare in general, since health related issues are already the most researched topics on the web (Yellowlees et al., 1999). Current estimates suggest that over 1.8 billion people have access to over 2.5 million sites on the Internet (Internet World Statistics, 2009) and these numbers are expected to grow with the increasing diffusion of the Internet. As many as 80% of Internet users in developed countries use the Internet to search for health information, typically to find information on conditions, symptoms, diseases and treatments (Shuyler and Knight, 2003; Pew Internet, 2006; Khazaal et al., 2008). For instance, in the US, around 20% of adults use the internet for health information (Baker et al., 2003) and a survey in seven European countries (Norway, Denmark, Germany, Greece, Poland, Portugal and Latvia) in 2005 found that 71% of all adults reported using the Internet for health information (Andreassen et al., 2007). In France, the study by Médiamétrie (2012) showed that 2011 had been an important year for the strengthening of internet use in France. More and more numerous – 40 millions, i.e. 6% more than in 2010 – the web-surfers were also more connected: about 2 French persons out of 3 connected to Internet every day more or less. Each web-surfer spent on average 1h25 every day online. The institute also reported that social networks represented 1/5 of the time spent on the web. Three people out of 4 were subscribed to a social network.

Generally speaking, public perceptions of the importance of the Internet as a source of health information have risen dramatically in the last decades (Kummervold et al., 2008). In this vein, the uptake of the Internet and related technology offers unprecedented opportunities to deliver online health promotion, prevention and early intervention strategies at a population level (Collin and Burns, 2008).

As for mental disorders, information is commonly accessed online, particularly by those with a psychiatric diagnosis or by their carers (Reavley and Jorm, 2011). John Powell and Aileen Clarke (2006) are believed to have been the first to study and investigate the population prevalence of the Internet use for mental health information and the relative importance of the Internet as a mental health information source. According to them, the Internet has been used as a source of mental health information by over 10% of the general population and by over 20% of those with a history of mental health problems. **Figure 6** lists the most visited and trusted websites for mental health information.

Table 2
Top-rated currently available websites for mental disorders.

Depression	
Top websites (2010) [26]	
Medicinenet.com	http://www.medicinenet.com/depression/article.htm
Netdoctor.co.uk	http://www.netdoctor.co.uk/depression/index.shtml
The Royal College of Psychiatrists	http://www.rcpsych.ac.uk/default.aspx?page50
Top websites (2008) [17]	
National Health Service (NHS)	www.nhs.uk/depression
National Institutes of Mental Health (NIMH)	www.nimh.nih.gov/health/publications/depression/complete-publication.shtml N2 10 71 www.nimh.nih.gov/publicat/depressionmenu.cfm www.nimh.nih.gov/medlineplus/depression.html
SANE	www.sane.org.uk/About___Mental___Illness/Depression.htm N3 10 66 www.sane.org.uk
Top Australian websites (2002) [19]	
beyondblue	www.beyondblue.org.au
BluePages	www.bluepages.anu.edu.au
University of New South Wales Clinical Research Unit for Anxiety and Depression (CRUfAD)	www.crufad.unsw.edu.au
Bipolar disorder (2009) [14]	
Black Dog Institute	www.blackdoginstitute.org.au
National Institutes of Mental Health (NIMH)	www.nimh.nih.gov
bipolar.about.com	www.bipolar.about.com
ADHD	
Top UK websites (2008) [43]	
BMJ Publishing Group Best Treatments	www.besttreatments.co.uk/btuk/conditions/10235.jsp
NHS Direct Health Encyclopaedia ADHD	www.nhsdirect.nhs.uk/articles/article.aspx?articleId=40&sectionId=27010
Pharmaceutical company Janssen-Cilag Products	www.janssen-cilag.co.uk/bgdisplay.jhtml?itemname=parents_background_adhd&_requestid=1343815&s=1
Top websites (2003) [34]	
National Institutes of Mental Health (NIMH)	http://www.nimh.nih.gov/publicat/adhd.htm
Interactive metronome	http://www.interactivemetronome.com/abstracts/NIH/NIHConcConf.htm
Northern County Psychiatric Associates	http://www.baltimorepsych.com/adhd.htm
Schizophrenia (2003) [34]	
Medical Journal of Australia	http://www.mja.com.au/public/issues/feb3/carr/carr.html
Treatment Advocacy Centre	http://www.psychlaws.org/
Healthcommunities.com	http://www.mentalhealthchannel.net/schizophrenia
Suicide prevention (2010) [36]	
Suicide.org	www.suicide.org
Suicideline	www.suicideline.org.au

Figure 6. List of websites for mental health information seeking (from Reavley and Jorm, 2011)

As for the aspect b), it has also been found that the Internet supports the primacy of health professionals as the most used and the most trusted sources of information for health problems (Pennbridge et al., 1999). In fact, the Internet is a sharing knowledge and expertise tool for professionals and also a powerful instrument for them to influence the public opinion. It can be used to prevent and promote about health issues since health professionals and experts can use it for counseling and support to patients. Last, but not least, the Internet can be used also as an indispensable tool for administrative relations and communication between medical staff. For these reasons, it is urgent to re-think the traditional relations between patients and doctors, the latter not having the monopoly of the access to knowledge (Akrich and Méadel, 2001).

In the light of all these changes in the provision of information – for both the aspects a) and b) - the Internet has been emphasizing more and more the role of communication experts in mental health research. More precisely, the Internet has pushed sociologists to investigate the use of the Internet and of all International Technology and Communication (ITC) instruments in the communication of health services and in the health information. There is a growing interest in understanding the effect that online information-seeking has on patients' experiences, empowerment and interactions with healthcare providers.

The Internet is in fact a new place to live which has radically changed the production and use of information and "e-health communication" (i.e. health promotion on the Internet) efforts that are mediated by computers and other digital technologies may have great potential to promote desired behavior changes through unique features such as mass customization, interactivity and convenience (Neuhauser and Kreps, 2003). E-health has actually proved to be an efficacious instrument to cut costs and improve the health of the public (National Research Council, 2000; Science Panel on Interactive Communication and Health – SPICH, 1999). Patients' use of the internet has been a focus of scholarship in sociology, medicine and health services research (Ziebland, 2004). This body of research has examined patients' use of the Internet to access health-related information (Czaja et al., 2003; Rutten et al., 2006, Seçkin, 2010), gain confidence in the health context (Hay et al. 2008, Ybarra and Suman, 2006) and gain a sense of control over their own health (Rains, 2007). As access to the Internet has become increasingly common in homes, workplaces, hospitals and educational institutions, researchers have sought to understand how individuals use this resource in relation to their own health. The Internet for health has become also an important subject for investigation thus enhancing a new field of studies called “e-health studies”, as also reported by the European Commission (European Commission et al., 2013).

After the evaluation of the advantages and disadvantages of the Internet **(paragraphs 3.1.1** and **3.1.2**), the quality of its information on mental health (**paragraph 3.1.3**), and the socio-economic status and residence compared to the use of the Internet (**paragraph 3.1.4**), the **paragraph 3.2** analyzes how young people look for mental health information and support on the Internet. Once reviewed some pre-existing surveys and questionnaires, the new **STUDY 3** (The Fils Santé Jeunes Questionnaire) and **STUDY 4** (The e-MentH Questionnaire) are presented. They were conducted within the Equipe DS3, Déterminants sociaux de la santé et du recours aux soins of the Institut National de la Santé et de la Recherche Médicale, INSERM, at the Université Pierre et Marie Curie, with Pierre Chauvin and Isabelle Parizot.

These two studies are aimed at showing how the Internet allows for a new way of thinking about mental health and new modalities of production and diffusion of the information developed by the web technology. The general public can access more mental health information thanks to the web and its several social applications. Being informed on mental health through the Internet can make patients be equipped, enabled, empowered, engaged, equals, emancipated and experts (Eysenbach, 2008).

3.1.1 Pros of the Internet

In theory, the Internet offers certain advantages as a health information resource. In particular, it provides convenient and anonymous access at any time, from any location, to a wide range of expert sources; and through virtual communities it can provide peer support and social interaction (Renahy, 2010). Health-related use of the Internet has been hailed as a tool to support the emergence of the informed and empowered health consumer (Hardey, 1999).

The anonymous status on the Internet (Mautner, 2005) and the diversity and the importance of accessible data seem to partially explain the success of health information seeking on the web. Information on the web has the potential to inform psychiatrists, educate patients (or carers) about treatment, assist the community in identifying common mental disorders and potentially useful treatments and inform the medical profession and the public health community about the views of consumers (Christensen and Griffiths, 2000).

As already mentioned, one of the main advantages of the Internet is the fact that it is widely accessible at low or no cost. It can then represent a useful tool for people living in deprived areas or in places where a few health services are provided. It is in fact possible that the distance from services make people address more to the Internet thus using online support in substitution to ordinary services. In this sense, the Internet is likely to increase the general public's access to treatment and to decrease unmet need. For instance, global accessibility of online mental health information has the potential to be very beneficial to physicians and families of patients in developing nations where there are 10- to 100-fold fewer psychiatrists per capita than in many developed nations (Miller, 2006). The Internet could then represent a therapeutic advance and even a major alternative to clinical care (Burns and Morey, 2008).

Moreover, the Internet is already a source of information that could be seen as an innovation in the care of patients. In fact, the Internet could help to reduce social inequalities observed in terms of primary prevention and health promotion along with the development of information systems, specific online health information of good quality as well as training in its use (Renahy, 2008a). Some in the medical community have espoused this potential positive impact of the Internet on increasing health education and promoting self-care. The growth of the Internet has enormous potential for facilitating the development of mental health literacy in the community and for providing mental health programs accessible to many who do not seek or cannot access professional treatment (Christensen and Griffiths, 2000).

As an information source the internet has also advantages of privacy and anonymity (Cline and Haynes, 2001). This is particularly important in mental health, where the internet may have a role in supporting those for whom stigma inhibits help-seeking through more traditional routes. People with stigmatized illnesses (such as anxiety, depression, etc.) often avoid seeking health care and education. The Internet may be a useful health education and outreach tool for this group (Berger et al., 2005). Stigma can lead to discrimination, ostracism, or persecution, and may cause feelings of embarrassment or humiliation in the stigmatized individual (Gilbert, 2001). All this is avoided if questions about mental health are made by e-mails or in online communities and discussion forums where people of all ages can talk about their troubles and issues with people experiencing the same situations. Looking for advice and reading other people's stories web-users cannot feel isolated and can make an easier first step before consulting a specific mental health service (Higgins et al., 2011).

In short, the Internet, given is cheap approach, can represent a money-saving tool to promote mental health and provide care.

3.1.2 Cons of the Internet

Concerns have been raised about the quality of information, the potential for unhelpful peer-to-peer interactions, and the exclusion of individuals who experience barriers to access. Some patients can in fact have logistical barriers to accessing the Internet.

However, the major problem of the Internet is the trust of the source of the information and consequentially its quality. For example some forums are exploited by some participants who take advantage of their anonymity and of the absence of real forum moderators to defend their own interests. This useful tool is becoming irreplaceable and very useful, but it must be "handled with care". In other words, sites and interventions on the Internet need to be constantly and formally evaluated (Christensen and Griffiths, 2000).

Even in the medical community, some have cautioned about the public health risks of the varying quality of health information (Kiley, 2000; Mcleod, 1998; Berland et al., 2001). For instance, during the acute crisis, patients tend to prefer to receive information related to their diagnosis, prognosis and treatment options from a trusted healthcare provider rather than through the Internet. Access to medically related information through the Internet is sometimes deemed to be untrustworthy and frightening. Reasons for avoiding online information-seeking can include fear of what they might find out, uncertainty about the accuracy of information online, being overloaded by the volume of information online and having been told not to go online by professionals.

Moreover, it is true that the active research of information about health on the Internet seems to be exclusively the object of very attentive people really worried about their health who have already access to other sources of information and who belong to a more privileged socio-economic status (Renahy et al., 2007). Young people are the main users of the Internet, but the questions and concerns about mental health seem to be of interest only for older generations who have less informatics skills (Hargittai, 2002).

Table 9 summarizes the main Pros and Cons concerning the Internet (Powell et al., 2011).

Characteristics of the health Internet	Potential public health benefits	Potential challenges to public health
• Vast quantity of information • Unregulated • Always on • Accessible from anywhere • Interactive • Information can be captured, archived, and retrieved • Content from both expert sources and user-generated sources • Content can be free or paid for • Users can organize in virtual communities	• Public education • Public empowerment supporting informed consumers engaged in their own care • Connect people with others who have similar problems • Online social support • Reduce barriers (time, location, and cost) to accessing information and services • Avoid the stigma of real-world consultation for certain problems • Deliver interactive interventions, as well as information • Integrated health services such as shared electronic records • Reduced travel and carbon emissions	• Misinformation leading to harm • Misuse of accurate information or services such as e-pharmacy • Exacerbation of inequalities in health caused by the digital divide • Challenges to the authority of health professionals • Disruptive behavior in virtual communities • Social isolation of users • Internet addiction of users • Ergonomic effects of computer use and reduced physical activity

Table 9. Advantages and Disadvantages of the Internet use for health information and support seeking

3.1.3 The Quality of mental health websites

The Internet represents a basic instrument and medium for the dissemination of information about mental health but the quality of such online information is not equal and is usually provided by non-experts. The World Wide Web offers a huge variety of information about health with the advantage of disposing of several interactive forms, but with the inconvenient of a disparate quality of the information which can generate social inequalities. Such a heterogeneity arises the important question of the trust young people have in the health information they find online (Reavley and Jorm, 2011).

Considering the several motivations behind the seek for mental health information on the net - the desire for reassurance; the desire for a second opinion to challenge other information; the desire for greater understanding to supplement other information; and perceived external barriers to accessing information through traditional sources - including the desire to avoid “bothering” their health care provider - it is necessary to check for the quality of mental health websites (Powell et al., 2011). Web-users are mostly not able to discern the source of the information they receive from the net and cannot easily understand how to behave after having consulted the net. Official communication is in any case necessary to raise public awareness about mental health and mental disorders since such issues are becoming the most researched topics on the web.

Against this background, it is evident that communication on the Internet must satisfy some quality criteria, thus meeting specific standards. In other words it is necessary to develop a quality standard for mental health information on the Internet so as to reach a condition of global digital welfare in Europe, especially among young adults.

In response to the widespread concern about the quality of Web-based health information designed for consumers, a number of initiatives have been developed to assist consumers in locating quality health information on the Web. These include the use of quality labels based on compliance with codes of conduct, portals that provide a gateway to websites of “high quality” and rating tools designed for consumer use. For instance, in France the The Health On the Net Foundation (HON) supported by the French National Health Authority (HAS) promotes and guides the deployment of useful and reliable online health information and their appropriate and efficient use (see **Box 8**).

In Italy, the Istat data for 2010 reported that the Internet users were the 49% of the population above 6 years old, with the European mean being 65% (ISTAT, 2012). For such a reason the Italian Ministry of Health has produced some specific "Guidelines for online communication about health protection and promotion" (Ministero della Salute, 2010). Such guidelines contain some recommendations on websites contents, usability, interactivity, editorial criteria, web 2.0, a self-evaluation form on the quality of the NHS and a customer satisfaction questionnaire. These guidelines were written by the Italian General Direction of the Communication and the Institutional Relations in cooperation with the Sapienza University of Rome and are aimed at planning the new Italian Internet portal of the Ministry for the National Health System's users. The Italian Ministry of Health proposes then a communication governance on health starting from the web which marks the passage from an institutional one-direction communication towards a bidirectional activity of information and communication based on dialogue and users' needs and satisfaction and produced by the cooperation of the Ministry with the other entities of the National Health System, the health staff and the patients associations.

These initiatives show how important it is to encourage quality assessment of health information sites (Risk and Dzenowagis, 2001).

THE CASE OF HEALTH ON THE NET (HON)

Created in 1995 and funded by the State of Geneva, HON is a non-profit, non-governmental organization, accredited to the Economic and Social Council of the United Nations, whose main aim is to certify websites about health through HON labels. Such labels are attributed only if the website meets specific quality criteria as far as the contents and provided information are concerned. For 15 years, HON has focused on the essential question of the provision of health information to citizens, information that respects ethical standards. To cope with the unprecedented volume of healthcare information available on the Net, the HONcode of conduct offers a multi-stakeholder consensus on standards to protect citizens from misleading health information. HON is funded by the State of Geneva, several European projects, the French National Health Authority (HAS) and the Provisu foundation. HON is also supported by the Geneva Hospital since its inception. The HON provide the following services: HONcode certification: Improving the quality of online health information; HONsearch: Search only reliable and trustworthy medical websites; HONtools: Use HON free services to enhance and improve ones’online experience; HONtopics: Access a varied list of reliable medical/health topics. The Health On the Net Foundation has elaborated the Code of Conduct to help standardise the reliability of medical and health information available on the World-Wide Web. The HONcode certification is free of charge and there is a continuous surveillance over the year and a systematic biennial review of HONcode certified websites. The HONcode is not an award system, nor does it intend to rate the quality of the information provided by a Web site. It only defines a set of rules to: hold Web site developers to basic ethical standards in the presentation of information; help make sure readers always know the source and the purpose of the data they are reading.

HON works to develop effective telemedicine through cross-border work in R&D projects and to encourage more medical professionals to use the Internet. More importantly, HON's MedHunt© and HONselect© offer all users the best-available Web sites and support groups, medical images and terminology, journal articles and news.

Box 8.

3.1.4 The Socio-Economic Status (SES), the Geographical Residence and the Digital Divide

There exist strong socio-economic and socio-demographic fractures as far as the use of Internet is concerned (generally speaking and as far as mental health information seeking is concerned). For instance, Internet health information seeking experience seems to be strongly influenced by age-specific lifestyle trends (Ybarra and Suman, 2008) and the use of the Web by digital natives is really different from the use of previous generations (O'Neil, 2009). However, the socio-economic inequalities (more social than economic) seem to be attenuated by the experience and the use of IT tools. This could have important repercussions on the public politics. On this issue, some scholars contend that the role of the Internet in patient empowerment is context dependent and constrained by patients’ socioeconomic backgrounds, attitudes toward self-advocacy and propensity to seek medical information online (Hirji, 2004; Henwood et al. 2003).

Specifically, online health information seems to especially benefit people already privileged in terms of health, health-care utilization and socioeconomic status (SES) (Renahy et al., 2010). They are more likely to access information and also more likely to benefit from it. There are, with regard to Internet access for health information seeking, numerous disparities in terms of demographics, SES and social integration. In fact, most of these disparities occur upstream as well, in Internet access thus underlining a double divide formed by socioeconomic, social and health disparities. Moreover, the probability of having previously searched for health information on the Internet also differs according to health status, health literacy and health perceptions (Renahy et al., 2006).

The cost of delivering mental health services is very high. In rural areas where face-to-face primary care is limited, it is likely that many people with mental health difficulties will not have their needs met through traditional forms of service delivery. As a result, there is a pressing need to develop alternative approaches to reduce the incidence of mental health problems in young people. Thus, the Internet offers a unique opportunity to provide mental health services to a large proportion of the population, including those in remote locales and during times when traditional service providers are unavailable (Gould et al., 2002).

In this vein, as far as the geographical residence of users is concerned, this variable is still less known than other individual factors affecting the use of the Internet for health information seeking. Some studies reported thet the probability of having already used the Internet for health questions is higher among people living in urban areas (Licciardone et al., 2001) or increases with the size of the residence agglomeration (Renahy et al., 2008b), whereas other studies show e non-significative result (Bundorf et al., 2006; Flynn et al., 2006). Consequently, considering a region (e.g. the Paris agglomeration) as a global entity often hide a huge variety of the territories and/or the populations in social, economic and cultural terms. In this context of social inequalities in accessing and using the Internet for health information and support seeking, and other than the individual characteristics, it seems interesting to analyze such geographical disparities at a smaller scale. In fact, several epidemiological and social studies underlined the importance of factors defined as "contextual", such as the geographical, economic and social residence environment, for understanding the social health inequalities (Chaix and Chauvin, 2002; Chauvin, 2005).

The socio-economic barriers to the Internet access, combined with the personal or family situation of the people, seem to be reinforced by the residence place. The residence neighborhood seems then to have a significative effect (Chauvin and Parizot, 2005). Actually the neighborhoods characterized by a high unemployment rate are associated to weaker probabilities of using the Internet. People in geographically isolated or disadvantaged communities remain less likely to have quality access to technology. Unstable or unreliable Internet connections and ageing infrastructure can limit access to highly interactive content.

Gombault (2013), instead, affirmed that the fact of living in a deprived zone does not seem to affect the utilization of the Internet and, actually, nowadays the digital divide is going to reduce its size. The differences in the use of the Internet are more evident among different generations but not in relation to either the socio-economic status or the geographical provenience especially with the introduction of mobile devices (cell phones, smartphones, tablets etc.) as access points to the Internet. The digital divide is changing then with the Internet, the mobile and the smartphones access approaching market saturation.

The Internet is expected to help reducing the social inequalities (both economically and psychologically) in the fields of primary prevention, health promotion and education. Internet use may exacerbat existing SES differences in health, but from a solely social point of view, the Internet tends to increase social interactions. All this is however possible only through the active promotion of the development and diffusion of online quality information adapted to different publics, but also through a training to its proper use.

3.2 Young people looking for mental health information and support in the Internet

The Internet is today one of the main information sources of health in general and mental health in particular, especially for young people, including those young adults and adolescents living in the most deprived countries (Department of Communications Information Technology and the Arts, 2005). The Internet is increasingly part of day to day communication and, on the other hand, the need to support young people’s mental health is more apparent than ever (Michaud et al., 2009). Adolescence and youth are times when many psychiatric disorders first manifest themselves (Hack and Jellinken, 1998). Almost 50% of syndromes emerge by age 14, with 75% of disorders having their onset before 24 years of age (Kessler et al., 2005).

By combining these two aspects together it is easy to understand that Internet can represent a useful tool for health promotion and prevention in childhood and youth (Horgan and Sweeney, 2010; Ybarra and Suman, 2008). In this sense, it can allow young people to address to those services which could be otherwise difficult to access, because of their costs or their geographical position or for any fear of being stigmatized (especially when referring to sexual and mental health). Mental health services for adolescents are not veery widespread and the Internet can provide a relevant and engaging opportunity to overcome the barriers to help-seeking and connect with young people (Burns et al., 2009).

However the information on the Internet is neither necessarily trustworthy nor appropriate. It is then necessary to better understand the behaviors of young people about information and data related to mental health in the Internet.

Several studies have been conducted in general population on the use of the Internet in relation to health (for instance Rice, 2006; Renahy et al., 2008a; Gallagher et al., 2008) but only a few have been focused specifically on adolescents and young adults, like the study by Burns and colleagues (2010) on mental health. The results of this Australian survey demonstrated that young people are twice as likely to turn to the Internet as contact a counsellor, community agency, teacher, doctor or minister, and are 5-10 times more likely to turn to the Internet than call a telephone helpline. The Internet is increasingly becoming the support of choice, with another US research demonstrating that young people are actively seeking health information and referrals through online discussion groups (Katz et al., 2001).

Given the lack of data on this age group in Europe, **STUDY 3** and **STUDY 4** were conducted to investigate the use of the Internet for mental health among young people. When talking of “young people” we refer to both adolescents and young adults. The **STUDY 3** refers more precisely to young people aged from 12 to 25, thus including middle and high school students plus university students, unemployed people, young workers, interns or trainees in general (for a work placement or just for personal training and education). When analyzing the results, young people were divided in age groups according to the current European Education System. For such a reason, a comparison of the different attitudes of young people towards the Internet use for mental health information seeking should also take into account the different education systems all over Europe. It goes without saying that a comparison of mental health systems is requested for a better understanding of the behaviors of young people facing mental health troubles. The provision of services naturally influences the fact of looking for information on the Internet. The difference in the provision of mental health services and in the organization of the whole mental health systems in Europe actually plays a fundamental role in the way young people seek for help and support. It would then be essential to know if young people can have a mental health support by accessing first of all general practitioners or if they can go directly to a psychologist or a psychiatrist. Moreover it should be assessed if such services are free or if young people can benefit from ad hoc fees.

STUDY 4 is instead addressed to all University students of the 5 years of their course. This study resonates with the current concerns about the increasing incidence of mental health difficulties among students, and the nationwide initiatives being taken to address this issue. As stated by the European Pact for Mental Health and Well-being (2009), in any education and training setting mental health should be considered as a fundamental business.

Youing people were investigated for several reasons. One of them is that young people may be more ashamed than adults in admitting a mental health trouble. Given their natural attitude to using the Internet, their shyness could push them to look for information and help firstly on the Internet. Young people are also one of the most vulnerable population groups. They should incur then in one of the major problems connected to information on the Internet, i.e. the self-treatment, also with medicines. Practitioners should themselves be aware of the different social networking sites frequented by their young adult clients, ask clients about their use of social networking, and encourage safe and responsible online behaviors.

Youth mental health is everyone's business because of the high prevalence and burden of mental ill-health in young people and the related impact on their families, communities and society (1); the significant contribution of currently identifiable and solvable problems to the burden of mental ill-health in young people (2); the compelling evidence of both unmet need and the availability of solutions that can inform better public understanding, better interventions and better policy (3); the enormous potential for further future development of better treatments and improved service design (4). Young people who need help or treatment do not seek it, cannot access help, or help is not available to them. Tangible barriers such as distance and cost stand between young people and treatment, yet cultural factors like stigma stand even stronger in preventing young people from accessing help. The reasons clinical services fail to reach young people are complex and include: societal stigma; lack of awareness of available services; poor mental health literacy; mistrust in primary and secondary health care systems; and a strong preference for using non-professional support (primarily family and peers). Many young people try to manage emotions problems alone, stating concerns relating to confidentiality, a fear that no person or service could help, and the feeling that the problem is too personal (Burns and Rapee, 2006; Burns et al., 2010).

Finally, it is clear that the Internet can provide an accessible space to support young people experiencing mental health problems or simply willing to find out more about mental health, but any service delivered online must be clearly thought through, well-planned, resourced and safely managed for a young and inexpert public (Chambers and Murphy, 2011).

Young people are also defined as the "C Generation", where "C" stands for "Creation, Communication and Collaboration", three actions which are fundamental in any use of digital technologies (CEFRIO, 2009). This definition of the new generation confirms once again that the Internet is the new world where young people feel at ease and where mental health services could find their place for this specific age group. The Internet is then one of the possible and easiest answers to the challenge of the poor quality of mental health services for young people (Michaud and Narring, 2010).

3.2.1 The Questionnaire: a communication tool to evaluate and compare information about mental health

There is limited information describing how and why people use online mental health information, or the effect of this on mental health status, although this literature base is growing (Dumitru et al., 2007; Lemire et al., 2008a; Lemire et al., 2008b; Atkinson et al., 2009; Ybarra and Suman, 2008;). A possible approach to research on websites and user behavior is the creation of specific questionnaires trying to identify consumers of mental health information on the Internet and how the various aspects of quality affect general and mental health behavior such as help seeking and use of evidence-based treatments. If it follows these guidelines, the questionnaire is a validated self-completion instrument easy to use for its brevity and validity. Cross-sectional surveys are useful in quantifying the views of a large number of people in a relatively cheap and timely manner. Such surveys have been used successfully in previous research into information-seeking (Case, 2002).

Questionnaires are actually among the most used instruments for data collection. Especially for behavioral analyses, they are used to understand the attitudes of people and then obtain a representative result for a defined population sample, by measuring knowledge, attitudes, practices and beliefs of the general public. The questionnaire is also a useful instrument to collect data describing the sample, i.e. socio-demographic variables like sex, age, education, work, place of living, together with the perception of one's general and mental health, and the practices of Internet use. A proper survey should in fact include demographic questions, a question on previous and actual psychiatric history and questions about the general use of the Internet before investigating in detail the behavior of web users about health issues.

Specifically, that of mental health is per se a field which poses a lot of difficulties in relation to stigmatization and privacy. Asking general public about their mental health status is undoubtedly more difficult than making questions about less private and personal information, even in comparison with questions about general health. When designing a questionnaire on mental health, it has to be decided whether it should contain more generic issues or if it should focus on specific mental diseases. Asking more generic questions could make the tool easier to be applied in different countries and in different contexts (e.g from university classes to middle and high schools) also in view of future research financing.

Surveys asking respondents to declare their behvaiors and attitudes which could be sensitive and reprehensible risk to be biased. Self-administered questionnaires are the traditional method to collect data on drug use, sexual behaviors etc. These questionnaires are meant to make the respondents feel free to say the truth without being traceable. Face-to-face surveys are preferably avoidable for this reason.

Given this, questionnaires (both in paper and online ones) are essential for getting a general, but representative, idea of peoples' attitudes and behaviors. However, online questionnaires conducted with a self-selected convenience sample could produce results which are not representative of the general population, nor is it possible to determine causality from the results. The use of e-mails or online forms could represent a bias for studies like the ones presented in this thesis - i.e. analyses on the attitudes of young people in relation to health information-seeking. Only people already using the Internet would in fact been involved in the study. The use of a paper questionnaire could be considered anachronistic and paradoxical given the nature of the research focused on the Internet use, but this can also allow for the control by the investigators of the compilation, thus avoiding any randomization.

When analyzing the results from the questionnaires several considerations must be taken into account. For instance particular attention must be paid to the answers given by adolescents who can be not too much reliable. Sometimes with teen-agers qualitative studies (like interviews or focus groups) can be more trustworthy. However, there already exist several validated screening questionnaires to assess the risk of serious mental health problems especially in adolescents (Hack and Jellinek, 1998). For mental health information seeking online the questionnaire by Burns and colleagues (2010) is a pillar for understanding how young adults use the Internet for their health. By contrast, such instrument should be integrated with face-to-face investigations thus proving that the right combination of quantitative and qualitative analyses can be helpful to activate prevention campaigns following a specific communication strategy.

In short, the best way to investigate people’use of the Internet for mental helth should be a parallel research using multiple methods, including focus groups and in-depth interviews. This approach will help to capture the richness and complexity of people’s stories about how they use technology in their everyday lives and in their care for mental health.

3.2.2 The Baromètre Santé 2010 survey: an example of the youngsters’ use of the Internet for health information seeking

Given the increasing importance the Internet is gaining in the spread of scientific information, namely on mental health care, there is a call for more research on the role of information and communication technology within mental health promotion. In this vein, the Equipe DS3 (Déterminants sociaux de la santé et du recours aux soins) of the Institut National de la Santé et de la Recherche Médicale (Inserm) in collaboration with the Université Pierre et Marie Curie of Paris and the INPES, the French National Institute for Health Prevention and Education, performed some analyses on the use of the Internet by young adults seeking information about health in general and mental health in particular (Beck, Montagni et al., forthcoming). The interest in young adults – from 15 to 30 years old – is due to the fact that without any guidance for developing young people and adolescent mental health policies and plans, there is the danger that systems of care will be fragmented, ineffective, expensive and inaccessible. Such policies and plans should then follow uniform guidelines all over Europe (WHO, 2005). The analyses were based on the national survey “Baromètre Santé 2010” conducted by the INPES in consultation with the French Ministry of Health. The survey took into consideration health in general but with a specific interest in mental health. Originally the

“Baromètre Santé 2010” was designed to measure the evolution of key indicators regarding health-related behaviors, attitudes and opinions in the general population. Through a CATI system, 27,653 people were interviewed over the phone from October 2009 to July 2010. The sample was based on a two-stage random sampling drawn from a random digit dialling covering all France metropolitan areas: firstly a random selection of households, secondly a selection of a member of the household. This population-based survey procedure was approved by the French commission on data privacy and public liberties (CNIL). From the initial nationally representative sample of 27,653 people aged from 15 to 85, a random sample of 1,052 young adults (50.5% men and 49.5% women) aged 15-30 (mean age was 22.6 years) answered a set of specific questions on their use of the Internet as an information tool for health-related issues. Data were weighted by the number of telephone lines and the number of eligible persons in the household. They were adjusted for French population structure (2008 census), according to age, gender, region, level of urbanization and educational level.

Results showed that the totality (92.9%) of young adults aged 15-30 were web-users, and this proportion slightly decreased with increasing age (from 96.2% to 90.1% for the 15-19 and 26-30 years old respectively). Among them, 51.5% had never used the Internet to look for health information and advice in the past 12 months: 75% of them reported being enough informed by other sources, 74.1% preferred seeing a doctor, and 67.1% did not trust the information found on the Internet. The youngest adults (aged 15-19) stated more frequently than the other respondents that they were enough informed through other sources (78.9% vs 75% for the average of the people aged 15-30) and that they did not trust the information found on the Internet (71.6% vs 67.1% on average), even though these differences were not significant. People with psychological distress were more likely to search for health information on the Internet than those without mental health problems. This could be explained by a greater interest of these people in specific health questions, such as, for instance, the presence of a mental health problem itself, either treated or not. Moreover, anxiety could lead these people to look for further health information or to verify information after medical consultations.

The analysed conducted on the sample of 15-30 years old population of the "Baromètre Santé 2010" represented the starting point for a first analysis of the available data and information on the use of the Internet for health information seeking in young people. In fact, on the basis of the literature review for the "Baromètre Santé 2010" survey, it was assessed that there is still little information about the impact of the Internet on people's mental health behavior, especially as far as youngsters are concerned. Assessment of the types, quality and usage of websites about mental health is lacking and with the purpose of increasing knowledge on this issue, two tools were prepared: the Fil Santé Jeunes (**STUDY 3**) and the e-MentH (**STUDY 4**) questionnaires.

3.3 STUDY 3 - The Fils Santé Jeunes survey: an example of the use of the Internet for mental health information seeking in French teenagers

In France more than 3 people out of 4 have globally access to the Internet, but the percentage of web-users in the population is noticeably higher among younger people than among adults and elderly people, with 99% of 12-17 years old teenager consulting the Internet versus 22% of more than 70 years old people (Bigot and Croutte, 2011). A questionnaire on the use of the Internet for mental health among young people was then deemed necessary given the constant use of this communication instrument in this age group. Moreover, given the potential for premature mortality and life-long disability in those with mental health problems, it is essential to assess what could be the most relevant and innovative pathways for young people to connect with the help they need. In order to reduce youth mental health difficulties in the long term, prevention and education programs should be developed according to the experiences of young adults (Burns et al. Szabo, 2002; McGorry et al., 2006). Understanding the interest in mental health information and the use of the Internet for help and support seeking is then necessary to check whether this medium can be of help for future mental health campaigns.

Background

After the research and review of previous surveys and studies, a first questionnaire was created for the French website Fil Santé Jeunes (FSJ) www.filsantejeunes.fr: the survey is called "Ta santé et ton bien-être sur Internet" (Your health and weelbeing on the Internet). It was created in collaboration with the Ecole des parents et des éducateurs of the Ile-de-France (EPE), a professional team based in Paris and specialized in helplines for young people. This team is composed of doctors and psychologists and all articles published on the Fil Santé Jeunes website are firstly validated by a committee of experts, including web professionals. The website www.filsantejeunes.com is financed by the INPES (see point 3.2.2) and the DGCS (Direction Générale de la Cohésion Sociale) and it was created in 2001 as the online complement of the Fil Santé Jeunes helpline (number 3224) created in 1995 by the French Health Ministry to answer all questions by young people in need for confidential information on health issues.

The www.filsantejeunes.com website was renovated in 2009 and at present (December 2013) it is made up of the following sections: the "foire à questions" (frequently asked questions), the "témoignages" (personal reports), the "quiz", the "enquêtes" (surveys), the documents (dossiers and tables), six thematic forums (love and sex; health; contraception; drogues; living with an illness; and living with a handicap) and the "boîte à questions", i.e. a service which allows young web users to anonymously ask experts questions about health and sexuality by e-mail. In 2010 more than 2000 answers were given, 1 747 visits on the website were recorded and 16 207 pages were read (FSJ Report, 2011).

In the "enquêtes" section we published our questionnaire on the 8th March 2013 with the aim of investigating the role that the Internet plays in the way adolescents and young adults (from

12 to 25 years) seek for health information and support online. The questionnaire was then aimed at studying the attitudes and behaviors of young people on this subject, with a specific focus on how much they trust the published information, together with some socio-demographic factors associated to their relationship with the health information and support provided by the Internet.

Materials and Methods

The "Ta santé et ton bien-être sur Internet" questionnaire (see APPENDIX) is composed of 17 items, of which 10 were inspired by the literature and 7 were taken or adapted from two surveys on the use of the Internet for health related issues: the Baromètre Santé 2010 (see point 3.2.2) by the INPES (Beck and Richard, 2013) and the WHIST survey (Renahy et al., 2007). It is divided into 4 main sections: the socio-demographic data of the respondent (I, items 1, 2, 3, 4 and 6), the use of the Internet for health information seeking in general (II, items 7, 8, 10, 12, 13 and 14) the use of the services provided by the Fil Santé Jeunes, i.e. website and helpline (III, items 5, 9 and 11) and, finally, the health perception and the use of health care services (IV, items 15, 16 and 17). We asked for the socio-economic status of the respondents (I) in order to compare their use of the Internet with their demographic, geographical and social origins. These variables were deemed interesting for a better understanding of the digital divide, especially between rural and urban zones (item 4). The place of living and the distribution of the services in that specific area should in fact be compared in any future project aimed at analyzing the use of health care services by young web users. As for the section II, we decided together with the representative members of the EPE association and the administrators of the website not to investigate young people on sensitive subjects like specific mental health questions, but to focus only on general health. However, thanks to their confidential nature, online questionnaires make it possible to overcome limits such as the need for a legal consensus by parents for minors. In section II we also asked if respondents knew what a labelised site is since we were interested in knowing whether young people are aware of the presence of official websites providing certified information and support. We wanted in fact to compare the answer to this question with both the consultation of such websites and the trust in the information provided by the net. Young people were asked from which support they accessed the internet and one question (item 12) directly asked if they owned a smartphone for surfing the net. Moreover in section II we also asked for the use of social networks with reference to mental health information and support seeking. Social networks are today the most visited websites in the world (Fox and Jones, 2009) and it is interesting to analyze the attitude of young people towards them when looking for mental health issues. The three items of section III were especially requested by the EPE association in order to evaluate the functioning and quality of the FSJ website. Finally, through the items of Section IV both mental and physical health status were investigated: it goes without saying that answers given by an ill person are interesting for the results of our survey. We also tried to investigate the relationship between the use of the Internet for health information seeking and the medical consultations and advice. A sort of behavioral model was constructed from the given answers.

The questionnaire was built up in a digital format by means of the online tool Survey Monkey (http://www.surveymonkey.com, Oregon). In order to guarantee the anonymity of the participants, no personal detail (name, address, telephone) was asked. Only the IP address was registered for each respondent but it was not used to geographically locate the computers used to compile the questionnaire. Moreover, the questionnaire was designed with the maximum care for respecting the privacy and sensitivity of the respondents. With this aim the questionnaire was revised in its Italian translation by a psychiatrist (Francesco Amaddeo, Professor and PhD), a psychologist (Valeria Donisi, PhD) and a social worker (Laura Rabbi).

We decided to limit this study to young people aged from 12 to 25 years since this is the age range of the public of www.filsantejeunes.com. Actually this age range includes the most sensitive years for education and training when any intervention and prevention to avoid health problems can be decisive for the future wellbeing of the youngsters (Burns et al., 2002).

From the 8th of March 2013 to the 10th of June 2013, 236 young people answered our questionnaire. They did it in a spontaneous way by visiting the www.filsantejeunes.com website or after having been informed of this survey by the official Facebook page of the FSJ, the FSJ newsletter or by mail or through social networks by the investigators themselves.

The analysis of the data

For a first intermediate report (Montagni and Parizot, 2013) the analysis of the data concerned the main variables on the use of the Internet in general and on the use of the website www.filsantejeunes.com. These variables were crossed with the socio-demographic characteristics of the respondents together with, in certain cases, their health status and their use of health care services. By asking their age, sex, working situation and place of living, we actually hypothesized that these characteristics could influence their behavior on the Internet. For example, the fact of living in rural place instead of a big city could complicate the access to health care services and increase consequentially the use of the Internet as a source of information on health. In this sense, the socio-demographic variables here investigated could give some interesting results as for the “digital divide”. The paucity of the sample limited the statistical power of the analysis for this first intermediate report. For such a reason only the results which seemed more appropriate were reported even when the associations between variables were not statistically significant. New reports are planned each six months.

The Results

The intermediate report refers to a first closing of the results of the survey on the 10th June, three months after the online publication of the questionnaire. A total of 338 people started answering the questionnaire but only 236 completed it.

Among the 236 respondents, 3 had the same IP address, which could mean that three different people had used the same computer to answer the questionnaire.

1. *Description of the sample*

The sample here studied is composed by 200 girls (84.7%) and 36 boys (15.3%): 22% have between 12 and 14 years, 44.1% between 15 and 17 years and 33.9% between 18 and 25 years. The **Figure 7** presents the distribution of boys and girls according to their age.

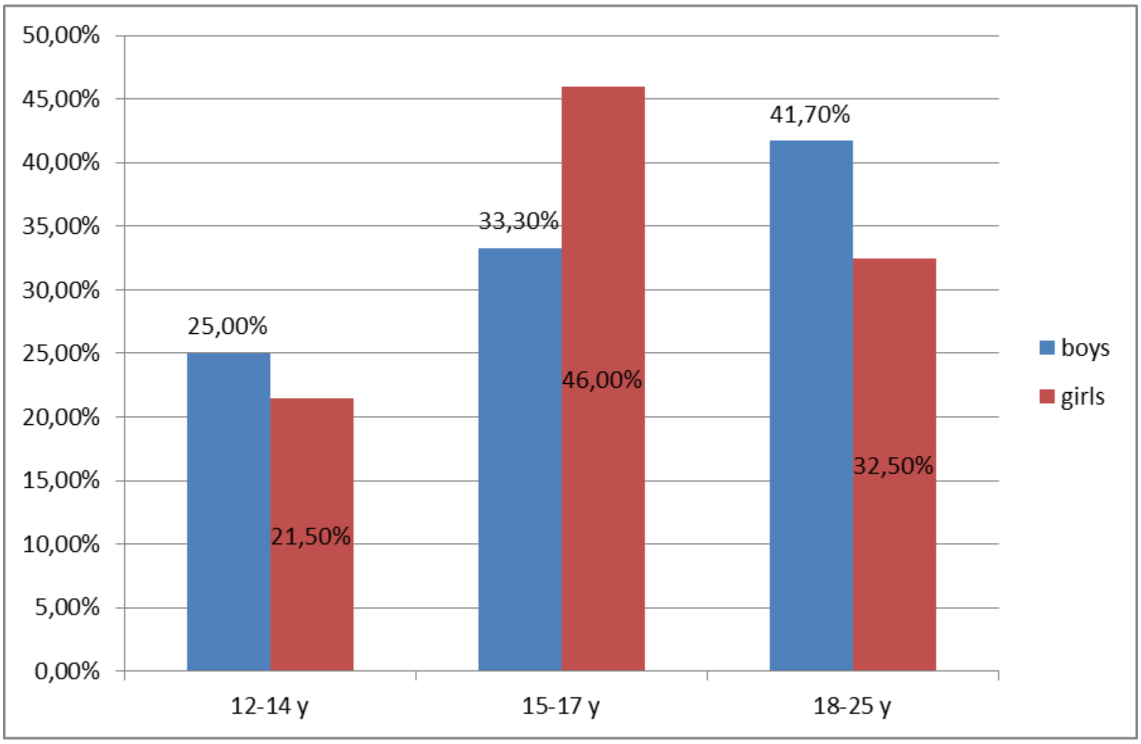


Figure 7. Age and Gender of the respondents

As far as the socio-professional situation is concerned, the respondents were mostly high school students (“lycéens”, N=88; 37.3 %) or middle school students (“collégiens”, N=76; 32.2 %). University students or trainees were two times less numerous (N=41; 17.4 %) while young people on work placement (N=11; 4.7 %), workers (N=10; 4.2 %) and unemployed people (N=9; 3.8 %) were even less numerous. Only one respondent defined himself as a self-employer or autnoumous worker. Then the most numerous group was that represented by young people attending compulsory education. The **Figure 8** illustrated the distribution of the occupations according to the gender.

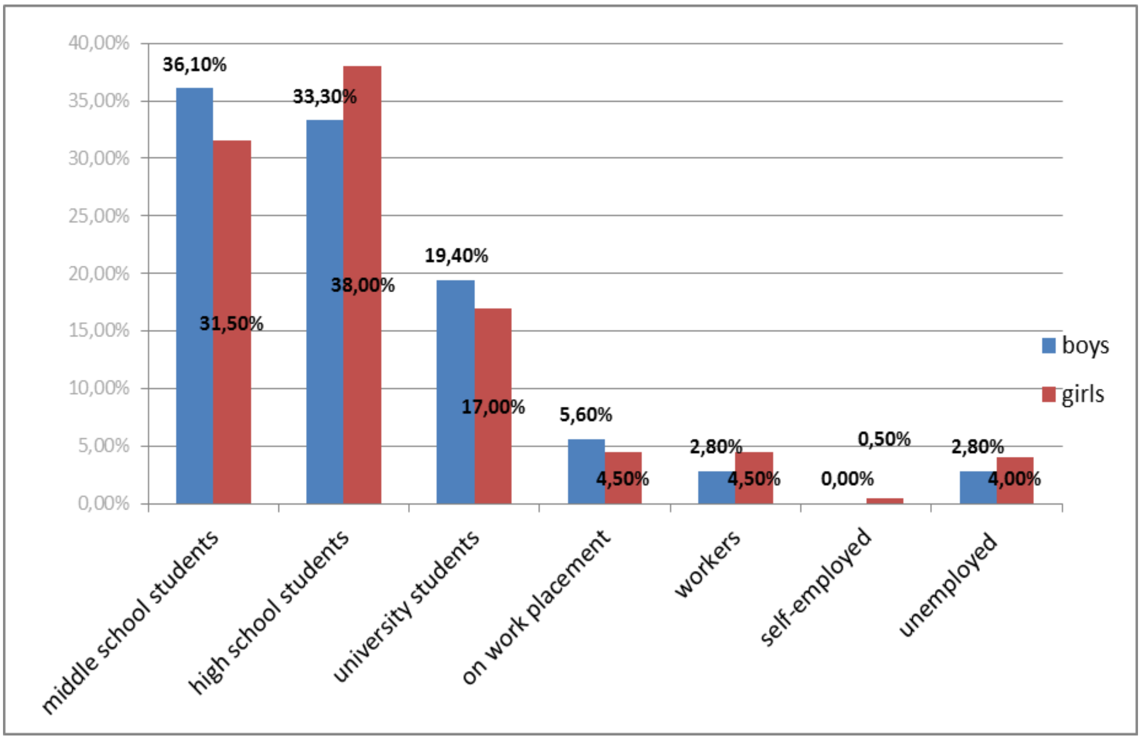


Figure 8. Occupation and Gender of the respondents

The 39.8% of the respondents declared living in a small village or in the countryside; 35.2% in a middle city and 25.0% in a big city.

The vast majority of the respondents (91.5%) personally owns a computer, a smartphone or a tablet with which they can directly access the Internet. The only 20 people who do not own any of these devices are 13 minors (12-17 years) and 7 young adults (18-25 years); 9 live in a small village or in the countryside, 8 in a middle city and 3 in a big city.

As far as the physical health status is concerned, 60.6 % of the respondents judge their health status as very good or good, 27.1 % quite good and 12.3 % bad or very bad. As for the psychic and emotional health status, 34.7% of the respondents judge their status as very good or good, 28.0 % quite good and 37.3% bad or very bad (**Figure 9** for the details). So, generally speaking, the respondents show a perception of their health more positive for heir phisical health in comparison with their psychic and emotional health.

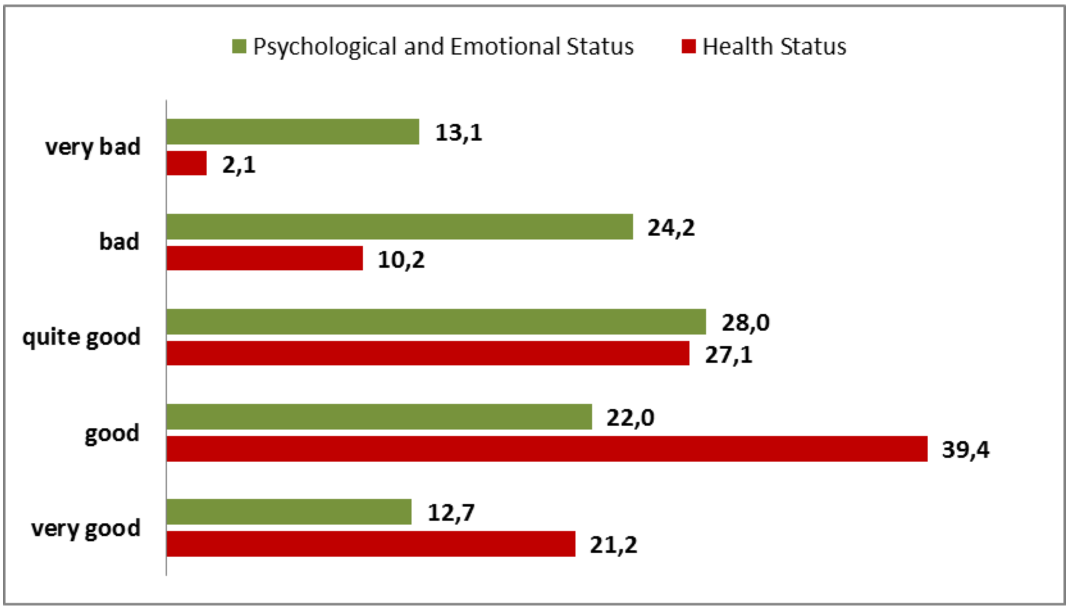


Figure 9. Health and Psychological and Emotional Status of the respondents

During the last twelve months, 88.1% of the respondents consulted a general practitioner or a pediatrician; 27.1% consulted a psychologist or a psychiatrist. Of the young people judging their psychological and emotional status as bad or very bad, only 40.2% addressed to a specialist in mental health in the reference year (March 2012-March 2013).

Among the several health professionals, the general practitioner is clearly the most frequently consulted doctor, more than (in decreasing order) specialists (41.5%), school nurses (36.1%), other health professionals (30.6%), psychologists or psychiatrists (27.1%) and gynecologists (24.1% of the participating girls). In total, 93.2% of the respondents consulted at least one of these health professionals in the last twelve months.

2. *The uses of the Internet for health information and support seeking*

Almost the whole sample of the young people answering our questionnaire (95.3%) used the Internet in the last twelve months before the survey for health information and support seeking – for themselves (88.4%), just for curiosity (56.4%) or, less frequently, for a member of their family or one of their acquaintances (42.5%).

Six main health themes were taken into account on the basis of the sections of the www.filsantejeunes.com website – i.e. the "Foire aux Questions", "La doc" and the Forums (**see Table 10**). Internet represents the information and support tool the most frequently cited by respondents for 5 of them, in comparison with the consultations with the physicians or the helplines. As for health in general (illnesses, allergies, treatments…) the majority of the respondents consulted in the last twelve months a doctor (53.3% while 48.5% said they had read some information on the Internet about this general theme).

	Consulting a doctor	**Being helped by an expert contacted on the Internet (e-mail, forum, chat)**	**Exchange in the Internet with other people (forums, social networks…)**	**Reading online information**	**Calling a helpline**	**Never looked for health information on the Internet**
Wellbeing (sport, nutrition, relaxation…)	23.3% (N=52)	6.7% (N=15)	14.3% (N=32)	**51.6% (N=115)**	1.3% (N=3)	29.6% (N=66)
General Health (illnesses, allergies, treatments…)	**53.3% (N=121)**	6.6% (N=15)	9.7% (N=22)	48.5% (N=110)	0.9% (N=2)	19.4% (N=44)
Sexual Health (sexuality and contraception)	17.6% (N=39)	10.8% (N=24)	14.4% (N=32)	**50.9% (N=113)**	3.2% (N=7)	31.5% (N=70)
Eating disorders (anorexia, bulimia, weight gain…)	11.0% (N=24)	5.0% (N=11)	15.5% (N=34)	39.7% (N=87)	2.3% (N=5)	**47.5% (N=104)**
Depression, panic, anxiety	18.3% (N=40)	7.3% (N=16)	14.7% (N=32)	**43.1% (N=94)**	3.2% (N=7)	40.4% (N=88)
Addictions (alcohol, smoking, cannabis…)	4.7% (N=10)	2.8% (N=6)	5.6% (N=12)	28.5% (N=61)	0.0% (N=0)	**65.4% (N=140)**
Total (having answered to at least one of the proposed items for these themes)	66.5 (N=157)	20.3 (N=48)	35.2% (N=83)	82.2% (N=194)	8.5% (N=20)	-

Table 10. Behaviors in the last 12 months concerning 6 health themes (% and number of respondents)

The use of the Internet for this six themes concerns mainly the reading of the information published online: this is the case of 82.2% of the respondents in the last twelve months. The exchange in forums or in social networks concerned 35.2% of them. Finally, one respondent out of five (20.3%) said having been helped by an expert contacted on the Internet (e-mail, forum or chat).

These behaviors are globally similar according to gender and the living accommodation. However there are some differences as far as age is concerned (see **Figure 10**). Among the respondents actually the 15-17 years group discussed the most these six themes in forums or social networks (44.2% vs 30.8% for the 12-14 years and 15.0% for the 18-25 years, not really significant differences but the number of respondents is low).

Similarly we noticed some differences in behaviors whether the respondents had already visited or not the website of Fil Santé Jeunes. Actually, those who had already consulted the website used more the forums or the social networks for one of these six health subjects in the last twelve months (42.3% vs 28.8% of the others); moreover they were also more numerous in having contacted (in the same period and for one of the six specific health themes) an expert through Internet (24.3% vs 16.8%, not significant differences).

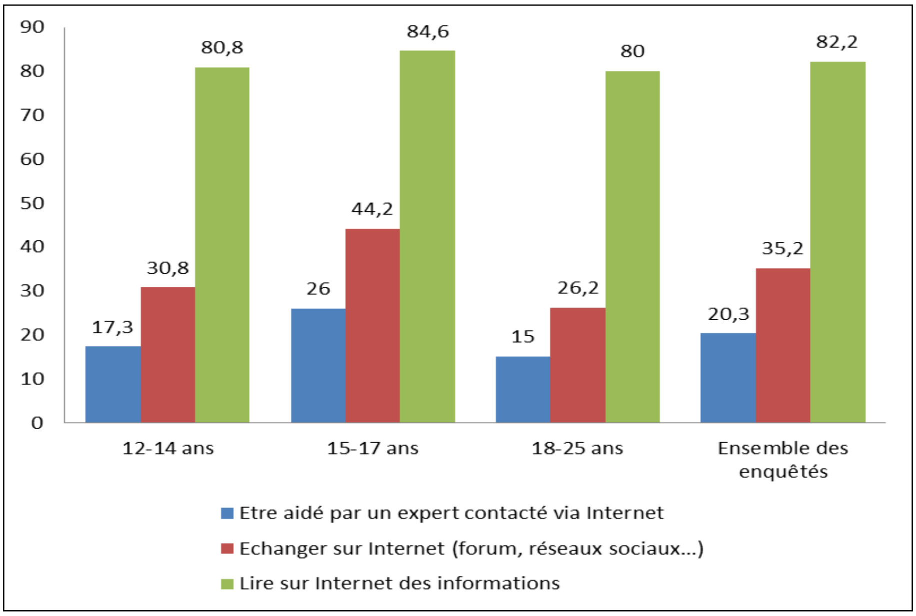


Figure 10. Use of the Internet according to age concerning wellbeing, general health, sexual health, eating disorders, depression, panic, anxiety or addictions

3. The themes researched on the Internet

When reading on the Internet some information related to health in the last 12 months, the respondents mainly did it in relation with wellbeing (48.7% of them), sexual health (47.9%) or general health (46.6%). The other themes interested less young people: 39.8% of the respondents read the information on the Internet concerning depression, panic, anxiety; 36.9% on eating disorders (anorexia, bulimia, weight gain…); and 25.8% on addictions (alcohol, tobacco, cannabis or other drogues).

The reading themes online seemed to be linked to the age of the respondents (**Figure 11**) even if no result was statistically significant (given the low number of participants). On the other hand, the place of living seemed not to influence the reading themes, with the sole exception for the reading of articles about wellbeing (sport, nutrition, relaxation) concerning less often those who live in the countryside or in small towns (39.4%) in comparison with all the others (57.6% of the young people living in a big city and 53.0% in a middle-size city).

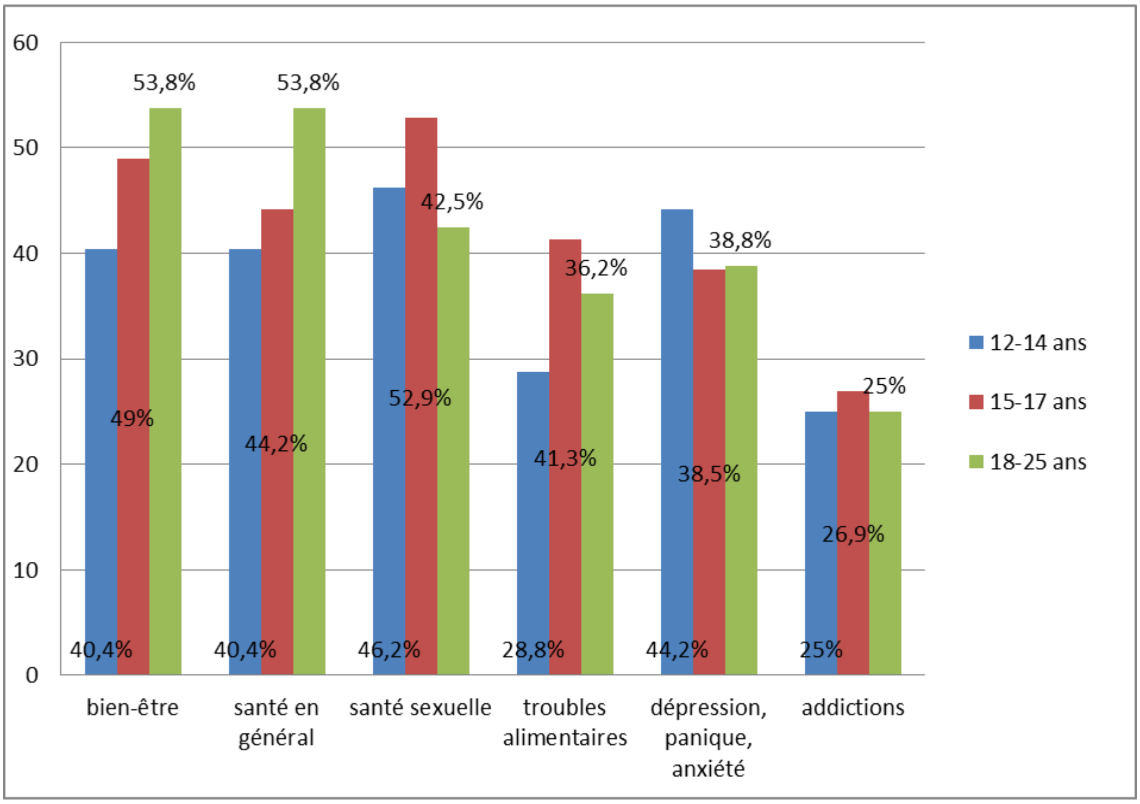


Figure 11. Rates of people having read online information in the last 12 months according to 6 health themes and age

As we could expect it, the information read on the Internet were partly correlated with the health status of the respondents. Even if the differences were not statistically significant (it is important to remark that the low number of participants actually limited the statistical power of our study), the **Figure 12** shows that those who considered their physical health status as bad or very bad were the majority to have read during the year 2012-2013 some information on "general health (illnesses, allergies, treatments...)" (58.6% vs 46.6 for the average of the sample), on "depression, panic, anxiety" (58.6% vs 39.8% on average), on "eating disorders" (51.7% vs 36.9%) and on wellbeing (51.7% vs 48.7%). However they are less numerous in reading online information on addictions and sexual health.

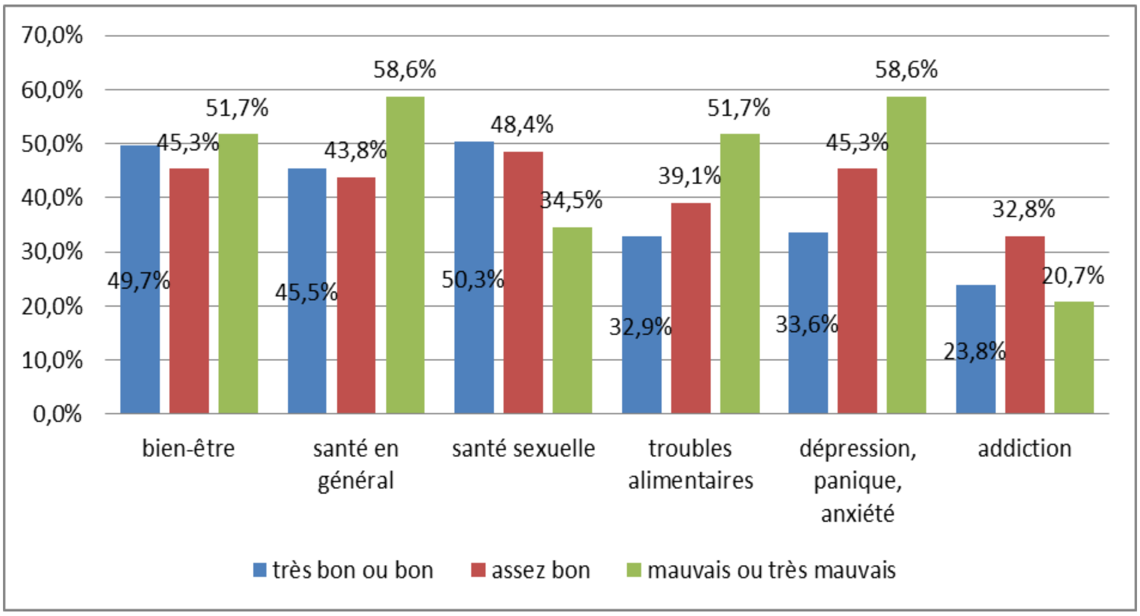


Figure 12. Distribution of people having read some information on the Internet during the last 12 months according to the health domains and the perceived physical health status

We can underline here a correlation between the themes read online and the psychological and emotional health status (with some of the differences presented in **Figure 13** being statistically significant). The respondents judging this health status as bad or really bad were definitively more numerous than the others having read some information on "depression, panic, anxiety": they are 61.4% in this case vs 40.9% of those judging it as quite good and only 15.9% of those judging it good or very good. Moreover they are more numerous in consulting online some information on “eating disorders” (respectively 50.0%, 31.8% and 26.8%) and, in a minor extent, on the addictions (respectively 31.8%, 18.2% and 25.6%).

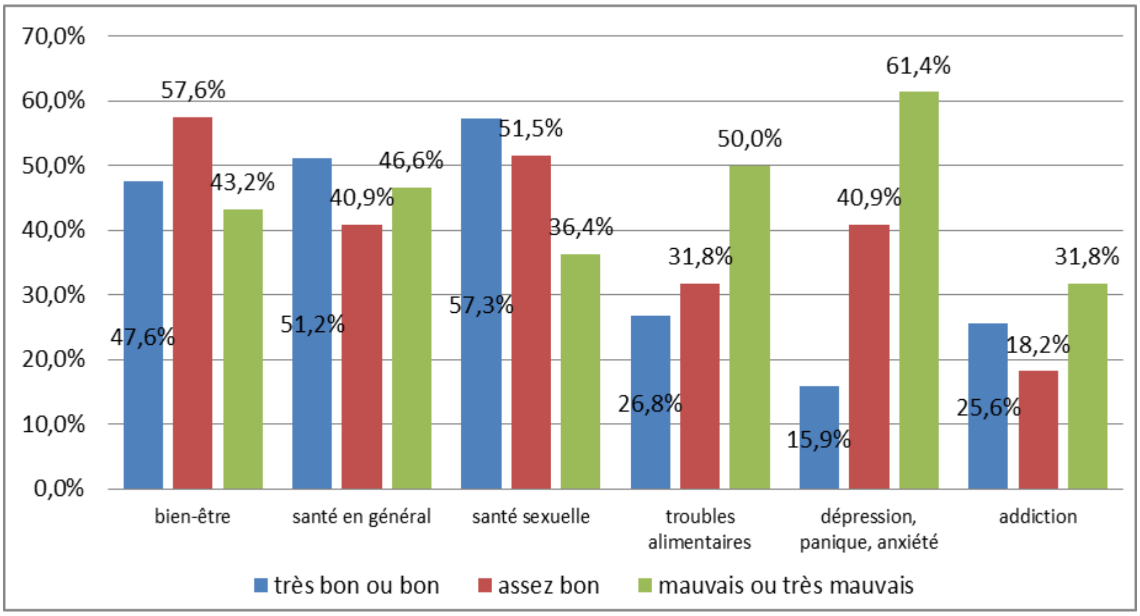


Figure 13. Distribution of people having read some information on the Internet during the last 12 months according to the health domains and the perceived psychological and emotional health status

4. *The use of the Internet vs the use of the health care services*

The use of the Internet could either be associated or not to the use of health care services. Actually 26.0% of the respondents said they had “very often” looked for information on the Internet “instead of seeing a doctor”, 30.3% “quite often”, 19.9% “rarely” and 23.8% “never” – and this without any significant difference whether it was or not the first time they visited the FSJ website. Especially the 15-17 years young people (34%) looked for information on the Internet “very often” “instead of seeing a doctor”, vs 28.6% of the 12-14 years group and 13.9% of the 18-25 years. They were mainly middle school (31.5%) or high school (31%) students.

Analogously, 24.8% of the sample said they had looked for information on the internet “very often” “instead of seeing a doctor”, 33.0% “often”, 19.1% “rarely” and 23% “never”, all without a significant difference in relation to the use of the FSJ website. The group of 18-25 years are the most numerous (26.6%) in this case, vs 24.0% of the 12-14 years and 23.8% of the 15-17 years.

A minor percentage of respondents looked for information “after a medical consultation”: 12.3% did it “very often”, 21.5% “quite often”, 26.3% “rarely” and 39.9% “never”. People who had already visited the website acted so two times more than the others (15.7% vs 9.2%).

Interestingly the place of living did not influence the use of the Internet before, after, instead of or without any relation to seeing a doctor. For instance, **Figure 14** shows that people who “very often” looked for online information “instead of seeing a doctor” were almost equally distributed among “big city” (26.3%), middle size city (27.5%) and small town or countryside (24.5%).

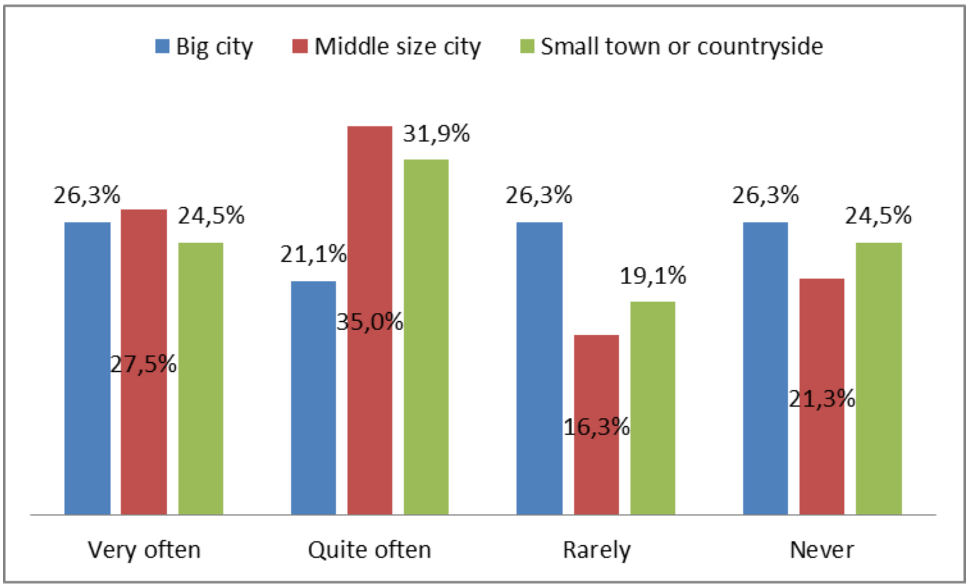


Figure 14. Frequency of the fact of looking for information on the Internet instead of seeing a doctor according to the place of living

We could see a sort of correlation between the searched themes on the Internet and the use of the health care services. In fact the respondents who had read online information in the last twelve months about “depression, panic or anxiety” were two times more numerous than the others in seeing at that time a psychologist or a psychiatrist (38.3% vs 19.3%). On the other hand, as for the other two domains of mental health (eating disorders and addictions), the tendency of consulting a mental health professional did not differ from whether the respondents had read or not the online information on this subject. However, having read information on general health (illnesses, allergies, treatments etc.) was not associated to the fact of having consulted or not a general practitioner (or a specialist) in that same year.

5. *The trust in the health information found in the Internet*

A vast majority of the respondents judged the information found online as trustworthy: 72.9% judged it “rather trustworthy” and 6.8% “absolutely trustworthy”; whereas 17.8% considered it “rather not trustworthy” and 2.5% “absolutely not trustworthy”. When comparing these data with the results from the Baromètre Santé 2010 (see **paragraph 3.2.2**) from which this question was taken, 79.0% of the young people from 15 to 30 years trusted in general the information found on the Internet, vs 79.7% of the 12-25 years of our sample (61.4% considered it as “rather trustworthy” vs 72.9% of our sample). About this issue, our sample was similar to the general population of 15-30 years.

The opinion on the quality of the information did not seem to be associated to the fact of knowing that some health related websites are “labeled”. In total, 61% of the respondents did not know what a labeled health website is. In the same proportion of the others, they considered the online information as “trustworthy” (79.9% vs 79.3%).

The trust given to the information published online seemed to vary according to the age of the respondents. Those who trusted more the information were young people between 15 and 17: 83.7% of them judged the information as absolutely or rather trustworthy, vs 78.8% of the 18-25 and 73.1% of the 12-14 years (not significant differences but the number of respondents is low). On the contrary, the level of trust seemed similar according to the place of living as well as according to the fact of having already visited the FSJ website.

Moreover the young people who trusted online information seemed (but their number is low) to be more than the others in using the Internet for seeking for information or support about health for themselves, a member of their family or a friend or just for curiosity. Almost the totality of them (96.8%) acted so, vs 89.6% of those who did not trust the information they found on the Internet.

6. *The public of the Fil Santé Jeunes website*

Totally 53.0% of the respondents had visited for the first time the FSJ website the day they answered our questionnaire and 47.0% had already consulted the website. For such a reason we called “users of Fil Santé Jeunes” all the people who had already visited the website, even if we did not know exactly how much they had used the website.

The 111 people who had already visited the website (94 girls and 17 boys) were distributed in age groups in a similar way to those who had visited the website for the first time: 12-24 years (20.7% vs 23.2%) ; 15-17 years (47.7% vs 40.8%); and 18-25 years (31.5% vs 36.0%). Similarly, the “users” and the “non-users” of the Fil Santé Jeunes did not differ from each other according to their place of living: 38.7% lived in a small town or in the countryside (vs 39.8% in average for the total sample), 37.8% in a middle size city (vs 35.2%) and finally 23.4% in a big city (vs 25%).

During the last twelve months, 97.3% of the respondents who had already visited the website had used in a general way Internet for seeking for support and information on health for themselves, a member of their family or a friend or just for curiosity. This percentage was very similar to those who had visited the website for the first time (93.6%).

The users of the Fil Santé Jeunes were more numerous than the “non-users” in having, during the last 12 months, been helped by an expert contacted on the Internet (email, forum, chat…), in having exchanged on the Internet their opinions with other people (forums, social networks), on one or more of the following themes: wellbeing (sport, nutrition, relaxation…), general health (illnesses, allergies, treatments…), sexual health (sexuality and contraception), eating disorders (anorexia, bulimia, gain weight…), depression, panic and anxiety, and addictions (alcohol, tobacco, cannabis or other drogues). Then 24.3% of the people who had already visited the website had been helped by an expert vs 16.8% of those who consulted the website for the first time in relation to this survey. Similarly, 42.3% of them had used some forums or social networks for information and support vs 28.8% of the others. Moreover, 15 « users » and 5 « non-users » had called a helpline (always during the last 12 months for one of the mentioned themes.

As far as the physical health status is concerned, there were no significant differences between the FSJ users and the other web-users as reported in **Figure 15**. On the other hand, the users considered more often their psychological and emotional health status as bad or very bad (**Figure 16**).

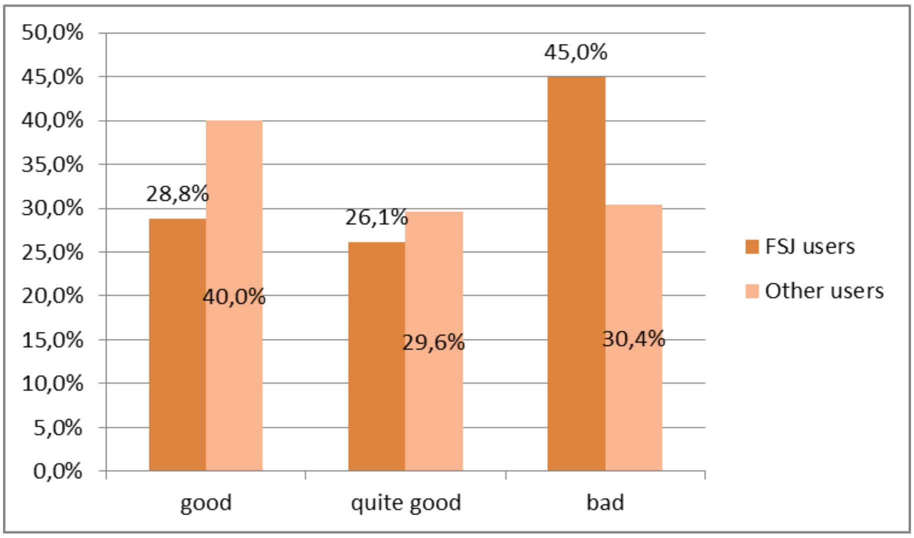


Figure 15. The perception of one's physical health status according the previous use of the www.filsantejeunes.com

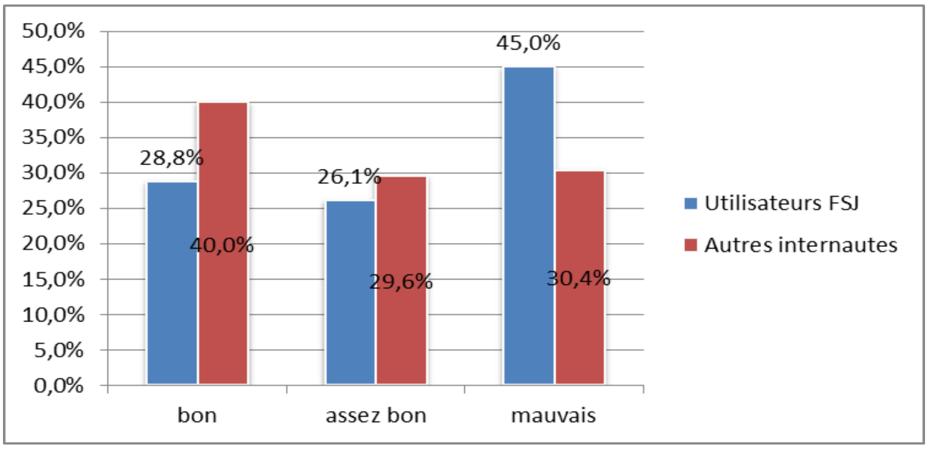


Figure 16. The perception of one's psychological and emotional health status according the previous use of the www.filsantejeunes.com

Furthermore we can see that there were some differences between the FSJ users and the others as for some behaviors in researching health information (**Figure 17**). For instance, if 65.4% of the sample searched “most of the times” by keywords from a search engine, a portal or ISP, the users were less numerous (56.9% vs 72.8%). Inversely, they were more numerous to directly visit a health website or a portal they already knew: 29.4% vs 19.8% (i.e. an average of 24.3% for the total sample). As for the evaluation of the quality of the information, 18.8% of the respondents looked “most of the times” at the date of publication and 25.2% at the person or institution disseminating the information. In both these cases the users of FSJ seemed to act so more often than the people who had come to the website for the very first time.

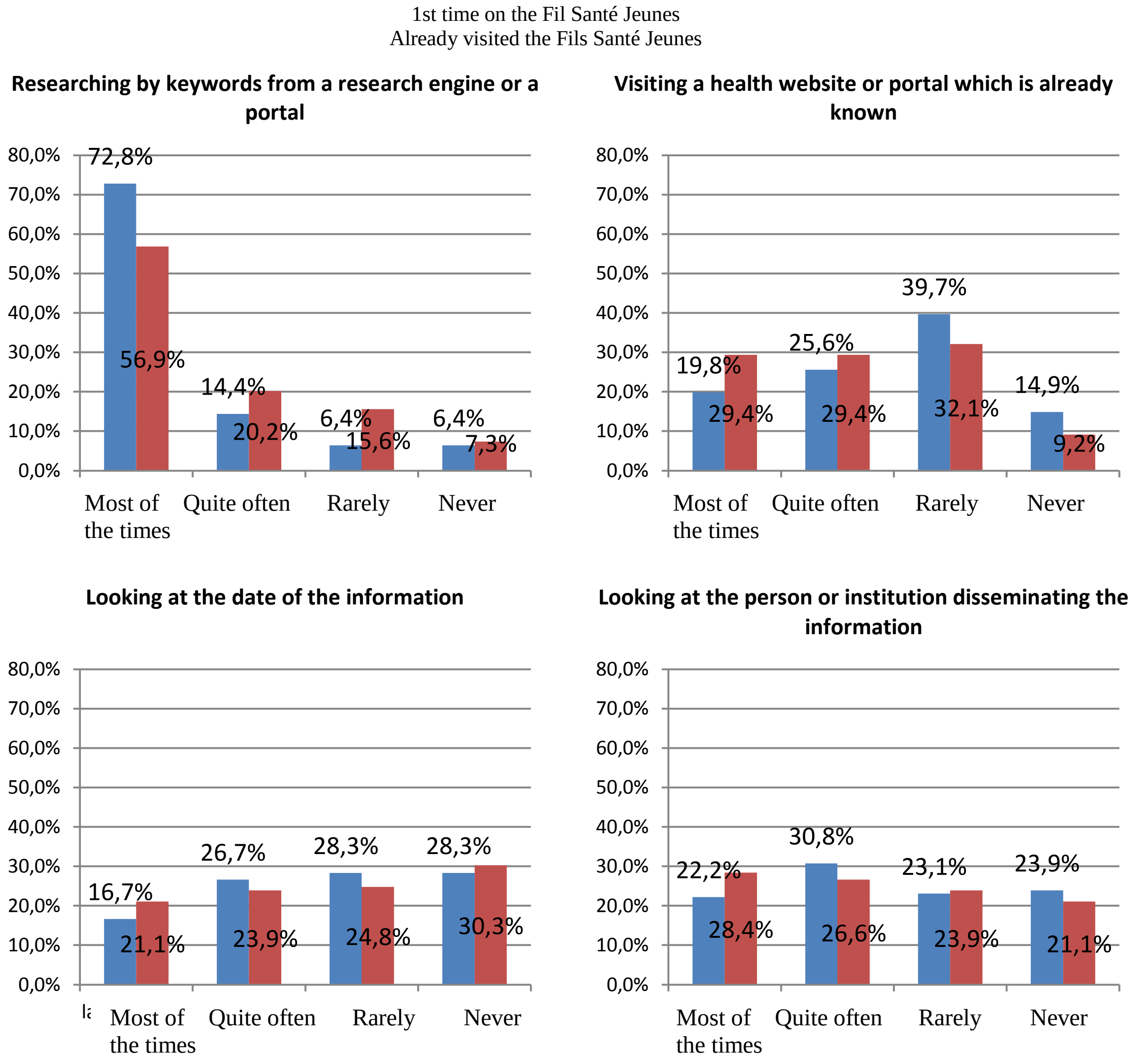


Figure 17. Frequency of 4 behaviors on the Internet when looking for information or advice in the domain of health or wellbeing, according to the previous use of www.filsantejeunes.com

7. *The use of the Fil Santé Jeunes website*

Even if the majority of the respondents (53.0%) had visited for the first time the www.filsantejeunes.com website specifically for this questionnaire, the 236 members of our sample answered on the themes searched on the website. The **Figure 18** shows that sexual health (sexuality and contraception) was the most searched theme.

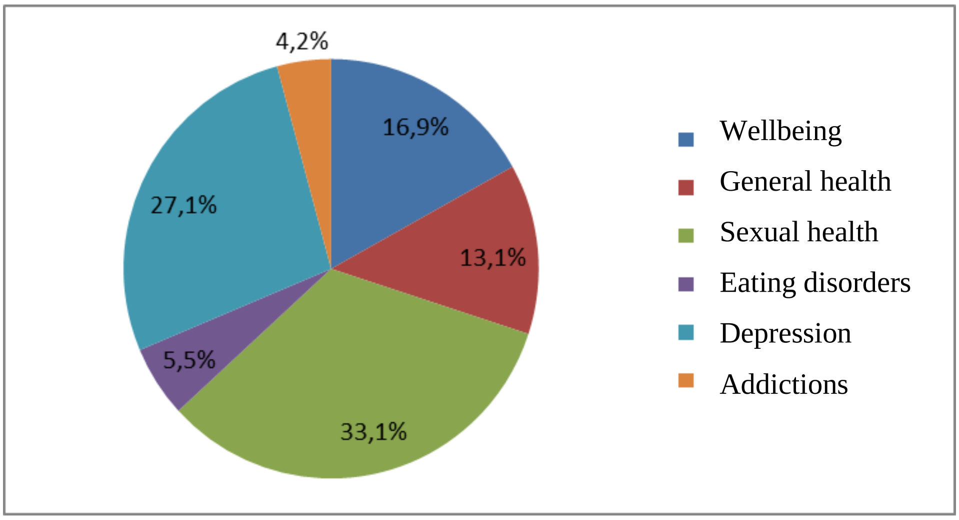


Figure 18. The themes searched on www.filsantejeunes.com

We cannot see any significant difference in the searched themes between the users of the Fils Santé Jeunes and the other web surfers (**Figure 19**). However it seemed that the users, more than the others, mainly looked for answers on "depression, panic, anxiety" (32.4% vs 22.4%); and less often than the others some answers about "wellbeing" (13.5% vs 20.0%).

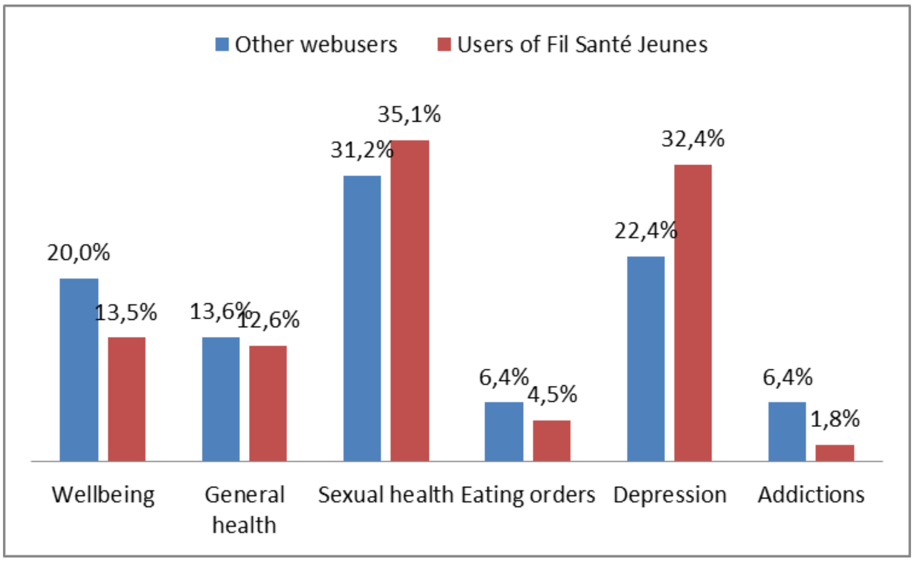


Figure 19. The themes searched for the users of Fils Santé Jeunes and for the other webusers

The FSJ website presents five principal sections where we can find some information and suggestions related to health: Forum, Boîte à questions, Articles and Quiz. For each of the six specific themes, the section "Articles" is the one the respondents consulted the most a priori. In total, 62.7% said they mainly looked for an answer to their questions in this section (**Figure 20**). The **Figure 21** shows in detail the sections which are more visited according to the different searched themes.

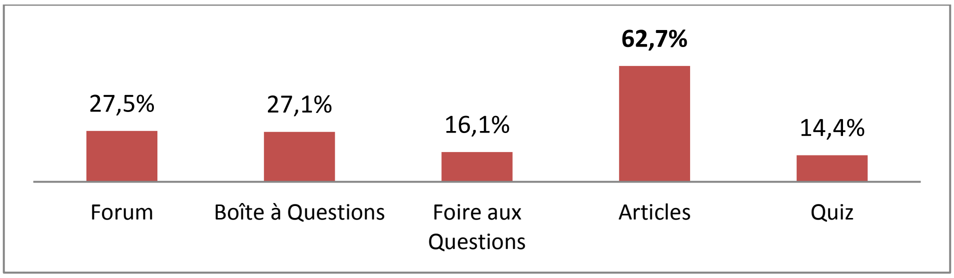
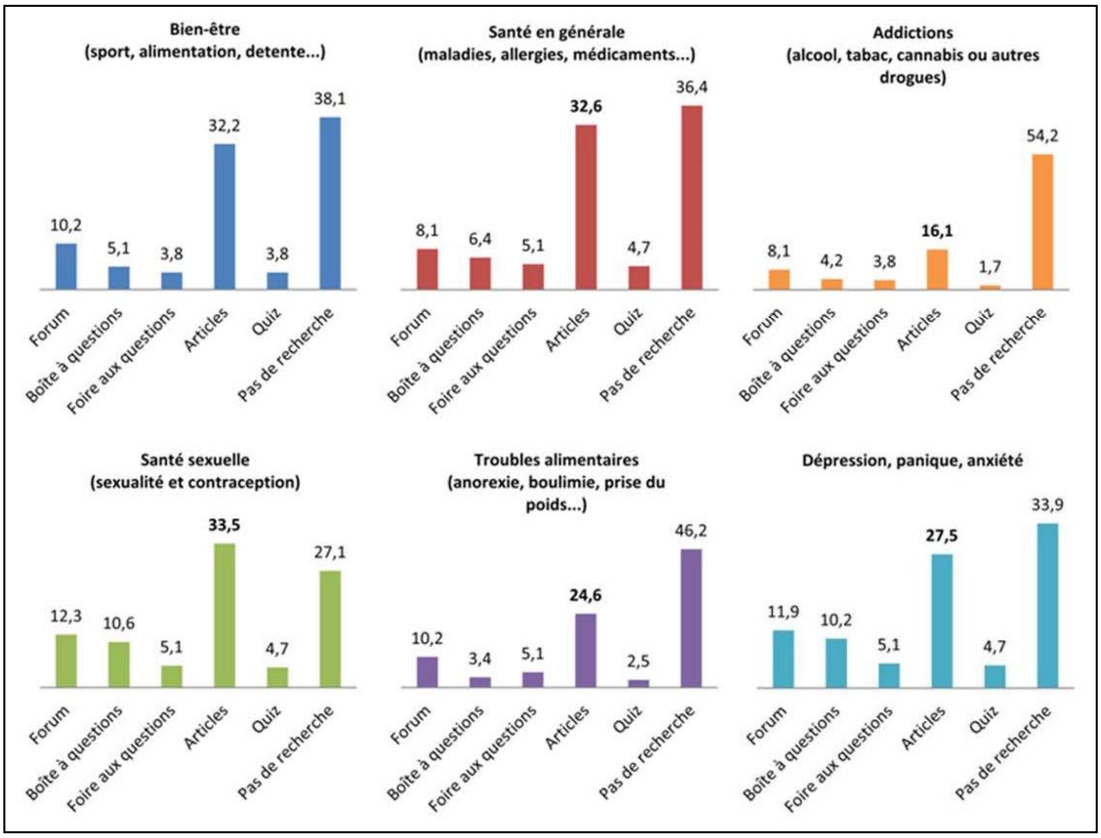


Figure 20. The consultation of the sections of the site www.filsantejeunes.com


Bien-être (sport, alimentation, detente...)

Santé en générale (maladies, allergies, médicaments...)

Addictions (alcool, tabac, cannabis ou autres drogues)

Santé sexuelle (sexualité et contraception)

Troubles alimentaires (anorexie, boulimie, prise du poids...)

Dépression, panique, anxiété

Figure 21. The sections of the site www.filsantejeunes.com consulted a priori according to the health themes

Conclusions

Questionnaires on the Internet always present the bias of the non-representativeness of the respondents. Online surveys are certainly easier to be carried out but in contrast with face to face interviews, for instance, they do not allow (with exception of some specific studies) to control the sample nor to verify the correct development of the study. The first results mentioned in the Intermediate Report FSJ (Montagni and Parizot, 2013) had to be read with particular attention, especially given the low number of participants to the survey in the first three months (N=236).

As far as the sample here presented is concerned, the survey was disseminated on the Fil Santé Jeunes website, on the official FSJ Facebook page and on the FSJ newsletter. It was also communicated to young people between 12 and 25 years known personally by the investigators. Their answers were recorded in a completely confidential way. Finally, 53% of the respondents went for the very first time on the website for answering the questionnaire and the investigators could not guess if they also had a look at the other sections of the website. In any case, this aspect of the sample authorized some analyses for the young people having different degrees of knowledge of this health information and prevention online tool.

This intermediate report was based on the data collected during the first three months of the online publication of the questionnaire. Actually, given the paucity of the respondents, some of the analyses were not statistically significant. However, the methodology here adopted could represent the starting point for other analyses and work on a more representative and numerous sample.

In fact, the questionnaire “Ta santé et ton bien-être sur Internet” is planned to be online for a longer period of time (at least one year more) and the investigators planned a new promotion campaign to solicit young people of 12-25 years to participate to the survey. This will definitively widen the studied sample for better and more exhaustive analyses. Moreover the results could be compared for future projects and researches with those of other investigations, i.e. the Baromètre Santé 2010 (Beck and Richard, 2013) and the Enquête WHIST (Renahy et al., 2007) from which some of the items of the FSJ questionnaire were taken.

With their increasing answers to the FSJ questionnaire, the young websurfers will help in the next months the Ecole des Parents et des Educateurs d'Ile-de-France (EPE) – the association managing the www.filsantejeunes.com website – to better understand the needs and attitudes of teenagers and young adults as for health information and support seeking. The results of the survey should more broadly help the piloting of French prevention programs addressed to young people.

The questionnaire can also show the way young people address to doctor. The doctor-patient relationship is here interestingly analyzed. Psychologists could use the WEB 2.0 and develop applications and websites to support young patients.

3.4 STUDY 4 - The e-MentH Questionnaire: a multicenter study (France, Ireland, Italy, Spain)

The e-MentH project was designed in January 2013 by adapting the questionnaire created for the University of Cork (Ireland) by Horgan and Sweeney (2010) and applied in the University of Verona (Italy), the University of Cadiz (Spain), the University Paris XIII – including the attached Institut de Formation en Soins Infirmiers (IFSI) of the Centre Hospitalier Robert Ballanger (CHIRB) – (France) and in the same premised of the University of Cork. Works conducted for the "Baromètre Santé 2010" and **STUDY 3** were of help to set the foundations of this study.

The multi-center approach of the e-MentH project was meant to allow for comparisons among four different European countries as far as the use of Internet is concerned when looking for information on mental health care and diseases. The project is still open for collaborations and interventions from other European (and hopefully also to extra-European countries) through online contacts via the official website (www.ementhproject.org) and promotion and dissemination of the first achievements and results of the study.

The e-MentH project was conceived to provide valuable data about young people who represent a cohort of study not deeply analysed so far with the vast majority of population-based studies being based on either middle-aged and elderly individuals or infants and children. Up to now we do not have a complete understanding of how students and young patients use the internet across a range of healthcare experiences, namely for mental health issues. E-patients and more frequent consumers of health online informations are on average 40 years old, at least in Canada (Statistiques Canada, 2007). The e-MentH project tries to understand the position young people/students have as e-patients, given that they are the strongest users of this technology and noticeably of social web (Skooiz, 2010). In this sense, it contributes to increase the knowledge of the use of and the trust in the Internet as a source of mental health information by a specific sector of the population thus fitting in the frame of other contemporaneous works aimed at better understanding how new technologies and their contents are used for improving one's mental health conditions (Lemire, 2009, Drolet, 2011).

Information on students' usage of the Internet, socio-demographic and health and emotional characteristics, trust in health websites and medical consultations were gathered and collected through an ad-hoc questionnaire. The questionnaire evaluated the level of empowerment of students as for their health with the online information helping to bridge the gap between doctors and patients and to make the patients participate more actively to their healthcare (Aubé and Thoër, 2010).

Background

Around 30% of the world's population is aged 10-24 (Michaud et al., 2009) and mental and behavioral disorders are the leading cause of disability in the population aged 18-24 (Chambers and Murphy, 2011). Notwithstanding the high prevalence of mental distress and disabilities in this age group, it is recognized that young people experience difficulties in accessing mainstream mental health services.

One potential solution is the use of the many websites available offering information and support for mental health problems (Horgan and Sweeney, 2010). The Internet is in fact a powerful mental health promotion tool, unrestricted by geographical, temporal or physical constraints (Ybarra and Suman, 2008) which in most countries is especially used by young adults under the age of 25 (Department of Communications Information Technology and the Arts, 2005). The Internet can promote the well-being of young people and for this reason there is the urgent need to improve their skills in safe Internet use. Information on Internet is abundant but often inaccurate or unreliable, and in some instances even potentially harmful. Knowing how young adults perceive the quality of the information on the websites is then essential to prevent any dangerous misinterpretation. In addition, given its potential, the Internet can also represent a new mental health service for all young adults fearing the stigma which is still associated to mental health troubles. It is then very important to describe the use of the Internet also as an aid for treatment. These two aspects (1 – Internet as a resource of information, and 2 – Internet as a support tool) are investigated within the e-MentH project.

Several studies have been conducted on the use of the Internet for general health information seeking in general population (Rice, 2006; Renahy et al., 2008a; Gallagher et al., 2008) however few have focused specifically on both the variables “young adults” and “mental health”. Namely, this usage of the Internet by young people has been examined in singular and separated contexts: a project conducted in the University of Cork (Horgan and Sweeney, 2010), the monitoring of mental health websites in Australia (Burns et al., 2009) and a new research project conducted in France on the www.filsantejeunes.com website (Montagni and Parizot, 2013), just to mention some of the few investigations conducted so far. Furthermore, to the best of our knowledge, the usage and views on using the Internet for mental health problems have never been examined in a multi-center context allowing the comparison of the behaviors of young people from different countries.

Given this background, the e-MentH project questions the students of four European Universities (Cork, Verona, Cadiz and Paris) about their use of the Internet for information and support seeking as far as mental health is concerned. Behaviors of students are described and statistically analyzed with a specific focus on the variables of geographical provenience of the students, their field of study and their health status.

Materials and Methods

The e-MentH questionnaire

Data were collected through a self-administered questionnaire (see APPENDIX) based on the tool developed for a study in Ireland (Horgan and Sweeney, 2010). The original questionnaire was modified and updated with new items from the French survey “Baromètre Santé 2010” (see **paragraph 3.2.2**) and two French Studies “WHIST” (Renahy et al., 2007) and “Fil Santé Jeunes” surveys (see **paragraph 3.3**). The final questionnaire took also into account the major themes identified from the literature on the use of the Internet by young adults for mental health information and advice and the most searched words on this issue (Phillipov and Phillips, 2003). An extensive review of the literature had then been undertaken to form the questions for this study.

The questionnaire consisted of 25 items divided into three sets: General Information, i.e. demographic details of age, gender, subject of academic study, type of accommodation, source of income and health condition (9 questions); General Usage of Internet (4 questions); and Use of Internet for Health and Mental Health (12 questions). General information was deemed important to provide insights into where and how the participants used the Internet. The questionnaire contained different types of questions such as multiple choice questions and Likert scales, allowing for only quantitative data to be entered.

The Translation of the Questionnaire

The original version of the questionnaire was written in English by the principal investigator and then revised and controlled by an English mother-tongue collaborator. Before translating it, the original English questionnaire was approved and validated by one psychiatrist, one psychologist and one social worker. Then translations into Spanish, French and Italian were produced by linguistic experts. Counter-translations were provided by professional translators and native Italian, French, English and Spanish speakers following a plan crossing source language (L1) and target language (L2) as showed in **Table 11**.

L1 → L2	Translator
English → Italian	I.M.
English → French	I.M.
English → Spanish	C.S.E
Spanish→ French	L.C.
Italian → Spanish	S.V.
Spanish→ English	M.A.
Italian → English	E.C.
French → English	E.R.
French → Italian	G.A.
French → Spanish	R.O.
Italian → French	N.P.
Spanish → Italian	G.S.

Table 11.

The translations followed a procedure of forward translation, qualitative reviews of translated items with regard to clarity, common language and conceptual adequacy, back translation, testing on lay panels, and a review by experts. A functionally equivalent questionnaire in the target language should have the same effect as the questionnaire in the source language, in other words the 'objective of a translated questionnaire is to produce the same responses from the patient that the original would' (Leplège and Verdier, 1995).

When applying the same tool in different countries it is essential to provide translations so that the collected data are well harmonized. A good way to proceed would be to develop a unique questionnaire at national level by a group of researchers who are later employed in the translation and adaptation of the same questionnaire. The translation of the questionnaire also arises another interesting point. The majority of pages on the World Wide Web are in English. Young people are more at ease with English, but this could represent a barrier for older web users.

Literacy, linguistic, cultural and disability barriers are important issues when translating a questionnaire, especially if it is meant for the Internet. Translation processes can be integrated in quantitative interviews (surveys) about mental health issues in multi-lingual research fields. While theoretical and methodological problems of language and translation have been thoroughly reflected upon from different perspectives in qualitative and quantitative research (Inhetveen, 2012), the literature provides little guidance for the translation of interviews about mental health in particular.

The increasing use of mental health questionnaires on the one hand and of multinational studies on the other hand, has resulted in the necessity to translate the same questionnaires in different languages. Guidelines for translation have been published, and there has been some discussion of how to achieve and assess equivalence between source and target questionnaires (Herdman et al., 1997). A major source about the translation of questionnaires is "Translating Questionnaires and Other Research Instruments: Problems and Solutions" by Orlando Behling and Kenneth S. Law (2000). This book covers the essential information needed to understand the problems involved in translating existing questionnaires and other instruments. It then provides researchers with a guide for construction of cross-national survey instruments. Actually, the discussion on the translation of quantitative methods is quite advanced, offering elaborate forms of controlled translation, especially in comparative survey research (Harkness, 2003).

Usually, translators depart from the literal wording and then opt for a pragmatic translation thus providing a final combination of different translation modes. However, translation is not merely a shift from one language to the other but also a discussion of questions arising from translation themselves and of substantial problems in the phenomena under study.

Multi-lingual researches seem to have become more frequent recently, especially for the development and implementation of multi-center studies like those financed by the European Union. In a multi-lingual research design, translation processes involving the cooperation of several researchers and/or translators become inevitable (Inhetveen, 2012). A basic difficulty of such design is that every translation involves an interpretation of meaning by the translator (Cappai, 2003). How to systematize translation in the research process is still an open question today.

The translation process of the E-MentH glossary suggested that there is an urgent need for a standardized terminology within the mental health field in general and the use of the internet for mental health issues in particular. The interest in multi-center studies involving different countries of different languages (see for example the call for European projects, Marie Curie actions, 7th Framework Programme etc.) is growing rapidly. Consequently, the need for translating research instruments from one language in other languages has emerged. Translated instruments are fundamental to enable comparisons of results across different language groups (Patrick et al., 1994).

In terms of mental health, it is interesting to make cross-cultural comparisons especially to standardize the provision of mental health care within countries, e.g. in the European Union. To compare data the same instrument must be used, instead of recurring to data collected by different national instruments. In order for the cross-cultural comparison of results to be valid, it is necessary to be able to show equivalence between translated versions of the same questionnaire (Herdman, 1997). There is a burgeoning literature on guidelines to improve the quality of the translation process, as well as some discussion of how to gain and assess the ‘equivalence’ of questionnaires in different languages (Doward, 1995; Guillemin et al., 1993; Meadows, 1994).

The participants

Data were collected from students of Nursing, Law and Computer Science at the University of Verona (Italy), the University of Cadiz (Spain), the University Paris XIII – including the attached Institut de Formation en Soins Infirmiers (IFSI) of the Centre Hospitalier Robert Ballanger (CHIRB) – (France) and at the University of Cork (Ireland). Students from all five years of each course were included in the study.

The protocol of this study was strictly followed in accordance with the Social Research Ethics Committee of the Universities involved. The Head of School of each course was contacted to seek access to participants. Once access was granted, the investigators studied the timetables to pick appropriate classes and approach individual lecturers to seek permission to distribute the questionnaire during class time. Students were informed that the participation was voluntary, that no personal sensitive health data were collected and that the questionnaires were anonymous. To maintain confidentiality of the records, no personal details like name, address, phone number or e-mail were requested. Only the course during which the questionnaire was handed out was recorded on the questionnaires managed by the investigators.

The questionnaire was distributed in class and recollected after 10-15 minutes. The distribution was carried out by the main investigator of the e-MentH project with the help, for larger classes, of some unpaid assistants. When handing the questionnaire out, students were informed that they could answer the questionnaire only once, thus avoiding double-count. Unpaid assistants distributing the questionnaire were prepared (with a precise standard speech when necessary) to introduce the questionnaire and explain in the most suitable manner the study.

For all courses in all Universities but Computer Science at the University of Cork, questionnaires were distributed to students in class at the beginning or at the end of the lesson. For Computer Science at the University of Cork, since the Head of School did not allow the intervention of the investigator during lessons, questionnaires were distributed in the corridors of the Faculty and compiled by students during their break.

The questionnaires were first distributed in the University of Cadiz (Spain) where the piloting phase of the e-MentH project was carried out (Montagni et al., *submitted*).

The Universities involved

The four Universities involved in the first stage of the e-MentH project (which is still open to future collaborations with new universities and centers of higher education) were chosen for their size (almost the same number of students) and their geographical location (small cities or suburban areas). These similarities were supposed to facilitate comparisons among the four universities.

The **Università degli Studi di Verona** (Italy) is located in the city center of Verona (Humanistic departments) and in the outskirts (Medicine and Science departments), besides the many other locations spread throughout the territory: Legnago, Vicenza, Bolzano, Trento, Ala and Rovereto. It was founded in 1982 and it is divided into 15 departments: Biotechnology; Business Administration; Computer Science; Economics; Foreign Languages and Literatures; Law; Life and Reproduction Sciences; Medicine; Neurological, Neuropsychological, Morphological and Movement Sciences; Pathology and Diagnostics; Philology, Literature and Linguistics; Philosophy, Education and Psychology; Public Health and Community Medicine; Surgery; Time, Space, Image, Society. The University has adopted the so called 3+2 system and offers a first level degree achievable in 3 years (Laurea Triennale), a specialization of 2 more years (Laurea Magistrale), a unique five-year degree (Laurea Magistrale Quinquennale), PhD courses and one-year specialistic courses (Master). In the academic year 2009-2010 (most updated data available), the total number of students was 22.372.

The **University College Cork** (Ireland) is a constituent university of the National University of Ireland and was founded in 1845. The University offers over 120 degree and professional programs through 7 schools and 27 departments. It has 4 colleges: Arts; Celtic Studies and Social Science; Business and Law; Medicine and Health; and Science, Engineering and Food Science. The University issues a Level 3 certificate after 3 years (Junior Certificate) and with 2 additional years a Level 5 certificate (Leaving Certificate). Students can then obtain a Level 6 (Advanced Certificate or Higher Certificate), a Level 7 (Ordinary Bachelor's degree), a Level 8 (Honours Bachelor's Degree or Higher diploma), a Level 9 (Master's degree or Postgraduate diploma) and finally a Level 10 (Doctorate degree or Higher doctorate). In the academic year 2011-2012 (most updated data available), the total number of students was 18.860.

The **Universidad de Cádiz** (Spain) is a public university located in the province of Cádiz, Andalusia and founded in 1979. In addition to the principal campus of Cádiz where there is the Rectorate, the university has three satellite campuses: Bahía de Algeciras, Jerez de la Frontera and Puerto Real. Among its main schools there are: Modern Languages; Health; Engineering; Labor Relations; Legal and Economic Studies; Pedagogy. Under the new European Higher Education Area, the former undergraduate degrees (Licenciatura or ingeniería lasting 4, 5 or 6 years; and the Diplomatura or ingeniería técnica lasting 3 years) are being replaced by the título de grado (Bachelor's degree) or the título de máster (Master's degree). In the academic year 2007-2008 (most updated data available), the total number of students was 17.280.

The **Université Paris Nord XIII** (France) is one of the thirteen universities in Paris which replaced the University in Paris in 1970. It is located in the northern area of Paris, in the communes of Villetaneuse, Saint Denis and Bobigny. It offers 21 Licences professionnelles and 27 Masters on the main subjects: Science; Technology; Health; Law; Culture and Communication; Social Sciences; Economy; Management. According to the Bologna Process this university issues the following degrees: the Bachelor degree after 3 years (Licence and Licence Professionnelle), a specialization in 2 years (Master 1 and Master 2) and a Doctorate. In the academic year 2009-2010 (most updated data available), the total number of students was 23.000.

The **Institut de Formation en Soins Infirmiers (IFSI) of the Centre Hospitalier Robert Ballanger (CHIRB)** (France) is a specialised Nursing school located in Aulnay-sous-Bois. It was founded in 1964 and recently, according to the French Education reform Loi Savary 1984, it is attached to the Health, Medicine and Human Biology Education and Research Unit of the Université Paris Nord XIII. It issues a 3-year degree in Nursing and proposes courses for assistive personnel and child care assistants. Each year students enrolled can be at most 150.

Results

Statistical analyses were performed using SPSS statistical software (version 20.0; SPSS Inc., Chicago, IL, USA). Descriptive and inferential statistics were used to address the study aims, including Chi-squared tests P<0.05 was considered statistically significant. Results are presented as numbers (unweighted) and percentages with 95% confidence limits.

The Sample

A total of 2 367 questionnaires were collected and analysed. For France, 518 questionnaires were collected: 211 for Computer Sciences, 204 for Law and 103 for Nursing. For Ireland, 607 questionnaires were collected: 200 for Computer Sciences, 204 for Law and 203 for Nursing.For Italy, 608 questionnaires were collected: 201 for Computer Sciences, 202 for Law and 205 for Nursing. For Spain, 634 questionnaires were collected: 213 for Computer Sciences, 203 for Law and 218 for Nursing. Questionnaires with more than 50% of missing answers were excluded from the analyses which resulted in a final refusal rate of 0%.

The profile of the young internet user: socio-demographic and health characteristics

The following **Figures** (from **22** to **28**) describe our sample in terms of gender, age, place of living, accommodation, employment and both physical and psychological status. Results are presented country by country.

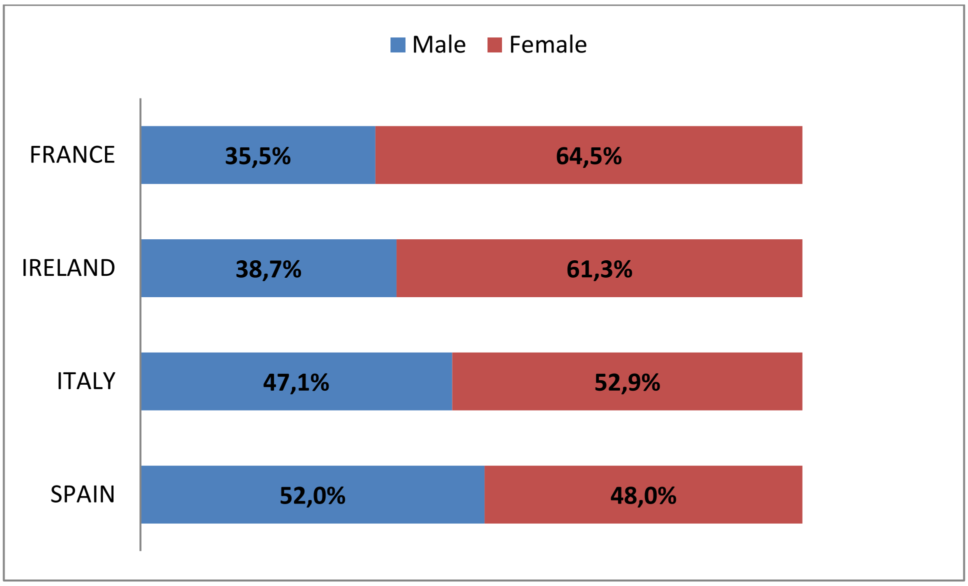
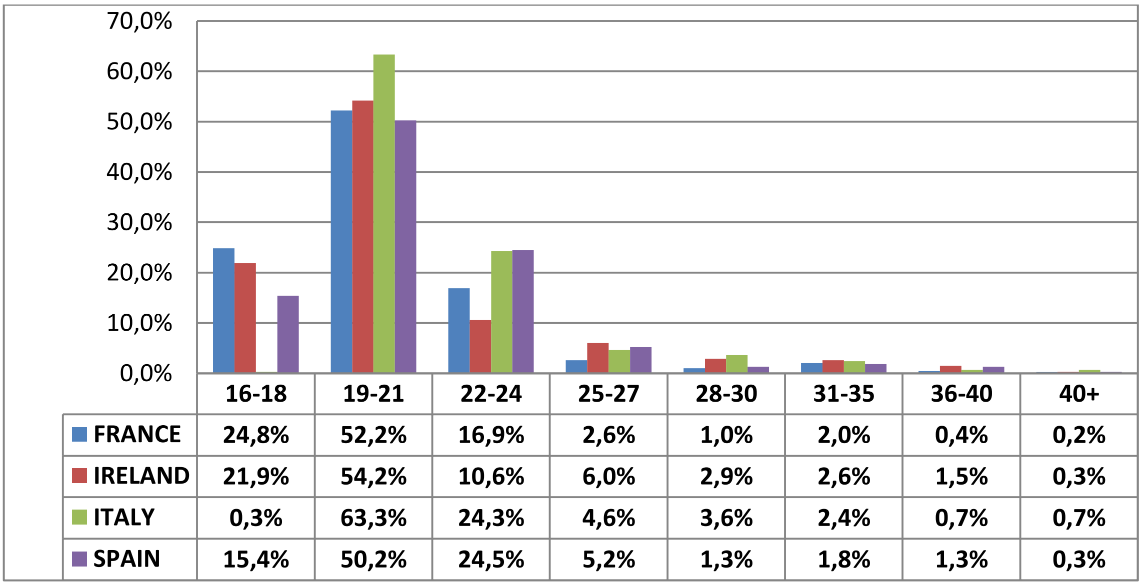
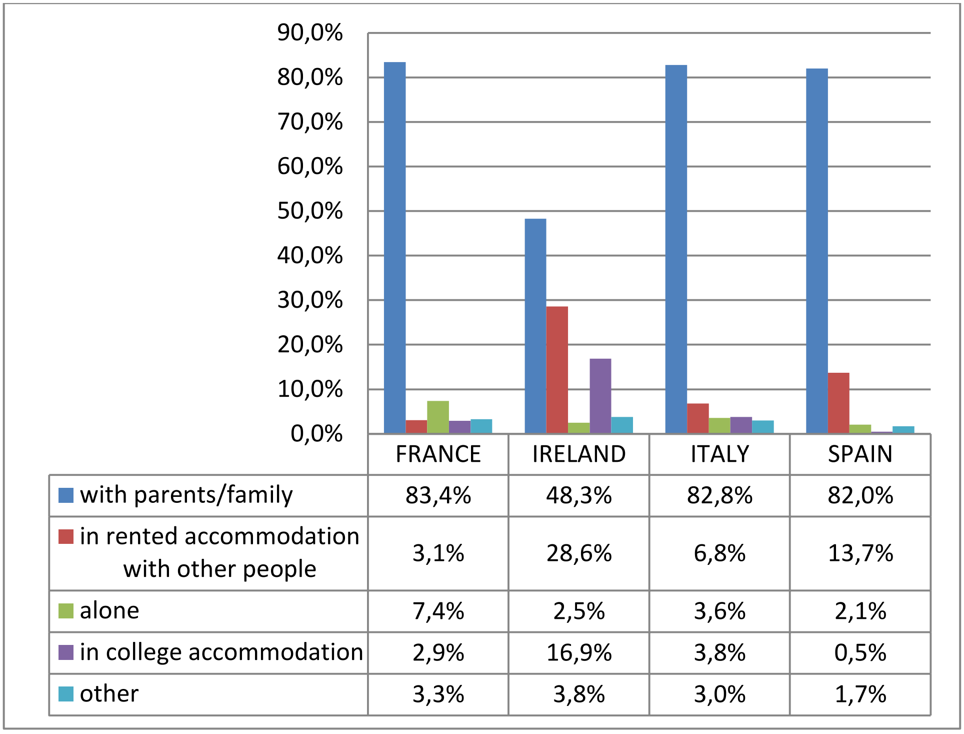


Figure 22. Gender of the e-MentH respondents



	16-18	19-21	22-24	25-27	28-30	31-35	36-40	40+
🟦 **FRANCE**	**24,8%**	**52,2%**	**16,9%**	**2,6%**	**1,0%**	**2,0%**	**0,4%**	**0,2%**
🟥 **IRELAND**	**21,9%**	**54,2%**	**10,6%**	**6,0%**	**2,9%**	**2,6%**	**1,5%**	**0,3%**
🟩 **ITALY**	**0,3%**	**63,3%**	**24,3%**	**4,6%**	**3,6%**	**2,4%**	**0,7%**	**0,7%**
🟪 **SPAIN**	**15,4%**	**50,2%**	**24,5%**	**5,2%**	**1,3%**	**1,8%**	**1,3%**	**0,3%**

Figure 23. Age groups of the e-MentH respondents



	FRANCE	IRELAND	ITALY	SPAIN
🟦 with parents/family	83,4%	48,3%	82,8%	82,0%
🟥 in rented accommodation with other people	3,1%	28,6%	6,8%	13,7%
🟩 alone	7,4%	2,5%	3,6%	2,1%
🟪 in college accommodation	2,9%	16,9%	3,8%	0,5%
🟦 other	3,3%	3,8%	3,0%	1,7%

Figure 24. Accommodation of the e-MentH respondents

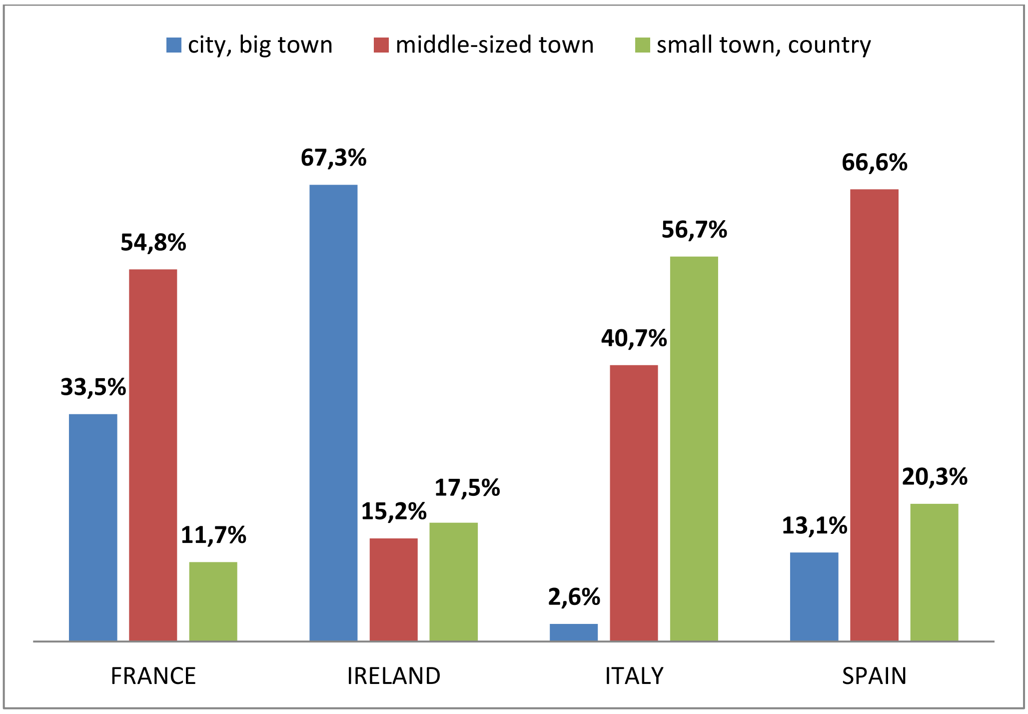


Figure 25. Place of living of the e-MentH respondents

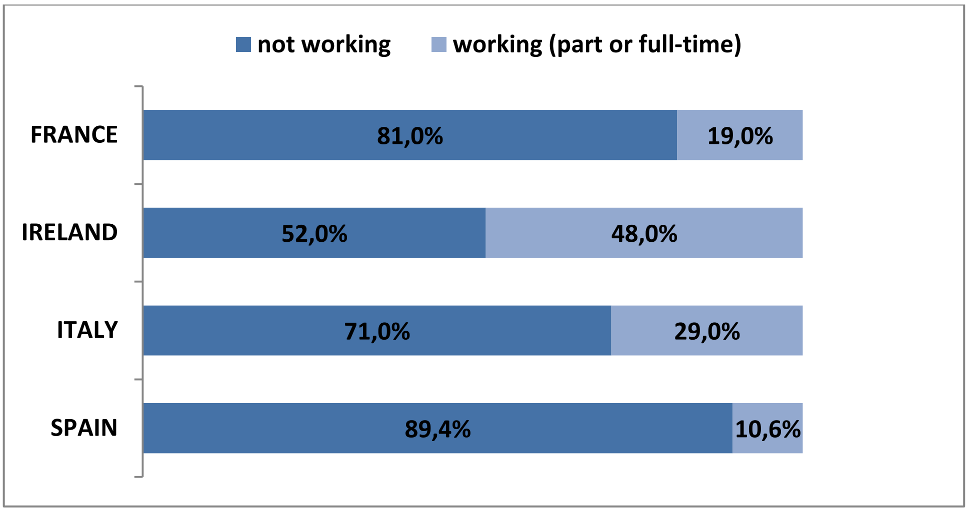


Figure 26. Working situation of the e-MentH respondents

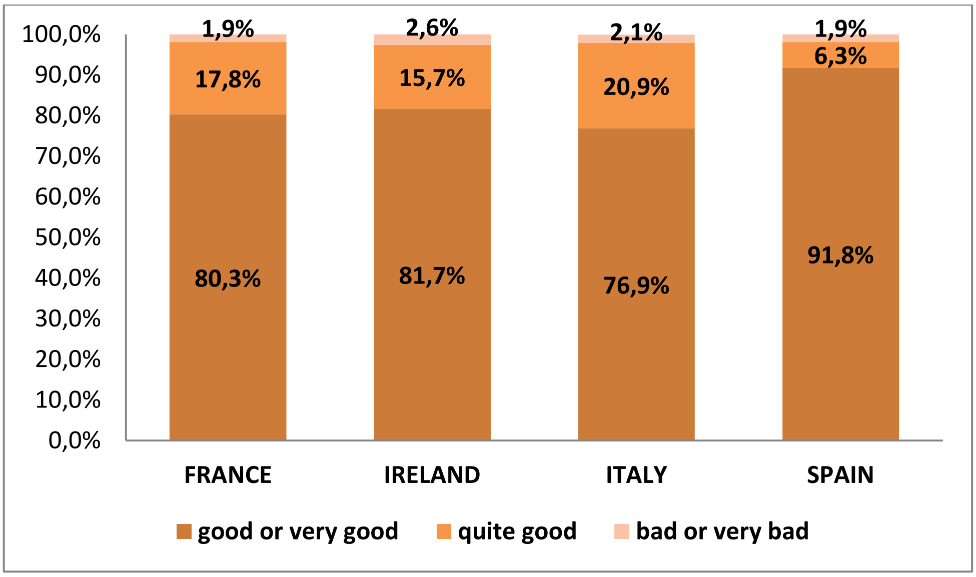


Figure 27. Physical health status of the e-MentH respondents

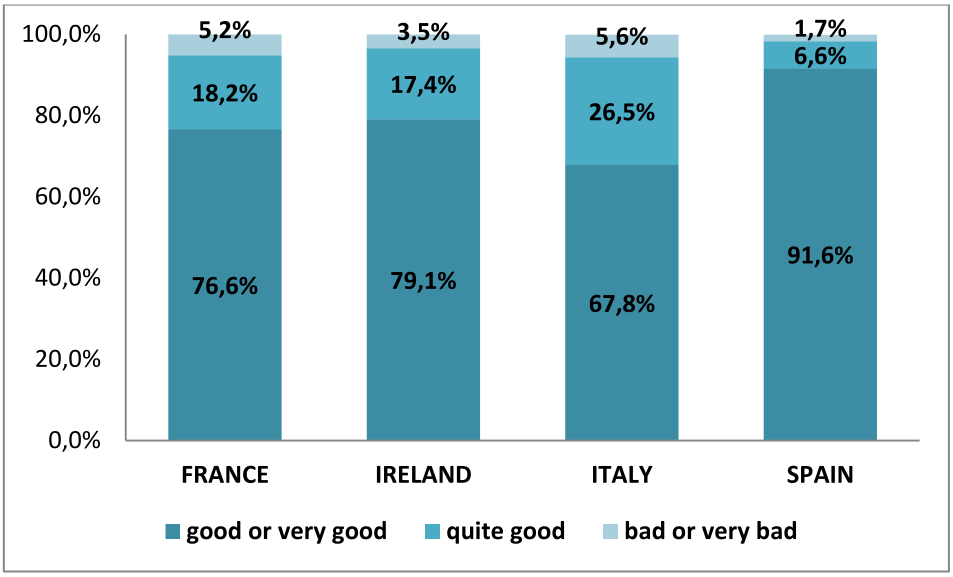


Figure 28. Psychological health status of the e-MentH respondents

The activities in the Internet

The following **Tables** (from **12** to **15**) report for each country the frequency of online activities carried out by students in each country.

Online activities	Several times a day	Once a day	Several times a week	Once a week	Once a month	Less often	Never
Sending emails (missing rate = 2,2%)	17,3%	16,9%	26,7%	16,1%	9,2%	11,2%	2,7%
Finding information for college (missing rate = 1,5%)	14,8%	18,6%	27,9%	14,4%	5,4%	12,8%	6,0%
Getting news updates (missing rate = 2,3%)	**46,2%**	13,2%	27,9%	5,5%	2,6%	3,1%	1,6%
Getting information on movies, music or TV (missing rate = 2,1%)	32,2%	15,7%	26,7%	7,5%	5,5%	9,4%	2,9%
Looking for health information (missing rate = 2,9%)	8,9%	6,1%	20,6%	12,9%	14,5%	26,1%	10,9%
Downloading music (missing rate = 2,0%)	19,5%	7,9%	23,0%	9,6%	10,8%	15,6%	13,6%
Playing games (missing rate = 2,6%)	15,0%	4,7%	8,1%	7,9%	3,4%	18,0%	**42,9%**
Buying something (missing rate = 2,7%)	4,1%	2,6%	7,3%	6,5%	25,4%	31,5%	22,6%
Participating in chat rooms (missing rate = 3,6%)	13,5%	4,8%	4,0%	3,0%	2,4%	14,9%	**57,3%**
Participating in discussion or message boards (forums) (missing rate = 3,7%)	6,6%	2,8%	2,0%	3,4%	3,6%	15,9%	**65,6%**
Social networks (Facebook, Twitter etc.) (missing rate = 1,1%)	**54,7%**	12,1%	11,7%	3,1%	0,8%	6,1%	11,5%
Watching videos (missing rate = 3,4%)	**52,5%**	14,4%	22,8%	4,2%	3,0%	3,2%	missing

Table 12. Online activities of French students

Online activities	Several times a day	Once a day	Several times a week	Once a week	Once a month	Less often	Never
Sending emails (missing rate = 2.2%)	25.8%	32.3%	22.3%	26.0%	31.9%	15.7%	**28.2%**
Finding information for college (missing rate = 1.5%)	**30.4%**	31.1%	21.9%	17.5%	13.8%	7.8%	missing
Getting news updates (missing rate = 2.3%)	24.1%	27.3%	21.9%	30.2%	31.2%	24.2%	**29.0%**
Getting information on movies. music or TV (missing rate = 2.1%)	23.5%	23.3%	26.6%	33.6%	22.4%	18.7%	30.7%
Looking for health information (missing rate = 2.9%)	13.9%	15.3%	14.6%	28.5%	36.5%	27.2%	24.7%
Downloading music (missing rate = 2.0%)	19.8%	20.1%	26.1%	29.0%	34.0%	23.8%	23.3%
Playing games (missing rate = 2.6%)	17.5%	22.1%	27.5%	30.6%	44.9%	27.7%	22.6%
Buying something (missing rate = 2.7%)	**33.3%**	40.4%	37.6%	39.3%	32.9%	22.4%	11.9%
Participating in chat rooms (missing rate = 3.6%)	8.5%	13.4%	17.2%	22.8%	34.5%	29.3%	**36.7%**
Participating in discussion or message boards (forums) (missing rate = 3.7%)	19.0%	20.0%	22.1%	25.8%	32.7%	25.8%	26.6%
Social networks (Facebook. Twitter etc.) (missing rate = 1.1%)	**28.2%**	27.6%	21.3%	16.0%	29.4%	9.6%	13.0%
Watching videos (missing rate = 3.4%)	26.1%	29.2%	23.0%	26.1%	28.1%	12.9%	missing

Table 13. Online activities of Irish students

Online activities	Several times a day	Once a day	Several times a week	Once a week	Once a month	Less often	Never
Sending emails (missing rate = 2.2%)	**25.8%**	20.7%	25.3%	28.8%	27.0%	30.9%	28.2%
Finding information for college (missing rate = 1.5%)	24.7%	27.5%	30.6%	24.7%	19.0%	10.0%	8.3%
Getting news updates (missing rate = 2.3%)	19.0%	28.9%	26.5%	30.2%	31.2%	34.8%	**46.8%**
Getting information on movies. music or TV (missing rate = 2.1%)	**26.4%**	27.6%	26.9%	20.7%	25.4%	22.2%	30.7%
Looking for health information (missing rate = 2.9%)	23.8%	29.7%	25.5%	27.6%	25.7%	25.7%	23.8%
Downloading music (missing rate = 2.0%)	22.8%	34.1%	25.3%	23.8%	25.2%	23.2%	31.6%
Playing games (missing rate = 2.6%)	22.0%	25.0%	26.0%	20.0%	22.5%	22.3%	**31.8%**
Buying something (missing rate = 2.7%)	18.2%	21.2%	24.3%	27.4%	24.6%	25.0%	29.3%
Participating in chat rooms (missing rate = 3.6%)	**48.6%**	52.3%	43.0%	34.2%	20.0%	18.7%	8.9%
Participating in discussion or message boards (forums) (missing rate = 3.7%)	22.9%	23.8%	22.7%	19.5%	20.8%	24.0%	29.3%
Social networks (Facebook. Twitter etc.) (missing rate = 1.1%)	24.7%	27.6%	29.0%	18.0%	11.8%	17.8%	**34.3%**
Watching videos (missing rate = 3.4%)	23.7%	25.7%	29.1%	26.1%	24.6%	31.8%	missing

Table 14. Online activities of Italian students

Online activities	Several times a day	Once a day	Several times a week	Once a week	Once a month	Less often	Never
Sending emails (missing rate = 2,2%)	26.5%	12.5%	35.9%	12.5%	3.0%	9.2%	0.4%
Finding information for college (missing rate = 1,5%)	**49.3%**	16.1%	27.0%	3.9%	1.8%	1.6%	0.3%
Getting news updates (missing rate = 2,3%)	41.5%	26.0%	14.5%	7.7%	1.8%	7.4%	1.0%
Getting information on movies, music or TV (missing rate = 2,1%)	21.4%	15.2%	28.8%	15.3%	6.2%	10.8%	2.2%
Looking for health information (missing rate = 2,9%)	4.5%	4.7%	18.8%	12.2%	13.6%	36.1%	10.1%
Downloading music (missing rate = 2,0%)	12.8%	5.8%	28.7%	13.7%	11.3%	20.4%	7.4%
Playing games (missing rate = 2,6%)	19.6%	7.3%	12.9%	7.3%	4.8%	24.4%	23.5%
Buying something (missing rate = 2,7%)	1.5%	1.1%	5.0%	5.6%	12.5%	41.3%	**33.1%**
Participating in chat rooms (missing rate = 3,6%)	24.8%	4.3%	8.8%	2.7%	2.0%	16.1%	**41.2%**
Participating in discussion or message boards (forums) (missing rate = 3,7%)	8.7%	4.7%	14.2%	8.8%	5.3%	29.8%	**28.5%**
Social networks (Facebook, Twitter etc.) (missing rate = 1,1%)	**70.5%**	12.5%	5.4%	2.6%	0.9%	3.4%	4.7%
Watching videos (missing rate = 3,4%)	**50.6%**	14.7%	20.3%	5.9%	1.8%	5.1%	1.6%

Table 15. Online activities of Spanish students

As for the use of online supporting tools in the last 12 months (missing rate = 2.5%), 1.4% of French students had used online therapy, 5.4% chat rooms and 14.1% forums/discussion boards. In Ireland, 2.4% of students had used online therapy, 1.4% chat rooms and 7.0% forums/discussion boards. In Italy 2.2% of students had used online therapy, 6.2% chat rooms and 3.8% forums/discussion boards. Finally in Spain 2.7% of students had used online therapy, 5.0% chat rooms and 7.6% forums/discussion boards.

The searched themes

When asked if they had ever looked for general health information on the Internet (missing rate = 0.4%) 21.7% of French students, 24.7% of Irish students, 26.0% of Italian students and 27.7% of Spanish students answered so. Percentages on the seeking for mental health information online were as follows: 24.2% of French students, 23.4% of Irish students, 24.3% of Italian students and 28.2% of Spanish students.

Through "Item 17" students were asked how often they had looked for sexual health information (sexuality and contraception) in the last 12 months (missing rate = 2.3%). French students consulting the Internet for sexual health information once a week or more were 18.0%, Irish students 13.5%, Italian students 28.1%, and Spanish students 40.4%

Students were asked in "Item 18" to select the themes about mental health they have looked for in the Internet (missing rate = 0.8%). They could select either all of them, just some or none. In France, the three most searched themes resulted to be "general information about mental health" (40.2%),"stress (also post-traumatic)" (35.4%) and "eating disorders" (26.5%). In Ireland students searched mainly for "suicide and self-harm" (34.8%),"depression" (33.9%) and "panic attacks" (29.8%). In Italy the three most searched themes were "panic attacks" (30.8%),"addictions" (30.6%) and "eating disorders" (29.4%). Finally in Spain students looked mostly for the following themes: "general information about mental health" (41.3%),"post-natal depression" (28.6%) and "eating disorders" (25.7%).

"Item 22" investigated the way students look for mental health information on the Internet. French students reported they looked for mental health information by "entering key words into a search engine, portal or ISP such as Google or Yahoo" very often (49.5%, missing rate = 7.1). Also Irish students very often "entered key words into a search engine, portal or ISP such as Google or Yahoo" (20.5%, missing rate = 7.1). The same for Italian students (36.4%, missing rate = 7.1). Finally, Spanish students very often looked for information by "paying attention to the date of the information" (26.0%, missing rate = 9.0%).

Trust in the websites

When asked whether in general they considered mental health information in the Internet as credible or not (missing rate = 5.1%), in order of percentage, French students answered “quite so” (66.7%), “not quite so” (26.8%), “absolutely not” (4.0%) and “absolutely yes” (2.5%).

Irish students answered “quite so” (52.9%), “not quite so” (38.7%), “absolutely not” (4.4%) and “absolutely yes” (4.0%). Italian students answered “quite so” (53.7%), “not quite so” (41.6%), “absolutely yes” (2.5%) and “absolutely not” (2.2%). Finally Spanish students answered “not quite so” (65.3%), “quite so” (21.5%), “absolutely not” (11.9%) and “absolutely yes” (1.3%).

However, when asked whether they knew what certified health websites are (missing rate = 4.1%), 65.8% of French students, 61.7% of Irish students, 71.6% of Italian student and 83.4% of Spanish students answered “no”.

The Relationship between the patient and the care provider

Trough “Item 9” students were asked whether in the last 12 months they had seen one of the following health professionals: general practitioner; gynaecologist; psychologist/psychiatrist or counselor; another medical specialist; school nurse; another health professional. **Figures** from **29** to **32** report the percentages for each country of all consulted health professionals (with missing rates between 0.3% and 0.4%).

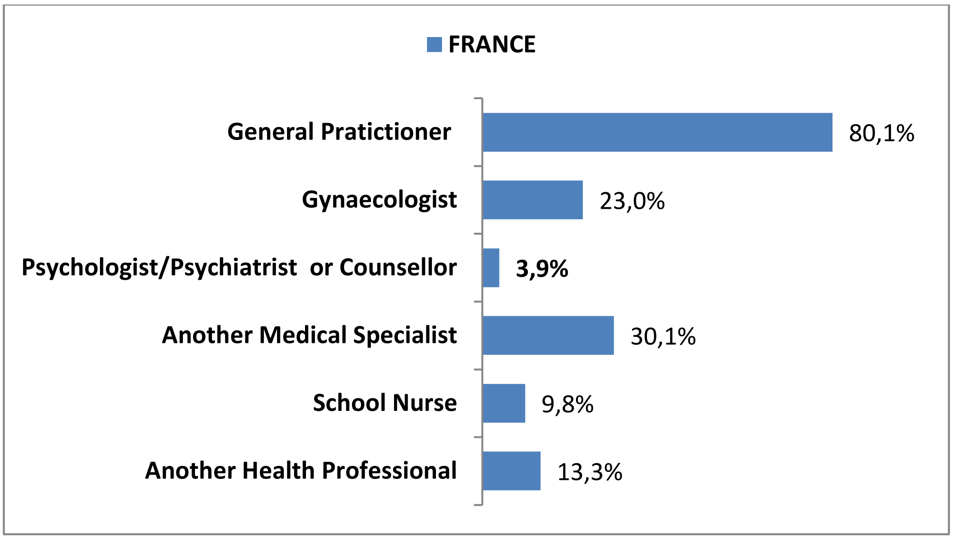


Figure 29. Consulted health professionals in France

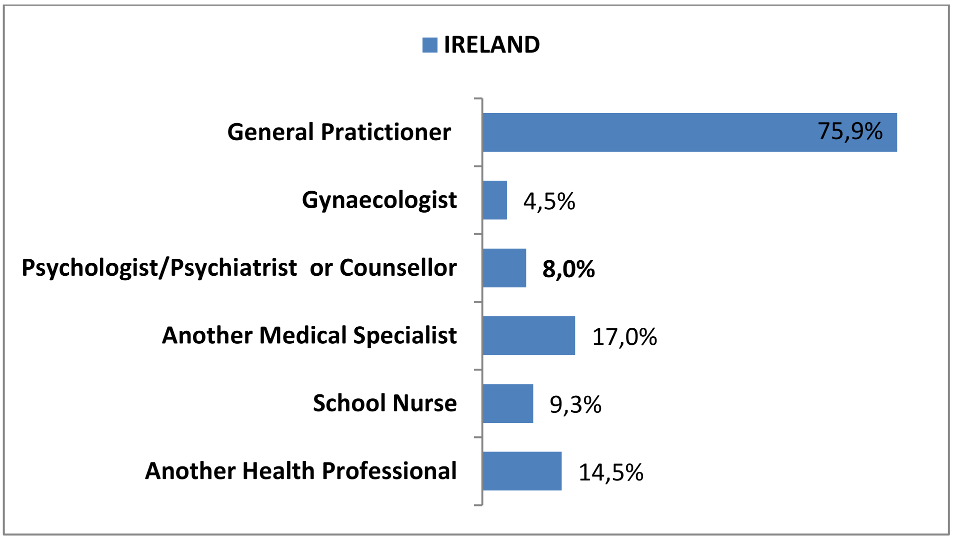


Figure 30. Consulted health professionals in Ireland

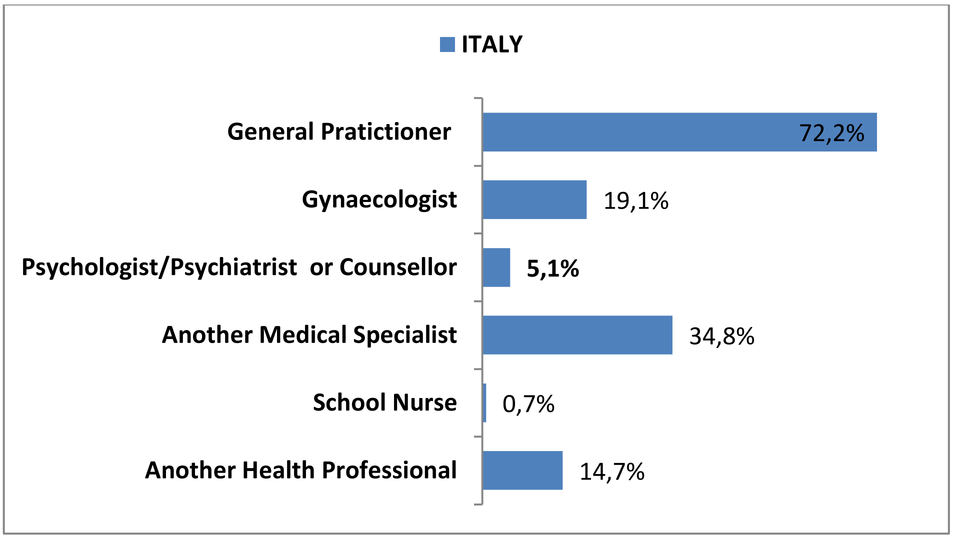


Figure 31. Consulted health professionals in Italy

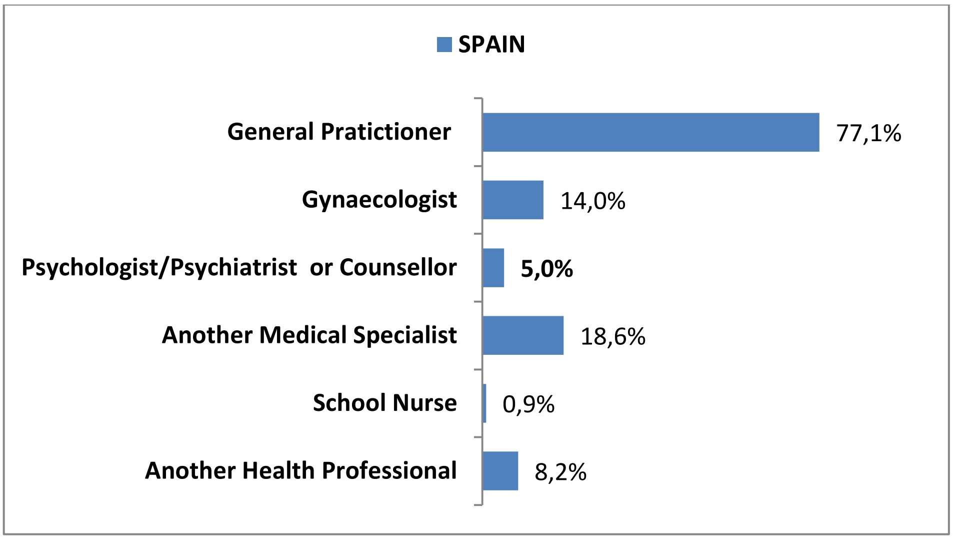


Figure 32. Consulted health professionals in Spain

Consultations with doctors where then analysed in relation to the search on the Internet of mental health information. Students were asked whether and with which frequency they consulted the internet "instead of going to a doctor" (missing rate = 9.1%), "before going to a doctor" (missing rate = 8.9%), "after a medical consultation" (missing rate = 9.9%) or "independently from any medical consultation" (missing rate = 9.6%). **Tables** from **16** to **19** show the results country by country.

	very often	quite often	rarely	never	don't know
Instead of going to a doctor	7.0%	12.9%	18.1%	58.5%	3.5%
Before going to a doctor	4.1%	15.1%	18.1%	58.8%	3.9%
After a medical consultation	3.7%	10.4%	22.9%	59.3%	3.7%
Independently from any medical consultation	6.7%	11.1%	22.4%	53.6%	6.3%

Table 16. Frequency of online mental health information review in relation to medical consultation in France

	very often	quite often	rarely	never	don't know
Instead of going to a doctor	8,6%	18,8%	19,9%	35,9%	16,8%
Before going to a doctor	10,8%	23,7%	21,4%	27,1%	17,1%
After a medical consultation	4,8%	16,7%	23,1%	37,4%	18,0%
Independently from any medical consultation	6,8%	14,1%	19,5%	36,5%	23,2%

Table 17. Frequency of online mental health information review in relation to medical consultation in Ireland

	very often	quite often	rarely	never	don't know
Instead of going to a doctor	3,0%	9,9%	23,0%	58,7%	5,4%
Before going to a doctor	5,0%	15,1%	22,8%	51,3%	5,9%
After a medical consultation	3,2%	9,9%	23,5%	56,4%	7,0%
Independently from any medical consultation	4,6%	10,6%	20,9%	52,4%	11,5%

Table 18. Frequency of online mental health information review in relation to medical consultation in Italy

	very often	quite often	rarely	never	don't know
Instead of going to a doctor	6,3%	8,3%	17,5%	55,1%	12,9%
Before going to a doctor	7,1%	19,3%	21,6%	38,6%	13,3%
After a medical consultation	5,3%	15,5%	20,0%	43,2%	16,0%
Independently from any medical consultation	8,0%	19,5%	16,5%	37,4%	18,6%

Table 19. Frequency of online mental health information review in relation to medical consultation in Spain

Future analyses

The high amount of collected information allow for further cross-country comparisons. Data could be analysed by taking into account different variables (e.g. gender or place of living) in all 4 countries. The sample of more than 2 400 questionnaires represents notwithstanding the missing information a valuable resource for future reports.

Discussion

The profile of the young internet user: socio-demographic and health characteristics

Through "Item 16" (missing rate = 2.6%) respondents were asked whether they had been looking for health information for themselves or for other people. This question is preliminary to any description of the interviewed sample, as the profile of students looking for health information for themselves could be different from that of people browsing the Internet for their family or friends. In France 61.0% of the respondents declared having used in the last 12 months the Internet to look for information and advice about health issues concerning themselves; 44.9% for their family or friends; and 43.7% for none in particular. In Ireland 70.9% of the respondents declared having used in the last 12 months the Internet to look for information and advice about health issues concerning themselves; 40.2% for their family or friends; and 26.4% for none in particular. In Italy, 63.0% looked for information for themselves; 48.7% for their family or friends; and 32.9% for none in particular. Finally in Spain, 55.3% looked for information for themselves; 44.1% for their family or friends and 40.9% for none in particular.

These results confirm that students were interested in health information especially for themselves. The description of the sample provides then a clear picture of the typical young web-users looking for health information mainly for themselves.

From a socio-demographic point of view, the sample is composed of quite similar proportions of females (56.3%) and males (43.7%). The sample is mainly (90.8%) constituted by young students aged 18-25 years and representing the most active and present population online. Students are confirmed to be the most frequent users of the Internet as suggested by Underhill and McKeown (2008). Age is an important variable to consider because first-year students can be compared with older students to assess the effect of being freshmen and adapting to a new situation, i.e. from high-school to university.

Notwithstanding the fact that people reporting bad or very bed physical and mental health conditions are important users of the Internet, the prototypical user is in good (mental?) health conditions and interested in preserving them. This result confirms the data collected by Fox and Purcell (2010).

Similary, the results of the survey by the Pasteur Mutualité (2010) were confirmed for the use of the Internet for mental health according to the place of living. People living in bigger cities used the web for mental health information seeking more than their peers living in the countryside or in villages.

Finally, it has been deemed important to ascertain the field of study of the students. Since Nursing students could skew the findings, we tested them to compare this group with the two other tested groups of students (from both humanistic and scientific studies). Studying health related subjects could influence the use of the Internet for information seeking, particularly for mental health. Similarly, the use of the Internet in general could be more frequent in Computer Science students. Degrees, subjects and courses provided by the four Universities have been checked in order to find similar disciplines to be compared. The involved universities offer similar courses and have quite the same size. A mean of 200 students for each of the three fields in each University was interviewed.

The activities in the Internet

Results confirm that the web is first of all a place of entertainment but also of information with the most recurrent online activities being finding information for college and accessing social networks. The recreational use of the Internet - playing online games, watching videos, downloading music etc.- of the e-MentH participants is in line with the work by Gross (2004), Hansen and colleagues (2003) and the Pew Internet survey (2009).

In addition to using the internet to browse for information, there are other health-related activities identified by the literature. In Andreassen et al.'s cross-country European study (2007), the authors found that 27% had participated in online forums or self-help groups and 30% had interacted with health professionals. The Pew research study in the US by Fox and Jones (2009) found that a majority of e-patients access user-generated health information with 41% having read a commentary/blog/newsgroup about a particular health or medical issue.

Females are more interested in health information than males, for themselves or for other people, confirming once again the results by Underhill and McKeown (2008) and Fox (2006).

The searched themes

When preparing the “Item 18” listing all the possible subjects of information seeking for mental health, data on the prevalence of mental health diseases in young people were taken into account. For example, in Italy early intervention on young schizophrenic patients is an important, well-developed and studied issue (Ruggeri et al., 2012), whereas in France schizophrenia is not associated to young people too much. The frequency of the searched themes could then be interestingly compared with the prevalence of mental health disorders in young people. It is estimated that 10−20% of young people in Europe have a mental or behavioural problem.The most prevalent mental health diseases in youths are the following: Anxiety Disorders, Bipolar Disorder, Borderline Personality Disorder, Depression, Eating Disorders, Psychosis, Self Harm and Suicide Prevention, Substance Use Disorders. These are serious mental disorders with peak onset in the 12–25 year period. Anxiety disorders (that is, generalized anxiety disorder, panic disorder, phobias, obsessive compulsive disorder, post-traumatic stress disorder and separation anxiety) are the most prevalent mental disorders among young people, with an average national prevalence rate of 10.4% (although cross-national variations exist). The second most prevalent mental disorders are conduct disorders (7.5%); while anxiety disorders are more prevalent among girls, conduct disorders are more prevalent among boys. Depression and depressive disorders come third, with a prevalence ranging from 4% to 8%. The lifetime prevalence of major depression is about 4% in the age group 12−17 and 9% at age 18 (twice as high in females as in males). The latest findings suggest an increase in the prevalence of adolescent depression (WHO, 2009b). Eating disorders are common in young people, especially in girls and young women, although young men can also be affected. In the general population 7% of boys and 13% of girls report some sort of disordered eating behaviors (Lopez et al., 2006). Psychotic disorders such as schizophrenia, schizoaffective disorder and affective and atypical psychoses are rare, but the incidence of schizophrenia increases typically after puberty and peaks in early adulthood. The prevalence of psychotic disorders is between 0.5% and 1% among young people (WHO, 2009b).

As reported by Fox and Jones (2009), students are more interested in health and well-being and specific mental health issues like depression, eating disorders and addictions. Sexual health is one of the most searched themes, following the results by Drolet (2011).

As for the pathway to sourcing information online, the first step is invariably a search engine rather than the direct access to a website. Students prefer starting their research from search engines and portals like Google confirming the results of the study by Drolet (2011) and Escoffery and colleagues (2005). The majority of health information seekers (66%) begin their search process at search engines such as Google or Yahoo, with 27% using a specific health-related website to start the search (Tang and Ng, 2006). However, once "googled", mental health and generalist websites are more popular than forums, bulletin boards and discussion or support groups. The e-MentH results are in line then with those by Burns et al. (2010) and by Tang and Ng (2006).

Trust in the websites

Online information is trusted more when its source is known and reliable. Official websites are preferred by students who click on governmental sites more than on other sites in the lists provided by Google (Giroux, 2009). Increased reliance on online services may exacerbate the avoidance of face-to-face contact (Biddle et al., 2008), as the following paragraph will show.

The Relationship between the patient and the care provider

Throughout the items 9 and the 23 of the questionnaire, we investigated the attitudes and behviors of students about medical consultations. The Internet is still not a substitute and the role of the patient and the relationship doctor-ill person is fundamental to understand the use of the Internet as for mental health information seeking. Actually, the introduction of the information and communication technologies represents a radical innovation in the mental health domain and it is also changing and affecting the professional practices and the relationships between health professionals and patients.

There already existed several studies and works about the relationship between patients and doctors compared to the use of the Internet. More precisely Boyer and Lutfey (2010), Casper and Morrison (2010) and Timmermans and Oh (2010), have argued that there has been a socio-cultural shift in healthcare encounters, marked by shifting patient and provider roles, increased patient consumerism and direct patient access to medical and health related information through the Internet. In this body of research on the changing relationship between patients and healthcare providers, scholars emphasized the central role of online information-seeking, suggesting that the introduction of Internet in the mental health domain (even if Internet is not the only information source) is susceptible to a considerable impact in the management and autonomy of one’s and other’s health, especially for those who disregard the traditional health system.

The widespread access and use of the Internet provides patients with quick, unfettered access to a broad range of health-related information and support, and this access has largely contributed to the shift from physician-as-expert to patient-as-consumer healthcare encounters. With the emergence of the Internet, direct-to-patient marketing and the social construction of the patient-as-consumer, the concept of the empowered patient has become an important framework for understanding shifting patient roles when interacting with healthcare. Within the empowered patient construct, patients are encouraged to be self-advocates and participate as equals in medical decision-making (Salmon and Hall, 2004). The Internet is often interwoven in discussions of patient empowerment, as it is seen as one of the primary vehicles through which patients can empower themselves with information, confidence and support to bring to their healthcare encounters. Research has documented the important role of the internet in enhancing patient self-advocacy in routine healthcare encounters and when confronting rare or contested illnesses (Barker, 2008; Gundersen, 2011; Schaffer et al., 2008). However, we do not yet have a complete understanding of how the Internet is used during times of potentially life-threatening and acute illness.

Access to resources on the Internet provides patients with direct sources of information that has not been filtered by their healthcare provider. It also has the potential to provide resources and information to bolster patients' abilities to question their physician's opinion, seek alternate treatment options and access second opinions.

This study tried to compare the relationship between the patient and the care provider in the Italian, French, Irish and Spanish students. What has emerged is the fact that France is characterized by a strong hierarchical tradition in the relationship between the patient and the doctor. Moreover, when taking into account also the SES conditions, people declaring the weakest levels of resources seem to be more at risk of consulting less often a doctor after having looked for health information on the Internet, whereas people in psychological distress, like those fearing illnesses or interested in health issues, tend to increase their frequence of consultations (Beck and Richard, 2013).

e-MentH results showed that the Internet seems to be a complementary source (Stevenson et al., 2007) that is sometimes useful in facilitating discussions with physicians (HON, 2005) and that can make better understand the medical advice and even complete it (Kivitis, 2006). This explains why some students look for the information online before or after a medical consultation. The Internet can help to answer those questions young people are afraid to ask their doctor during their visit or it can be a support to deeply understand the received diagnosis. The Internet is the main alternative to the dialogue with peers or the consultation of a health expert and it often represents a first step in the pathway for seeking information on health as already stated by Ackard and Neumark-Sztainer (2001).

According to the INSEE (National Institute of Statistics and Ecomical Studies of France), 3 French young web users out of 10 declared in 2012 having searched for mental health information online instead of visiting a doctor. More precisely, a third of the French population aged between 15 and 30 years confirmed having changed their health behaviors after their online research (Gombault, 2013).

Finally, some students prefer consulting the Internet instead of addressing to other sources of information (above all health professionals and peers) when their health question and/or problem concerns more intimate domains and it is considered as "confidential", "delicate" or "private". For instance, sexuality is searched in the Internet more than it is directly discussed with health experts.

Against this background it will be necessary that doctors discuss with their patients what they find in the Internet. Patients should feel free to talk about the information they found online so that doctors can help them to understand which advice is good to be followed. In some cases, students surf in the Internet after the medical consultation in order to validate the diagnosis they have received. In both cases (before and after the consultation) the information found online do not replace the medical advice and doctors are always considered as the main and most reliable source of information. Health service providers should then aim to harness the potential benefits of health-related Internet use, rather than see it as a burden or challenge. Students prefer firstly to address to their entourage to ask for mental health information as already reported by Borzekowski and colleagues (2001 and 2006) and Gray (2005).

Clinicians may direct patients and family members to other resources for more comprehensive and accurate information about mental illness.

Limitations

Questionnaires were distributed in different semesters. The fact of asking to students at the end of a semester instead that of at the beginning could bias the emotional state of the students. Moreover, the time for completing the questionnaire varied from class to class. Especially depending on the time when the questionnaire was distributed: at the beginning of the lesson vs. the end of the lesson; in the morning vs. in the evening; in nursing vs. in computer science.

The questionnaire did not include any item referring to the ethnicity and/or nationality. In a future research it will be interesting to consider if the fact of being an immigrant, an Erasmus student or coming from a multicultural family could be a variable of interest for the questionnaire.

Conclusions

It is often difficult to address to young people on health issues. One of the latests approaches and methods employed in the last few years from the promotion actors is the investment in Internet and its social networks which are used a lot by young people (Burns and Morey, 2008). However little is known on how young people consider and seek for mental health information on the Internet.

This multi-center study tries to answer the need for a better understanding of how young people actually use the Internet, what they do with the information they find and how Internet help-seeking relates to other help-seeking behavior. By examining the role of the Internet in meeting information needs, psychiatric services and practitioners could harness the Internet as a tool to educate and support young patients. This is particularly important in mental health, where the Internet may have a role in supporting those for whom stigma inhibits help-seeking through more traditional routes (Berger et al., 2005).

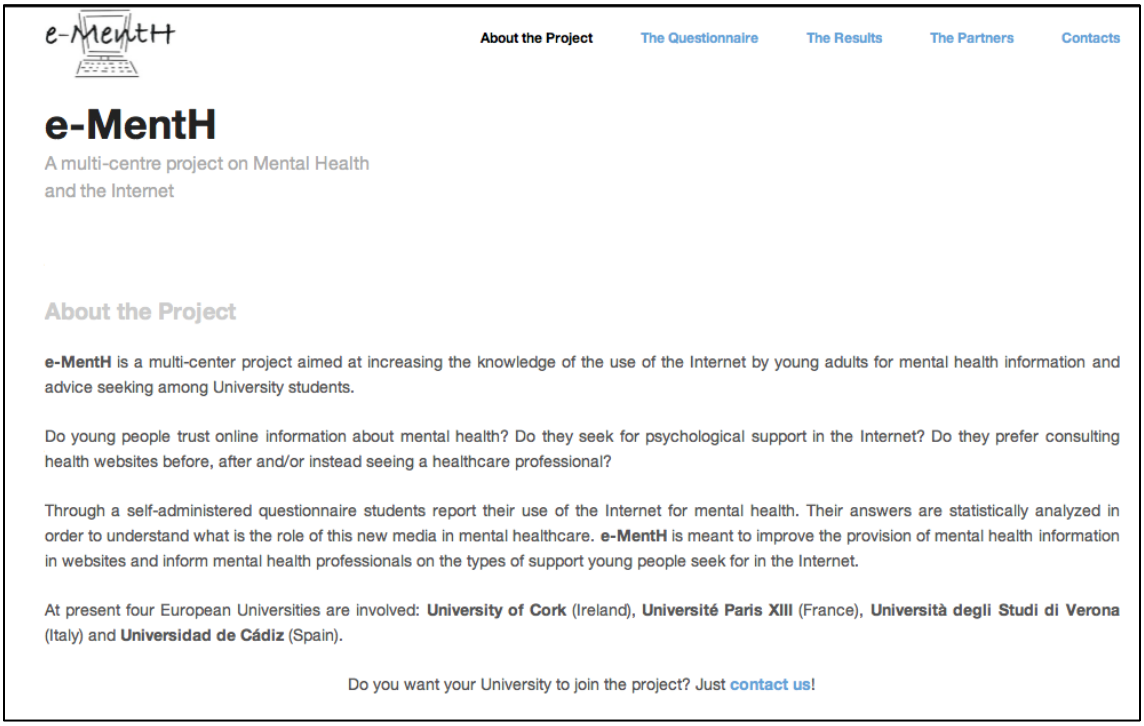
A better diffusion of information about criteria defining the quality of the contents of websites, and about useful methods for searching such needed information, can be particularly useful to young in general and young patients in particular.

Practitioners and policy makers must also take note of the role of the Internet in help-seeking behaviour. The results of this study could then be of help for financing the right and more appropriate health prevention and promotion programs. Given increasing resource constraints, policy makers need to seek ways of promoting efficient and appropriate health service use, and should aim to harness the potential benefits of the Internet, informed by an understanding of how and why young people go online for health (Powell et al., 2011).

Various strategies are likely to be useful in responding to the mental health problems of young people. The mental health care system should offer 'youth-friendly' services that take into account the social context, developmental stage, and emerging autonomy of their young patients. The University setting can be used in many countries to implement and sustain broader mental health promotion initiatives in the age group. Ideally, some of the most effective mental health interventions are likely to be enforced by new media and namely the Internet.

The e-MentH project answers the necessity to understand the way young people use the Internet for mental health information seeking, starting from a full comprehension of their perspectives. Only after having understood their behavior, a strategy of interventions of health prevention and promotion addressed to young people can be elaborated.

The www.ementhproject.org website is aimed at disseminating the results of the project and to promote the study in other Universities for future collaborations and comparisons (**Figure 33**).



e-MentH

A multi-centre project on Mental Health and the Internet

About the Project

e-MentH is a multi-center project aimed at increasing the knowledge of the use of the Internet by young adults for mental health information and advice seeking among University students.

Do young people trust online information about mental health? Do they seek for psychological support in the Internet? Do they prefer consulting health websites before, after and/or instead seeing a healthcare professional?

Through a self-administered questionnaire students report their use of the Internet for mental health. Their answers are statistically analyzed in order to understand what is the role of this new media in mental healthcare. **e-MentH** is meant to improve the provision of mental health information in websites and inform mental health professionals on the types of support young people seek for in the Internet.

At present four European Universities are involved: **University of Cork** (Ireland), **Université Paris XIII** (France), **Università degli Studi di Verona** (Italy) and **Universidad de Cádiz** (Spain).

Do you want your University to join the project? Just **contact us**!

Figure 33.

Results can help organize and develop: mental health education interventions, prevention programs, promotion and consciousness of mental health behaviors, support platforms and devices, tools for covering mental health care, information sources for general public or for more specific sectors of the population etc. Briefly, the e-MentH project results will contribute to a better orientation of any online communication strategy for students in particular and for e-patients in general.

Until now, private companies - a clear example is the French www.doctissimo.fr - seem to be more present online while national governments are requested to invest more in their web resources in the mental health domain.

CONCLUSIONS

Research today must be international, pluridisciplinary and longitudinal. The development and consolidation of local, national and international communication strategies for mental health research constitute an important approach for mutual learning and an efficaceous way to diffuse innovation in accordance with the perception that knowledge and research are socially built up. Communicating means creating spaces for dialogue and facilitating critical and creative thinking, which are the basis for any research activity, namely for mental health research.

The four studies here presented provide useful examples on how important communication processes and skills are for transmitting knowledge about mental health research among actors with different backgrounds. Notwithstanding their methodological and thematic differences, all 4 studies share the same international and comparative orientation, together with the interest in improving any form of communication about mental health research.

STUDY 1 and **STUDY 2** provide interesting insights on how researchers are trying to communicate with policymakers but also (and maybe, above all) among themselves. The need for standard classifications of the services (**STUDY 1**) and of a commonly agreed terminology (**STUDY 2**) show how international research should first of all try to reach an internal common language before disseminating its results to other communication actors. Once established and strengthened this internal communication process, researchers can share their work. At this final stage also journalists can be involved.

STUDY 3 and **STUDY 4** are mainly dealing with the relationship between the researchers and the general public. Journalists, medical staff and policymakers are laterally involved in this communication process.

What all four studies underline is the need to generate an impact on general public and all categories of experts (from doctors to stakeholders) about mental health. In order to generate any efficacious impact, it is fundamental to establish networks and relationships with research users. Involving users of research at all stages of the research, including working with user stakeholders and participatory groups can positively affect the outcomes of the research (Thornicroft et al., 2005).

Especially the communication between researchers and policymakers should be taken into serious consideration. The current situation of crisis affecting all European countries is creating a lot of challenges for the funding and organization of mental health services. Struggle for investment in services to protect mental health increases during time of economic uncertainty. Economic shocks have consequences for the mental health of the population - with an evident correlation between economic hardship and depression (Hong et al., 2011) - and this must be of great impact when deciding about policymaking in this sector (Wahlbeck et al., 2011). Mental health researchers should then collaborate with the financial industry and communication is necessary since guidance for creditors on dealing with customers with mental health needs should be properly written (Davey and Fitch, 2010). Against this background, it is important to predict the economic resources which are appropriate for communication any time we want to make an efficacious governmental action about health directly or indirectly involving citizens.

Communication improves and enhances research and its results. This is even more evident with international studies and projects where it is necessary to coordinate the different partners and actors of research through an appropriate communication approach. A harmonized methodology (including research instruments and tools) allows better comparisons and it is the clear outcome of an *ex-ante* well-planned communication strategy. As far as comparable data are concerned, **STUDY 1** and **STUDY 2** show the need to create an inventory of all international instruments and tools. Only with comparable data collected through harmonized instruments it is possible to measure the efficacy of national policies and plans; understand the influence of the context of a country (history, values…) on the behaviors of people; and to show some explicit factors which may be common to all countries. An answer to all challenges presented by European comparisons is a multi-disciplinary approach where communication is the leading discipline.

Future outcomes: Communication as promotion

Among the main evident outcomes of a deep understanding and analysis of the different ways mental health issues are communicated there is the creation of proper prevention campaigns. There is a strong need to optimize mental health campaigns, especially for young adults. All communication strategies are funded on the precise knowledge of the public opinion on that specific matter, which, in our case, is Mental Health. There should be training and learning programs for general public about Mental Health communication of information. Especially young people should learn how to identify the source of all information and thus be able to play an active role in their health conditions. In schools it is necessary to teach children and teenagers to identify the sources of all messages concerning Mental Health, to unveil the interests behind each message, advertisement and any piece of information, either scientific or administrative. This will help to create a democratic approach to mental health.

The need for information and the need for education of general public are crucially connected to communication which answers these needs through promotions and campaigns.

Promoting mental health in children and adolescents is an investment for the future. But it is also essential to improve individual capacity in the work environment, as well as among old people. Promotion campaigns about mental health should then be addressed to all age groups of the population in order to diminish the burden of mental disorders which have noticeable economic repercussions. Raising public awareness of mental health disorders can also reduce stigma and discrimination.

Future outcomes: the Internet as a support tool

STUDY 3 and **STUDY 4** showed how important it is for mental health care, including psychiatric services and practitioners, to harness the Internet as a tool to educate and support patients. Internet should then be used as an efficacious tool for actions of mental health education and training, prevention programs, mental health promotion and awakening of public opinion about mental health risks, support devices but also for the mere diffusion of information among isolated and/or alienated groups. The impact of promotion and prevention actions on the Internet should then be studied, analyzed and fully reported.

Institutional communication for mental health plays a strategical role in the relationship between any National Health System (NHS) and citizens. In the last decade, the Internet has made this role even stronger. For such a reason Internet should be used more and more for mental health campaigns. Furthermore, the democracy imposed by the Internet pushes and obliges providers of services to dispose of a website to diffuse information for users.

Moreover it could important also to assess which are the mostly researched key words in the Internet. An evaluation of the most recurring terms in search engines could be useful. On the other hand, there should be an assessment of the mental diseases of young people which are mostly discussed in the web. Some official health websites provide the lists and linkrolls of websites treating specific diseases. It could be interesting to determine the most visited websites and the most trusted ones by the young public. It could also interesting to assess if parents look for mental health information and support on the Internet for their children.

A new domain of the online support for mental health as emerged with smartphone applications. In Dartmouth, USA, the unit coordinated by Professor Robert Drake within the Center for Technology and Behavioral Health (http://www.c4tbh.org) is focused in transferring psychiatric research into practice through technology-based therapeutic tools. They create specific applications which represent a clear example of how psychological support can be given today also through new mobile devices. An evaluation of such systems will be fundamental in the future research on mental health communication.

THE WEB 2.0

Web 2.0 is an interactive, participatory and collaborative approach that encourages self-expression and the building of online communities. As a consequence, an important aspect to take into consideration in further studies is the expansion of the Web 2.0. Social media encompasses groupware, online communities, peer-to-peer and media sharing technologies, and networked gaming. Instant messaging, blogging, microblogging, forums, email, virtual worlds, texting, and social network sites are all genres of social media (Boyd, 2008). Social media are then all platforms and applications allowing any exchange through Internet. Moreover, social networks like Facebook, Youtube and Twitter are really popular among young people between 18 and 30 years (Pew Internet, 2010) and are easy to access requiring minimal cognitive aptitudes and technical abilities. General health information is usually searched through Facebook and the blogosphere (Chou et al., 2009).

The use of social networks and blogs is increasing and the involvement of the users in the construction of the contents of the Internet is an interesting point to bear in mind when analyzing the way people seek for health information and support in the web. For instance, writing about one's health problems (e.g. weight loss, anorexia, depression etc.) in online journals or blogging has expanded rapidly in recent years. Blogs can function as supportive community forums since they are a space of social interaction and to some degree, bloggers and readers seek mutual affirmation. Some patients even describe using the Internet to connect with other types of resources to bring to their battle with illnesses. This included communicating with friends and family and connecting with new sources of support. Individuals living with a mental illness are more likely than those not living with a mental illness to report engaging in various social networking activities that promote connectivity and making online friends. Young adults (18-24) living with mental illnesses are currently using social networking sites and express high interest in a social networking site specifically tailored to their population with specific tools designed to decrease social isolation and help them live more independently. These results indicate that practitioners should themselves be aware of the different social networking sites frequented by their young adult clients, ask clients about their use of social networking, and encourage safe and responsible online behaviors (Sawyer et al., 2012).

Box 10.

Future outcomes: possible new studies

Results from **STUDY 1** and **STUDY 2** have shown the need to routinely collect and compare data about mental health services all over Europe. Tools like the REMAST 2.0 (in its revised version) should be applied to other European countries to facilitate an equal distribution of financing allocations from the European Union. On a larger scale, the tool could be improved for international comparison by extending its application to extra-European countries. The glossary developed in the **STUDY 2** would then be of help for standardizing the definition and classification of extra-European mental health services.

As for **STUDY 3**, it could represent the starting point for the evaluation of other online services. In fact, it would be very interesting to evaluate the current (and increasing) offer of on-line services for mental health information and support like websites, social networks or applications for smartphones. This evaluation should be extended to all countries and consequently take into account different languages in which mental health information is presented. Only through an accurate translation of evaluation tools like questionnaires (as for **STUDY 4**), researchers can obtain comparable data of good quality.

STUDY 4 could be the object of a future European financing for investigating the behaviors of young students in other European and extra-European countries. As for the Digital Divide, it could be interesting to compare our European results to those of young people living in poor countries (for instance Africa or India). Also middle and high schools students could be included in the study and it could also be interesting to compare these results with a new wave of questionnaires made in specific mental health centers for young people like the “Centres médicaux psychologiques” or the “Mutuelle éducation sur la Santé des Jeunes (MGEN)” in France or the “Consultori” in Italy, thus extending the sample from University students to real current users of mental health services. Furthermore, it will be interesting to add in the questionnaire an item referring to the ethnicity and/or nationality of the respondents. In a future investigation it will be useful to consider if the fact of being an immigrant, an Erasmus student or coming from a multicultural family could be a variable of interest for the questionnaire.

The results of the **STUDY 3** and **STUDY 4** could be compared to those of national surveys like the Baromètre Santé 2010 for France or the generic Eurostat data. The prevalence of mental health troubles and diseases could be compared with the audience of mental health internet information together with their socio-economic status. Patients could be interviewed in hospitals, out-patient facilities, day centers etc., following specific inclusion and exclusion criteria. Their results could be compared to that of a "control group" made of a representative sample of the general population. Maps on prevalence (to compare with the SES, the diseases prevalence and the use of the Internet) could also be created (Khazaal et al., 2008).

Finally, the Web 2.0 (see **Box 5**) which was partially analyzed in **STUDY 4** with Items 13 and 21, should also be deeply investigated in future studies as this domain provides interesting prospective for the future of mental health care online.

Take-home message

This thesis underlines the need for implementing the communication between the actors of research in the domain of mental health, including very different figures ranging from patients to stakeholders. Through four studies which produced both qualitative and quantitative results, an overview of the different processes concerning communication of mental health research results has been provided. STUDY 1 and STUDY 2 showed the challenges and difficulties of communication between researchers and policymakers. The creation of a coding and mapping system and of a specific glossary for mental health services is necessary for informing financing parties and politicians of the current status of mental health care. STUDY 3 and STUDY 4 provided interesting insights on the use of the Internet as a tool for patients to acquire knowledge about mental health issues and for doctors to integrate their treatment and therapy strategies. All four studies showed that research means, today more than ever, sharing.

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Health on the Net Foundation: http://www.hon.ch/

Internet World Statistics - Internet Usage Statistics: www.internetworldstats.com

ISTAT: http://www.istat.it

Médiamétrie: http://www.mediametrie.fr/internet/

Ministero della Salute: http://www.salute.gov.it/portale/home.html

OECD Policy Brief: http://www.oecd.org/els/healthpoliciesanddata/41686440.pdf

The Rosalynn Carter Fellowships for Mental Health Journalism: http://www.cartercenter.org/health/mental_health/fellowships/index.html

World Health Organization – Regional Office for Europe: www.euro.who.int

THE COURSES INVOLVED IN THE e-MentH project

LAW

Cork: http://www.ucc.ie/en/ck301/

Verona: http://www.giurisprudenza.univr.it/fol/main?ent=cs&id=390

Cádiz: http://asignaturas.uca.es/wuca_fichasig1213_asignaturas_xtitulacion?titul=30305

Paris XII: http://www.univ-paris13.fr/dsps/les-formations-de-lufr/licences/licence-droit

COMPUTER SCIENCE

Cork: http://www.ucc.ie/en/ck401/

Verona: http://www.scienze.univr.it/fol/main?ent=cs&id=420

Cádiz: http://asignaturas.uca.es/wuca_fichasig1213_asignaturas_xtitulacion?titul=21714

Paris XIII: http://www-galilee.univ-paris13.fr/etu_licences_info.htm

NURSING

Cork: http://www.ucc.ie/en/nursingmidwifery/courses/undergrad/

Verona: http://www.medicina.univr.it/fol/main?ent=cs&id=471

Cádiz: http://asignaturas.uca.es/wuca_fichasig1213_asignaturas_xtitulacion?titul=20103

Paris XIII: http://www-smbh.univ-paris13.fr/formations/ifsi.html

APPENDIX

1. THE REMAST TOOL

2. REFINEMENT GLOSSARY

3. FIL SANTE JEUNES QUESTIONNAIRE

4. E-MENTH QUESTIONNAIRES

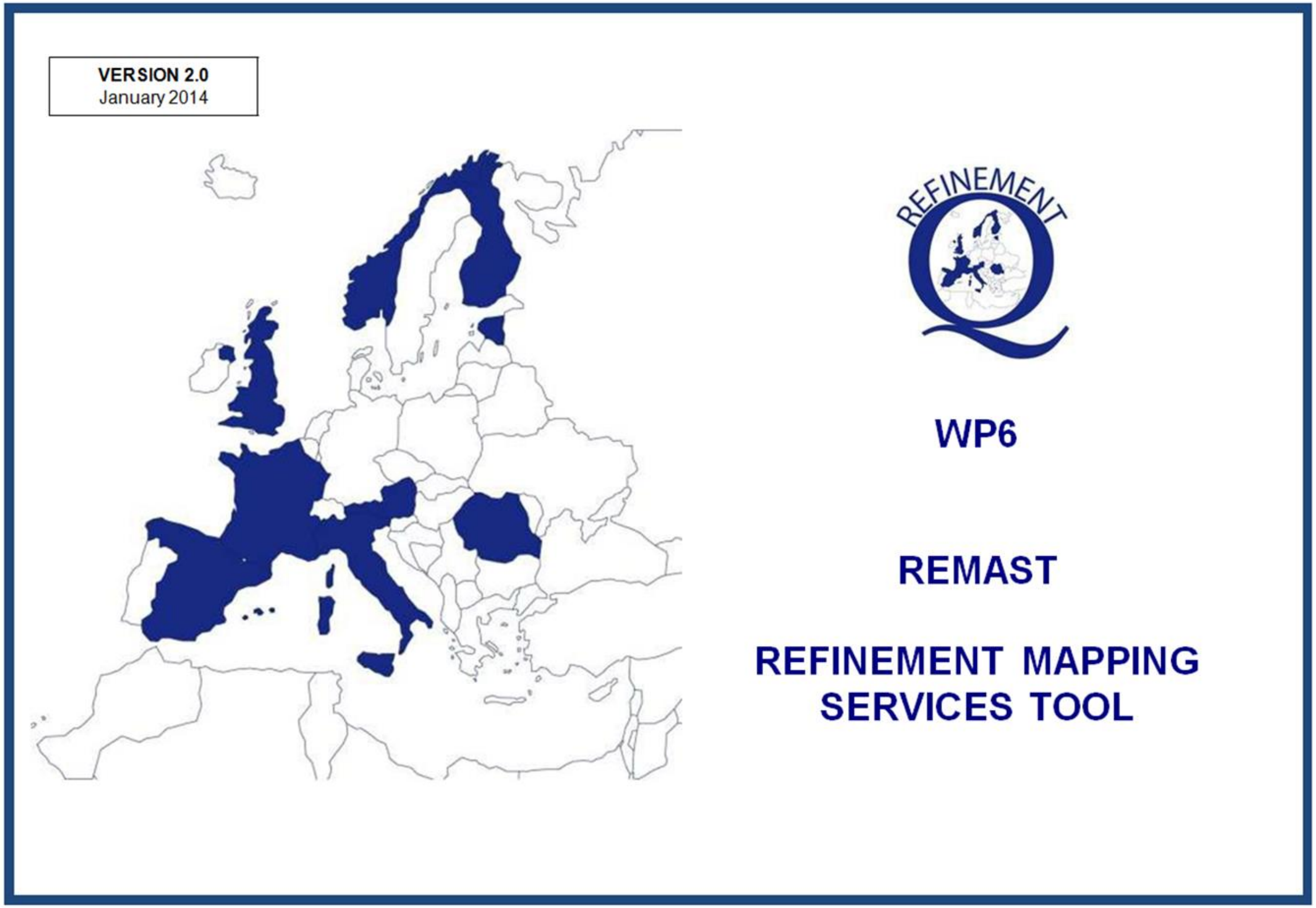
a) ENGLISH QUESTIONNAIRE

b) FRENCH QUESTIONNAIRE

c) ITALIAN QUESTIONNAIRE

d) SPANISH QUESTIONNAIRE

1. THE REMAST TOOL VERSION 2.0



VERSION 2.0
January 2014

WP6

REMAST

REFINEMENT MAPPING
SERVICES TOOL

INDEX

INTRODUCTION

The REFINEMENT MApping Services Tool (REMAST) is designed to allow a detailed description of:

1) the structure of **health care** (primary, general and specialist care) and **social care services** addressed to people with mental health disorders in a specific Study Area[1].
2) the characteristics of the Study Area in terms of socio-economic environment.

This detailed description can be used to illustrate the spatial distribution of health and social services in selected Study Areas according to specific inclusion and exclusion criteria. In fact the tool is intended for services of the working age population and it excludes those services targeting exclusively minors and/or elderly people.

The tool was built using the experience of previous developed and validated international instruments: the European Services Mapping Schedule (ESMS), the Description and Evaluation of Services and Directories in Europe (DESDE-LTC) and the WHO Assessment Instrument for Mental Health Systems (WHO-AIMS). A first attempt to provide a description of the mental health services had also been made previously in the European EPSILON study in respect solely of specialist services for people with schizophrenia. The existence of these studies and of their attached tools shows the great interest research has in trying to standardise the description of services (de Jong, 2000) to aid in such comparisons (Johnson et al., 2000). More in detail, the European Psychiatric Care Assessment Team (EPCAT) developed the ESMS to describe mental health services for the population of a Study Area provided by public sector health and social service agencies, voluntary sector and private sector providers (Johnson et al., 2000). The instrument classified provision in a “service mapping tree” on the basis of operationalised definitions of mental health services. It also documented the associated levels of service provision and was used to compare

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[1] The definition of “Study Area” is given in the User Manual, page 8.

services in Study Areas across countries e.g. comparing services in cities in Germany, Italy and Spain (Becker et al., 2002). A further development of this approach had been the creation of a new instrument, the DESDE-LTC, which is the adaptation of this instrument to long term care populations (Salvador-Carulla et al., 2009; Salvador-Carulla et al., 2013).

What has been missing from these service mapping instruments to date is a common comparison of primary care, general health and social care services that may be used to support people with mental health needs. The majority of people with common mental health problems, such as depression for instance, in a number of countries will be treated almost exclusively by general practitioners whilst social care services can have play a critical role in providing a route back to employment and/or in providing support to allow independent living.

The REMAST takes also into much consideration health geography by devoting considerable attention to the spatial distribution of health facilities as an important factor that influences overall population health (Guagliardo, 2004). The issue of spatial organisation and distribution of health care facilities is one element of the spatial equity of public services. As synthesised by Macinko and Starfield (2002), equity is defined as the absence of differences across socially, economically, demographically or geographically defined population groups. The notion of equity and the issue of who can profit from service delivery embraces a wide variety of research topics and requires different approaches and analytic tools.

The REMAST tool tries to analyse the spatial dimension of mental health care delivered by health and social services. The notion of spatial equity implies the use of accessibility as a tool for assessing whether or not equity has been achieved (Talen & Anselin, 1998). Accessibility measures can be viewed as a social indicator when they assess and show the availability of social opportunities for individuals (Geurs & Van Wee, 2004). The REMAST can then be used in combination with Geographical Information System (GIS) for a broad range of mental health services; to date such a type of studies have only been conducted on single services at a local level (Curtis, 2007). Finally, the changing balance between long stay institutional and community based care has led to an increasing reliance on a diverse range of community-based services funded and/or delivered by the public, voluntary or private sectors (Becker and Vázquez-Barquero 2001, Thornicroft and Tansella

1999). An increasing focus on comparative international analysis of mental health policy and practice is aided by a good-quality common description of mental health service provision. This is important to ensure that researchers, service planners and policy makers in different regions, countries and at the European level, compare ‘like with like’ and to allow adequate use of the data from different service systems. This aspect is also covered by the REMAST tool.

In future, European policy-makers and providers of care should be able to use the data collected with REMAST and any subsequent analyses to understand the complexity of the mental health care system and of the structure of interfaces and interconnections between component services, including those provided by primary and social care services.

THE THREE LEVELS OF THE REMAST TOOL

The REMAST Tool is organised in three levels:

1. Description of the general context where the Study Area is included.

2. Description of the ecological setting of the studied population, i.e. the social and physical environmental features of the population. Socio-economic characteristics in the ecological setting are important health determinants and also determinants of demand for health services.

3. Description of service distribution and utilization. The use of services across the continuum of care, by the specific population of interest, provides an important view of the resources allocated. This information can be framed with health determinants, risks and health status as well as place.

USER MANUAL

Guide to the use of REMAST tool.

This Tool is a folder that contains several instruments: a manual that guide the researchers in the use of the different parts of the tool, a glossary that explains and clarify the terms used in each instrument, and a reference list.

The REMAST tool allows to:

1. describe all services (general health, mental health and social services) available for people with mental illness;
2. explain the complexity of the models adopted in each Study Area to deal with mental disorders;
3. compare the models used in each Study Area;
4. develop an Atlas of Mental Health Care that will give decision-makers within countries/regions more detailed accounts of services.

For the services description, the first step is to choose a defined, geographically limited and detectable “Study Area”. Given the complexity of the data collection exercise, it is recommended to choose a Study Area with a population between 200,000 and 1,500,000 inhabitants. Preferably the Study Area should cover a health district or a municipality (or have other administrative boundaries) served by a defined range of health services.

The second step is to choose a "Macro Area". The Macro Area must include the Study Area and it is recommended to choose a Macro Area with a population between 1,500.000 and 10,000,000 inhabitants, to be identified as a NUTS1 or NUTS2 (see the Nomenclature of Territorial Units for Statistics).

The data that will be required for the Macro Area are only general data (in most cases, mean values for the whole Macro Area). For the Study Area a detailed data collection is necessary. These data must be collected using the specific web application available at this address:

http://www.psychiatry.univr.it/REFINEMENT/REFINEMENT_sif

Users can be identified and registered by using their email as username and a password.

The reason to collect data in parallel for the Study Area and for the Macro Area (***see Figure 1***) is to statistically obtain information on how far the characteristics of the Study Area are from a Macro Area of reference. This will make understand whether the Study Area is representative of the macro level where it is included or not. If it is not, it will be feasible to know how different it is from the Macro Area and in which direction.

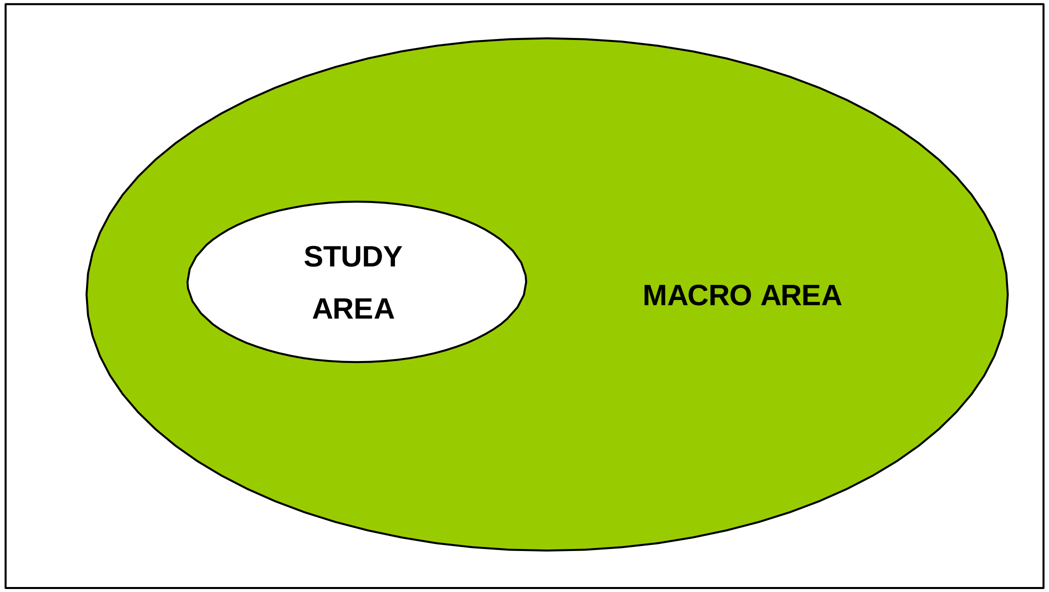

Figure 1. Macro Area and Study Area for REMAST

PRACTICAL REMARKS

Study Areas are to be analyzed according to the level of details available in each country (municipalities, health or administrative districts, census blocks, electoral blocks, postal codes, etc.).

For both the Services Inventory and the Mental Health Systems Checklist sections, only the services which are located in the Study Area should be included, except services which are specifically dedicated to serve the population of the Study Area (perhaps among populations of other areas), but are located outside this area. In these exceptional cases only the part(s) of the service which is/are dedicated to serving the Study Area should be included.

According to the Macro and Study Areas division, the different sections of this tool are ordered from general to particular analyses.

THE SECTIONS OF THE REMAST TOOL

1) **POPULATION DATA**
2) **VERONA SES INDEX**
3) **MENTAL HEALTH SYSTEMS CHECKLIST**
4) **GEOGRAPHICAL DATA**

POPULATION DATA

	Macro-Area	Study-Area
Name		
NUTS Code*		
Reference Year		

	Macro-Area			Study-Area		
	Males	**Females**	**All**	**Males**	**Females**	**All**
Total Population						
0 – 17 years						
18 – 64 years						
65 and more						

** Indicate the NUTS Code for the Study-Area only when applicable.*

VERONA SES INDEX

*** Please attach to this tool one or more files with the detailed datasets.**

Name of the file

	Macro-Area		Study Area*	
	Result (%)	*Year*	*Result (%)*	*Year*
Single-parent families *Number of single-parent families with children / number of families*				
Workers employed in each working sector *Number of economically active individuals employed in each working sector[2] / economically active individuals (employed and unemployed)*				
Rented accommodation *Number of occupied rented accommodation / occupied accommodation[3]*				

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[2] As defined by your National Institute of Statistics. Ideally, we would like to have the number of employed people for each NACE sector

[3] Excluding accommodation occupied by only non-residents and kinds of accommodation different from buildings

Individuals with Elementary School level *Number of individuals with elementary school as maximum level of education / residents over 5 years old*			
Individuals with Tertiary qualification *Number of individuals with any tertiary qualification as their level of education / residents over 5 years old*			
Individuals married *Number of individuals by marital status: married / residents*			
Individuals separated or divorced or widowed *Number of individuals by marital status: (separated + divorced + widowed) / residents*			
Unemployment rate *Number of total economically active individuals unemployed or looking for occupation or first occupation / economically total active individuals (employed and unemployed)*			

OTHER VARIABLES NOT INCLUDED IN THE VERONA SES INDEX

	Macro-Area		Study Area	
	Result (%)	*Year*	*Result (%)*	*Year*
Population density *Number of individuals / squared kilometers*				
Average number of people per household *Number of individuals / number of households*				
Ageing index *(Number of individuals over 64 / number of individuals below 15)*				
Dependency ratio *(Number of individuals either below 15 or over 64 /number of individuals between 15 and 64)*				
Households made up by 1 person *Number of households made up by 1 person / number of households*				
Households made up by 5 or more people *Number of households made up by 5 or more people / number of households*				
Individuals below 5 years old *Number of individuals below 5 / residents*				
Immigrants *Number of foreigners / residents*				

MENTAL HEALTH SYSTEMS CHECKLIST

Items of this section are derived from WHO-AIMS (WHO, 2005)

Please compile this section with the most updated data you have at your disposal.

Available data refer to the year:

Please answer the following questions by checking:

- **Yes (Y)**,
- **No (N)**,
- **Unknown (UN),**
- or **Not Applicable (NA)**.

Each category of items is provided with a box (called “**Observations**”) where you can add your own comments. If you answer some questions by checking **Not Applicable (NA)**, please use this box for explanations and clarifications. When requested, insert the number, percentage or fraction in the data slots. It is recommended to insert both raw data and ratios in the slots. Please fill in the boxes colored in green with the sum calculated from the Service Inventory data (see Services Inventory section of this tool).

POLICY AND LEGISLATIVE FRAMEWORK

Mental Health Policy

Definition: Mental health policy refers to an organized set of values, principles, and objectives to improve mental health and reduce the burden of mental disorders in a population.

- **At which level is the mental health policy document established in your country? (E.g. national, local…)**

- **Which is the year of the last version of the mental health policy document in the areas you have selected for this study?**

- **Are the following components included in your mental health policy?**

1. Organization of services: developing community mental health services	Y	N	UN	NA
2. Organization of services: downsizing large mental hospitals	Y	N	UN	NA
3. Organization of services: developing a mental health component in primary health care	Y	N	UN	NA
4. Human resources	Y	N	UN	NA
5. Involvement of users and families	Y	N	UN	NA
6. Advocacy and promotion	Y	N	UN	NA
7. Human rights protection of users	Y	N	UN	NA
8. Equity of access to mental health services across different groups	Y	N	UN	NA
9. Financing	Y	N	UN	NA
10. Quality improvement	Y	N	UN	NA
11. Monitoring system	Y	N	UN	NA

Mental Health Plan

Definition: A mental health plan is a detailed scheme for action on mental health which usually includes setting priorities for strategies and establishing timelines and resource requirements. A mental health plan usually includes action for promoting mental health, preventing mental disorders and treating people with mental illnesses.

- **At which level is the mental health plan established in your country? (E.g. national, local…)**
- **Which is the year of the last version of the mental health plan the areas you have selected for this study?**
- **Are the following components included in your mental health plan?**

1. Organization of services: developing community mental health services	Y	N	UN	NA
2. Organization of services: downsizing large mental hospitals	Y	N	UN	NA
3. Organization of services: reforming mental hospitals to provide more comprehensive care	Y	N	UN	NA
4. Organization of services: developing a mental health component in primary health care	Y	N	UN	NA
5. Human resources	Y	N	UN	NA
6. Involvement of users and families	Y	N	UN	NA
7. Advocacy and promotion	Y	N	UN	NA
8. Human rights protection of users	Y	N	UN	NA
9. Equity of access to mental health services across different groups	Y	N	UN	NA
10. Financing	Y	N	UN	NA
11. Quality improvement	Y	N	UN	NA
12. Monitoring system	Y	N	UN	NA

- **What are the strategies in the last mental health plan?**

1. Budget is mentioned in the last mental health plan	Y	N	UN	NA
2. A timeframe is mentioned in the last mental health plan	Y	N	UN	NA
3. Specific goals are mentioned in the last mental health plan	Y	N	UN	NA
4. Have any of the goals identified in the last mental health plan been reached within the last calendar year?	Y	N	UN	NA

Mental Health Policies and Plans

Definition: Write in the following box a list of two, three policies or plans (the most updated ones) which have had important repercussions on the Study Area services.

Monitoring and Training on Human Rights

Definition: Monitoring and training on human rights protection in mental health services.

- **What are the functions of review bodies assessing the human rights protection of users in mental health services?**

	Macro-Area				Study Area			
1. Oversee regular inspections in mental health facilities	Y	N	UN	NA	Y	N	UN	NA
2. Review involuntary admission and discharge procedures	Y	N	UN	NA	Y	N	UN	NA
3. Review complaints investigation processes	Y	N	UN	NA	Y	N	UN	NA
4. The review body has the authority to impose sanctions (e.g. withdraw accreditation, impose penalties, or close facilities that persistently violate human rights)	Y	N	UN	NA	Y	N	UN	NA

MENTAL HEALTH SERVICES

Organizational Integration of Mental Health Services

Definition: Organizational integration of mental health services across facilities.

- **Do functions of a "mental health authority" exist in your macro/Study Area? What are their roles?**

	Macro Area			Study Area		
1. A national or regional mental health authority exists.	Y	N	NA	Y	N	NA
2. The mental health authority provides advice to the government on mental health policies and legislation	Y	N	NA	Y	N	NA
3. The mental health authority is involved in service planning	Y	N	NA	Y	N	NA
4. The mental health authority is involved in service management	Y	N	NA	Y	N	NA
5. The mental health authority is involved in monitoring and quality assessment of mental health services	Y	N	NA	Y	N	NA

- **Do catchment areas/ service areas exist as a way to organize mental health services to communities?**

Macro-Area	Y	N	NA
Study Are	Y	N	NA

SERVICES INVENTORY

INTRODUCTION

Data and/or version of the document

The REMAST Services Inventory section is aimed at mapping and providing specific information on all Mental Health Care services of the Study Area which meet the inclusion and exclusion criteria described in the following box.

SERVICES INCLUSION and EXCLUSION CRITERIA

Please note that these criteria concern exclusively the Services Inventory. The other parts of the REMAST are not affected by these criteria. Analogously, the definition of the population included in this inventory is not intended to refer to all workpackages/tasks of the whole REFINEMENT project.

The inventory includes all those **services providing Health and Social Care to people with a psychiatric disorder** who are **at least 18 years old** (no upper age limit is applied).

The inventory **excludes**:

a) all services especially dedicated to the treatment of individuals with **F0- and/or F1- and/or F7-diagnoses** (as per ICD-10), e.g. specific rehabilitation centers for alcohol and drug withdrawal, memory clinics, institutions for individuals with intellectual disabilities etc.

b) all services especially dedicated to the treatment of the **elderly** (e.g. nursing homes, mobile home nursing services, etc.), unless they provide services especially for people with mental disorders (again, except services as per a)

c) **forensic services**

d) services exclusively for **child and adolescent disorders**.

By the way, all services which treat individuals with F0- and/or F1- and/or F7-diagnosis or elderly people or forensic patients **amongst others** (F2-F6) will be included. Then all relevant non-specialist and general services in the health and social care system (including e.g. homeless shelters, non-psychiatric hospital wards, psychologists in private practice etc.) should be included in the mapping.

Finally, the inventory includes all those services which are located in the Study Area. When possible, as to get a complete overview of the services available for the residents, please include also those services which are located outside the Study Area but which serve the patients of the Study Area. For GPs and Social Care, include only those services which are located in the Study Area.

The Services Inventory is composed of two parts:

1) the present REMAST tool section which describes and explains the items of the Services Inventory File (SIF).
2) the Services Inventory File itself.

The compilation of the file will provide information on the general context of each service, its ecological setting, distribution and utilization.

Five types of information are required for each service: Service basic information, Location and Geographical information about the service, Useful information and contacts, Service Data, and Evaluator information. Each of these five categories includes specific questions to answer with numbers, acronyms or short sentences.

When data are not available, please leave the box blank and write in the Observations box why you cannot provide any answer to those specific questions.

Hereunder you can find all the explanations of the data slots you have to compile in the SIF according to the five categories mentioned above.
Refer to the REFINEMENT Glossary for the definitions you have to choose for describing each service.

DESCRIPTION

1. Service basic information

a. IDNUM

Associate each service (Basic Stable input of Care-BSIC or Main Type of Care-MTC, according to DESDE-LTC terminology, www.edesdeproject.eu) to an Identification Number (IDNUM) where the first two letters refer to the country and the figures are progressive numbers (ex: *IT0001*). Use the ISO country codes with 2 letters to identify your country (*e.g. AT Austria, EN England, ES Spain, EE Estonia, FI Finland, FR France, IT Italy, NO Norway, RO Romania etc.)*

b. ADDID

The **IDNUM** and the **ADDID** are two compulsory variables needed to identify each service (BSIC or MTC, according to DESDE-LTC terminology, www.edesdeproject.eu).

Insert consecutive numbers (**ADDID**) starting from 1 for describing more than one MTC belonging to the same BSIC. If a BSIC has no MTC, please put the value 1 (see details in the ***figures 2a and 2b***).

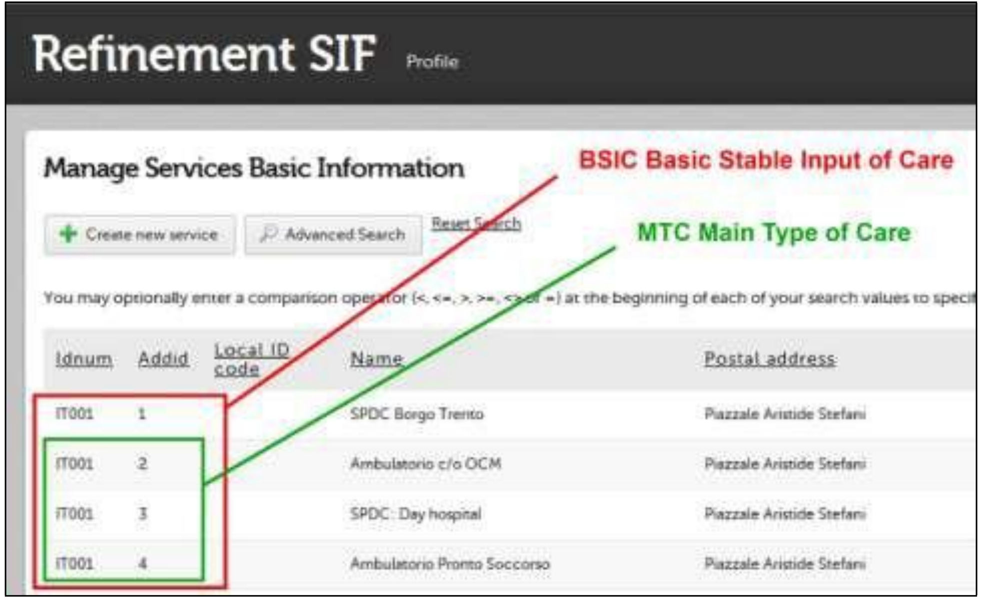
c. Local ID

Indicate the existing Identification numbers of the local country BSIC when available.

d. Name of the Service

Write the exact name of the service in your language.

Figure 2a. Example of BSIC with MTC

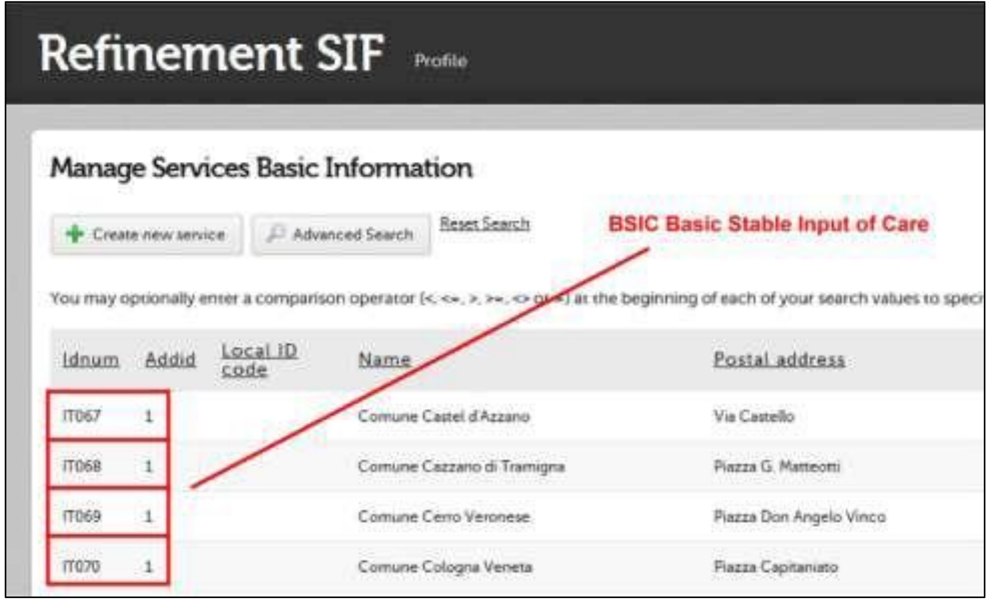


Manage Services Basic Information

You may optionally enter a comparison operator (<, <=, >, >=, <> or =) at the beginning of each of your search values to specif

Idnum	Addid	Local ID code	Name	Postal address
IT001	1		SPDC Borgo Trento	Piazzale Aristide Stefani
IT001	2		Ambulatorio c/o OCM	Piazzale Aristide Stefani
IT001	3		SPDC: Day hospital	Piazzale Aristide Stefani
IT001	4		Ambulatorio Pronto Soccorso	Piazzale Aristide Stefani

Figure 2b. Example of BSIC with one MTC



Manage Services Basic Information

You may optionally enter a comparison operator (<, <=, >, >=, <> or =) at the beginning of each of your search values to speci

Idnum	Addid	Local ID code	Name	Postal address
IT067	1		Comune Castel d'Azzano	Via Castello
IT068	1		Comune Cazzano di Tramigna	Piazza G. Matteotti
IT069	1		Comune Cerro Veronese	Piazza Don Angelo Vinco
IT070	1		Comune Cologna Veneta	Piazza Capitaniato

2. Location and Geographical information about the service

a. Postal Address, House Number, Post Code, Municipality, Province, Region

Provide the full postal address of the service.

b. Catchment Area

Indicate the served geographical area and list the different served neighborhoods and/or little towns. Specify the level of availability of the service:

- Whole country
- Macro-Area
- Study Area
- Sub-Area

c. Real Potential Users

Provide the number of people the service addresses to. For example, for adult services the number would be the total population in the Study Area excluding those who are under 18 years old.

3. Useful info and contacts

a. Telephone, Fax, E-mail, Website

Provide all useful contact information when available.

b. Official Starting Year of the Service

Insert the year when the service officially started.

c. Local Definition of the Service

Write in both English and in your own language the name of the service.

Ex.: Centro Diurno/Community Mental Health Center

d. Sector

Specify the sector to which the service belongs to among the followings:

- General Health
- Mental Health
- Justice
- Education
- Work
- Social
- Other

Figure 3. Example of the first section of the SIF

4. Service Data

a. Number of Opening Days per Week

Provide the number of opening days (from a minimum of 1 to a maximum of 7) of the service per week. When a service is open 24 hours a day all week long insert 7 for the days.

b. Number of Opening Hours per Week

Provide the number of opening hours per week. Minutes must be indicated by the apostrophe (‘). When a service is open 24 hours a day all week long insert 168 for the hours. Add in the Observation Box (see point 6. c.) if it is possible to calculate the hours after special appointment.

c. Staff

Provide the full-time equivalents (FTE)* of the staff members working in the service:

- Psychiatrist: a medical doctor who has had at least two years of post-graduate training in psychiatry at a recognized teaching institution. This period may include training in any sub-specialty of psychiatry.
- Psychiatrist in training: a medical doctor who is currently attending at least two years of post-graduate training in psychiatry at a recognized teaching institution. This period may include training in any sub-specialty of psychiatry.
- General Practitioner (GP): a physician whose practice consists of providing ongoing care covering a variety of medical problems in patients of all ages, often including referral to appropriate specialists (synonyms: Family Doctor, Primary Health Care Doctor, Primary Care Practitioner or Primary Care Physician).
- Other medical doctor: a health professional with a degree in modern medicine who is authorized/licensed to practice medicine under the rules of the country.
- Nurse: a health professional having completed a formal training in nursing at a recognized, university-level school for a diploma or degree in nursing.
- Psychologist: a professional having completed a formal training in psychology at a recognized, university-level school for a diploma or degree in psychology.
- Social worker: a professional having completed a formal training in social work at a recognized, university-level school for a diploma or degree in social work.

- Occupational therapist: a health professional having completed a formal training in occupational therapy at a recognized, university-level school for a diploma or degree in occupational therapy.
- Other health or mental health workers: health or mental health worker that possesses some training in health care or mental health care but does not fit into any of the defined professional categories (e.g. medical doctors, nurses, psychologists, social workers, occupational therapists). *Includes*: Non-doctor/non-nurse primary care workers, professional and paraprofessional psychosocial counsellors, special mental health educators, and auxiliary staff. *Excludes*: This group does not include general staff for support services within health or mental health care settings (e.g. cooking, cleaning, security).

Put the value 0 when a specific staff role is not present in the service. When mapping a stand-alone service (for instance a single-handed GP or psychiatrist), please put the value 1 in the corresponding cell and 0 in all other cells . All cells should be completed for the reliability of the compilation.

*****Full-time equivalent (FTE), is a unit to measure employed persons in a way that makes them comparable although they may work a different number of hours per week. FTE is often used to measure a worker's involvement in a project, or to track cost reductions in an organization. An FTE of 1.0 means that the person is equivalent to a full-time worker, while an FTE of 0.5 signals that the worker is only half-time.

d. Management, Legal system, and Economic information

- Management Agency
  Provide the name of the agency responsible for the employment of staff and the management of the service.

- Owner of the service
  Specify if the legal owner of the service is:

  1. *Private for profit*
  2. *Private not for profit*
  3. *Public*
  4. *Semi-public (e.g. "company" owned by government)*
  5. *Other (please specify)*

- Legal System
  Specify the legal status of the service by selecting one of the following definitions:

  1. *Registered Charity*
  2. *Foundation*
  3. *Cooperative*
  4. *Social Firm*
  5. *Public Corporation*
  6. *Private Company*
  7. *Other (please specify)*

- Type of Care:
  All services can be divided into three categories which describe whether the service is financed through:
  1. *Health*
  2. *Social*
  3. *Mix of Health/Social funds*
  4. *Other (please specify)*

  Distinguish services by adding the acronym Health (H) or Social (S) or Health/Social (HS) in the specific box. Use the Observation Box (see point 6. c.) to add any useful comments on the type of care.

- Payment mechanisms for service providers: how is the service paid?
  For each service mapped please check how the service is paid. Several of these mechanisms can apply to a specific institution. Please code as many of the following categories as apply. For instance, for single handed GPs it is often “capitation” and “fee-for-service”, for hospitals “FLAT RATE” and “FEE-FOR-SERVICE”, for primary care centers “capitation” for the service and “salary” for the employed doctors there. The following items are derived from FINCENTO (i.e. REFINEMENT WP4/WP5 tool).

  1. *GLOBAL BUDGET: The service provider receives a fixed lump sum for the whole service for a certain time period (usually one year). This may be based on past (“historical”) budgets or it may be determined based on an assessment of community need. It might also include an element of case-mix adjustment to take account of differences in population and past activity in terms of severity of cases treated. There are usually limited or no restrictions on how this budget may be then allocated to different activities delivered by the service provider, unless this is specified in a contract.*

  2. *LINE ITEM BUDGET: the service provider gets a fixed lump sum for the whole service for a certain time period, usually one year, without flexibility for the service to transfer money between cost groups.*

  3. *CAPITATION: A method that can be used to determine the level of resources received by service purchasers as well as to pay service providers. For instance in the case of service providers payment is made per head of a defined population. The provider is paid a specified sum of money for the care of this population for a specified period of time. Payment is independent of services used. Ideally payments to purchasers and service providers are risk adjusted (weighted to take account of factors such as age and geographical location). Capitation systems are often linked to geographical location, for instance in the case of some primary care systems which require registration with a particular practice (Unit of Payment: Persons Registered).*

4. *CAPITATION – RISK ADJUSTED: Risk adjusted capitation is a capitation payment method through which payment rates are adjusted for risk by taking into account factors like age, sex, health status and prior health care utilisation as well as socio-demographic factors such as residence, income etc.*

5. *FEE FOR SERVICE: In fee for service systems payment is made for units of service or specific procedure performed. In the case for health care services for instance, for a physician consultation or MRI scan. Fee for service systems are usually based on fee schedules which classify service provider activities with varying degrees of precision (Unit of payment: Specific fee per unit of service received/procedure performed or per contact).*

6. *FLAT RATE: A fixed monetary fee received per case treated regardless of diagnostic group or severity of need. Flat rate fees can be used in different ways , per a fixed time period, per service user contact, per stay in an inpatient facility.*

7. *ACTIVITY BASED FUNDING (ABF) SYSTEM: ABF is a financing mechanism that allocates funds to service providers (e.g. hospitals) according to the type and volume of activity they provide. Through ABF service providers are paid/reimbursed on the basis of the activity they undertake, i.e. payment varies according to the activity level. Usually ABF will make use of case-mix systems to adjust the level of funding provided relative to clinical need. In other words ABF systems usually fund homogenous patients in the same way, with different levels of payment for different patient groups. One example of an ABF system is the Diagnose Related Group (DRG) approach to funding.*

8. *DAILY RATE: the service provider gets a fixed sum -regardless of the diagnosis - for each day on which a patient is in an institution -hospital, social care home. This fixed sum may depend on patient characteristics, not necessarily diagnosis, and may be graded according to length of stay, e.g. reduced daily rate after a certain length of stay. Unit of payment: Days.*

9. *SALARY: Employees are paid a set wage for working for a set period of time. Remuneration is independent of volume of work done. Employees work within defined hours specified in contracts. Salaries may be negotiated at local level, but often are negotiated at a national level by budget holders. Overtime payments may also be made. In some cases contracts allow extra income to be earned through second jobs and private work after hours work.*

10. *PERFORMANCE RELATED PAYMENT: This term covers a number of different payment mechanisms that reward service providers for the achievement of specific goals . These tend to be related more to the level of throughput rather than to achievement of specific clinical (or broader) quality related outcomes. It is rarely the dominant payment mechanism but a supplementary payment mechanism. Performance related payment mechanisms can include target payments; i.e. models where income is (partly) related to the provider reaching certain predefined targets and relative target payment; i.e. models where providers compete for a limited reward based on their internal rank. Some performance related payment schemes will also impose penalties for “underachievement”; i.e. models where payment is withheld or even deducted when providers do*

not meet specific performance targets.

11. *OUT OF POCKET PAYMENT: A charge that individuals must pay personally for the use of a service sometimes at the point of service and sometimes at a later point in time. In some cases a proportion or all of the out of pocket payment can be reimbursed. Out of pocket payments can take different forms, they can be a fixed fee or proportional to the total costs of the service received. There may also be ceiling on the maximum level of out of pocket payments in a defined time period. In the case of long stay residential care, especially care provided outside of the health sector, there may be substantial regular out of pocket payments for care, often charged by the week or month.*

12. *INCOME FROM SALES: This source of funding describes the revenues raised from sales of good and services, for example in sheltered workshops and enterprises.*

13. *OTHER: If selecting Other, please specify the payment mechanism in the Comments Box. (E.g. known practice of unofficial co-payments; or for patients with mental disorders who are compulsorily admitted and/or treated - forensic patients – the ministry of justice may pay).*

Classification Coding section

The classification codes are derived from ESMS-R and from DESDE-LTC 2.0. DESDE-LTC 2.0 is an updated version of DESDE-LTC (Description and Evaluation of Services for Long Term Care in Europe) (Salvador-Carulla et al., 2011) adaptation of the 'European Service Mapping Schedule' (ESMS-I) (Johnson et al, 2000) (it also incorporates modifications included in ESMS-II), and the 'Description and Evaluation of Services for Disabilities in Europe' (DESDE) (Salvador-Carulla et al, 2006) and related instruments (DESDAE and DESDE). These instruments have been developed by the EPCAT Group (European Psychiatric Care Assessment Team) coordinated by Centro Studi e Ricerche in Psichiatria (Torino, Italy), the PSICOST Association in Spain and the DESDE-LTC Group.

For details about DESDE-LTC see the website: http://www.edesdeproject.eu/

Provide the Classification code following the instructions of the guide provided at the following link:
(http://www.refinementproject.eu).

a. **Diagnostic group:**

- MD (Mental Disorders)
- MG (Generic Medical Users)

b. **Mapcode (letter+number) according to the Classification branches (see Figure 5):**

R	Residential Care
O	Outpatient Care
D	Day Care
I	Information for Care
A	Accessibility to Care
S	Self-Help and voluntary care

For a comprehensive details of all the DESDE-LTC codes available, please see the following pages of the guide: p.18 Information, p.20 Accessibility, p.22 Self-Help, p.26 Outpatient, p.31 Daycare, p.36 Residential.

c. Code Number

(the second number of the service DESDE-LTC code when present): from 1 to 4.

d. Additional Codes (letters) in the specific cases:

- a (acute care – complementary)
- c (closed care)
- d (domiciliary care)
- e (eCare)
- h (care provided in a hospital setting)
- i (institutional care)
- j (justice care)
- l (liaison care)
- m (case management)
- n (new)
- o (physician ‘on call’)
- p (care provided in a primary care centre)
- r (reference main type of care in an area)
- s (specialized care)
- u (unique)

All instructions for the identification of the codes are explained in the guide.

e. **Subtypes of services:**

The following items are derived from FINCENTO (i.e. REFINEMENT WP4/WP5 tool).

- Subtypes of physician-led primary care services:
    1. *Self-employed PHC physician, single handed*
    2. *Private company or partnership owned by the practising physicians (group practice*
    3. *Physician-led public primary care organisations where physicians are employees*
    4. *Other, please describe*

- Subtypes of specialist mental health outpatient care:

1. Psychiatric ambulatory care services:

1. *Self empolyed psychiatrist, single handed*
2. *Self empolyed psychologist/ psychotherapist, single handed*
3. *Self empolyed psychiatrists/ psychologists/ psychotherapist, in group practice or similar*
4. *Standalone outpatient service (e.g. "policlinic")*
5. *Outpatient service of a hospital*
6. *Outpatient service of a mental health/psychiatric centre" (with several other types of care provided), community mental health centre, community team*
7. *Other, please describe*

2. Psychiatric day care services:

1. *Integrated with inpatient section in a hospital*
2. *Separate organisational structure of a hospital and located in hospital*
3. *Separate organisational structure of a hospital but not located in a hospital*
4. *Part of a psychiatric centre / community mental health centre*
5. *Other, please describe*

3. Psychiatric mobile services:

1. *Organisationally part of a specialist psychiatric unit*
2. *Organisationally part of a community mental health team*
3. *Organisationally part of a stand alone community mobile mental health team*
4. *Organisationally part of local/regional government social care services*
5. *Other, please describe*

4. Consultation/ liaison psychiatric services:

1. *Consultation service provided by psychiatric services based in the same hospital*
2. *Consultation service provided in a hospital by psychiatrists who are not based at the same hospital: e.g. working in a community*
3. *Mental health service or another hospital with psychiatric services or based in an independent practice"*
4. *Other, please describe*

5. Telephone, internet and computer based services:

1. *Organisationally part of a specialist psychiatric unit*
2. *Organisationally part of a community mental health team*
3. *Organisationally a stand alone specialist service*
4. *Organisationally part of local/regional/national government services*
5. *Other, please describe*

- <u>Subtypes of inpatient mental health care:</u>

1. Psychiatric ambulatory care services:

1. *Stand-alone psychiatric facility– acute care*
2. *Stand-alone psychiatric facility – long-term care*
3. *Stand-alone psychiatric facility – long-term and acute care*
4. *Part of a psychiatric centre / community mental health centre*

2. Non-psychiatric beds in acute general hospitals used for patients with mental health needs

- Subtypes of selected additional services for housing, employment and vocational rehabilitation of inpatient mental health care:

1. Housing support:

1. *Time limited provision of housing for independent living for a single person/family without onsite support*
2. *Non time limited provision of housing for independent living single person/family without onsite support*
3. *Time limited provision of block of housing for independent living for a single person/family with onsite support*
4. *Non time limited provision of block of housing for independent living single person/family with onsite support*
5. *Independent group living housing without onsite support*
6. *Independent group living housing with onsite support*
7. *Financial benefits to help support rent / mortgage payments.*
8. *Other, please describe*

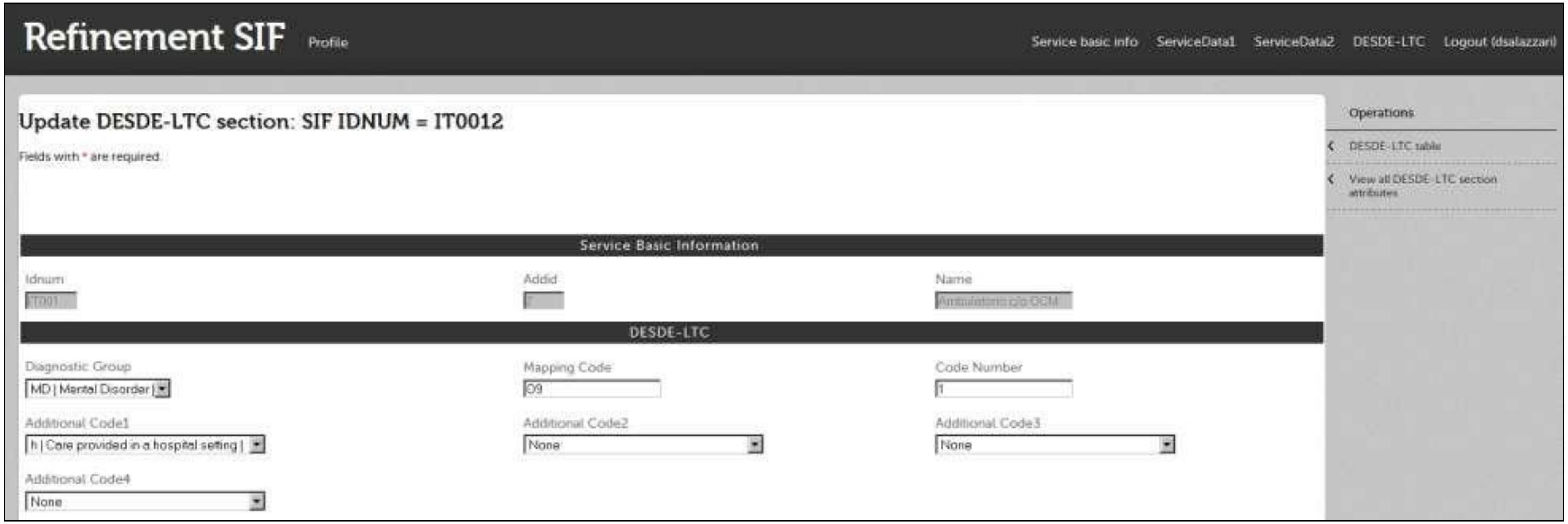
2. Employment intermediation services:

1. *Services provided by public employment services (mainstreamed)*
2. *Services provided by specialist public employment service*
3. *Services provided by private sector employment services under contract (mainstreamed)*
4. *Services provided by private sector specialist mental health employment services under contract*
5. *Other, please describe*

3. Vocational rehabilitation services:

1. *Vocational rehabilitation services provided by specialist public employment services*
2. *Vocational rehabilitation services provided by specialist rehabilitation service*
3. *Services provided by a clubhouse or similar organisation*
4. *Other, please describe*

Figure 4. Example of DESDE-LTC section of the SIF



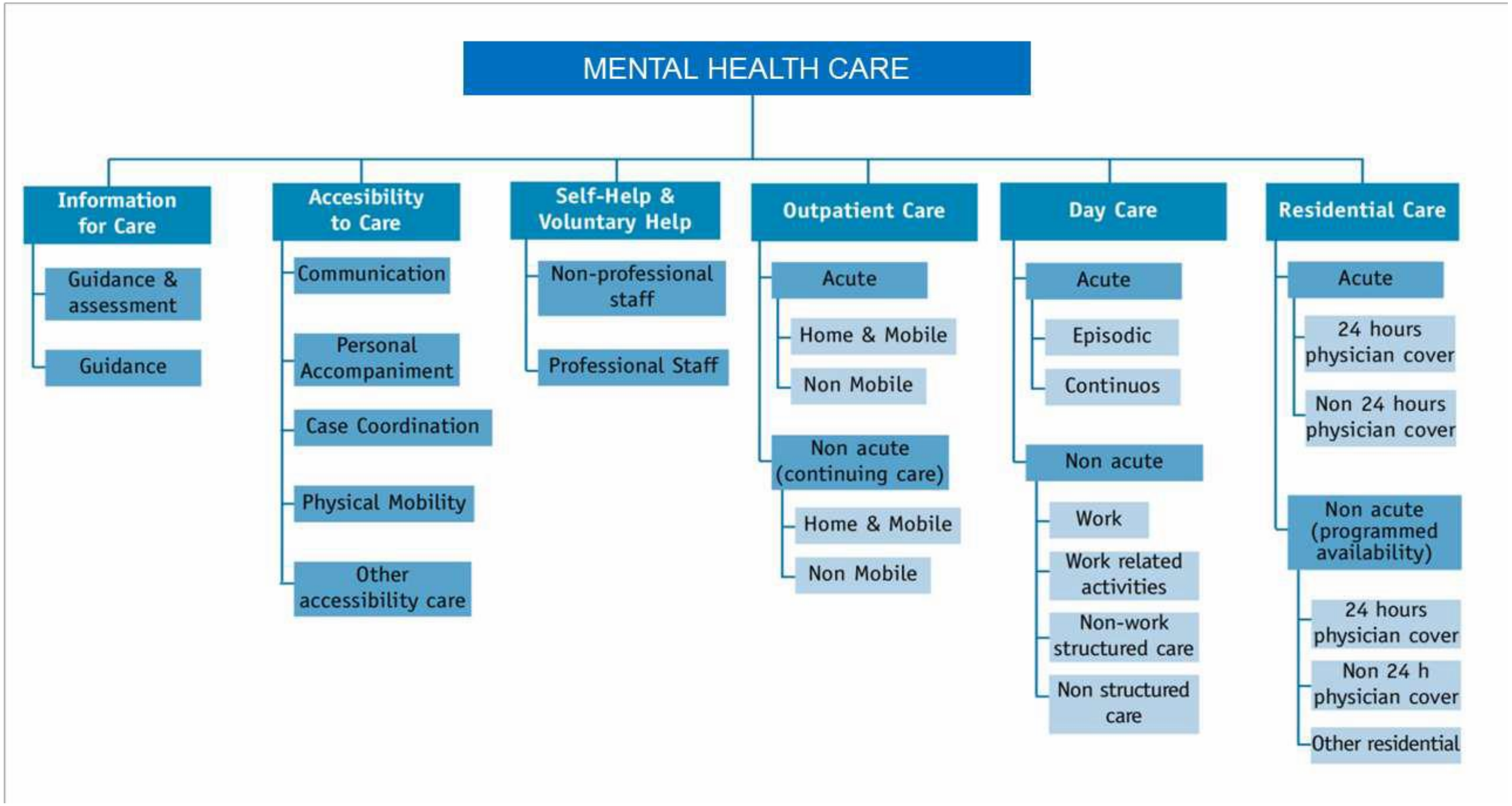
Update DESDE-LTC section: SIF IDNUM = IT0012

Fields with * are required.

Idnum: IT001
Addid: 1
Name: Ambulatorio c/o OCM

Diagnostic Group: MD | Mental Disorder |
Mapping Code: O9
Code Number: 1
Additional Code1: h | Care provided in a hospital setting |
Additional Code2: None
Additional Code3: None
Additional Code4: None

Figure 5. Classification mapping tree: main branches



f. ICHA-HP Code

Provide the ICHA-HP code following the classification of providers in SHA 2.0 available at the following link: http://who.int/entity/nha/sha_revision/sha_2011_final1.pdf?ua=1

According to the table provided in the guide, choose among HP.1 (Hospitals), HP.2 (Residential long-term care facilities), HP.3 (Providers of ambulatory health care), HP.4 (Providers of ancillary services), HP.5 (Retailers and other providers of medical goods), HP.6 (Providers of preventive care), HP.7 (Providers of health care system administration and financing), HP.8 (Rest of economy) and HP.9 (Rest of the world). Please select the specific category and establishment.

g. User Profile

- Age: Lower and Upper limits
  Indicate the minimum age of users to benefit from the service. Indicate the upper age limit, too. If there is no upper age limit, insert the value 0.
- Gender
  Specify if the service is addressed exclusively to males (M) or females (F) or to both genders (MF).

h. Number of Users

Indicate the total number of users referring to a precise year (previously selected for the entire compilation of this tool).

i. Number of Contacts or Admissions

Indicate the total number of contacts referring to a precise year (previously selected for the entire compilation of this tool). If you are referring to a Hospital or Residential Structure (DESDE-LTC code: R), consider the Admissions and not the Contacts. For further information, check the definition of “Contact” in the REFINEMENT Glossary.

j. Number of Days in Hospital or Residential Structure

Indicate the total number of days ONLY if you are referring to a Hospital or Residential Structure (DESDE-LTC code: R). If not so, leave the box blank.

k. Number of available beds or places.

Provide the number of available beds (for R codes) or places (for D codes) for those services which own them.

l. Links with Other Services

Insert the SIF IDNUM of correlated services or write a short sentence summarizing the type of correlated services. By definition, correlated services are services which cooperate with one other through protocol agreements, conventions etc.

5. Evaluator information

a. Name and Phone Number of the Source Reference

Name the source of information used to complete the schedule. Provide their phone number as well.

b. Name and E-mail of the Evaluator

Provide the name and the e-mail address of the evaluator of this specific service.

c. Observations

Write any comments or additional information in this section. Insert here all specifications and definitions of the items where you answered "Other".

GEOGRAPHICAL DATA

Available data refer to the year: ☐

Dataset	Macro-Area	Study Area	Notes
Land cover	Corine land Cover (1)	Gmes Urban Atlas (2)	Land cover classification is grouped into 3 broad classes : Urban fabric, Industrial, Other (for further details, see http://sia.eionet.europa.eu/clc2000/classes)
Degree of urbanization 2011	x	x	degree of urbanisation at LAU2 (local administrative units level 2) level, a LAU2 consists of municipalities or equivalent units in the 27 EU Member States (for further details, see http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Glossary:Revision_of_the_degree_of_urbanisation)
GEOSTAT population grid 2006	x	x	The GEOSTAT 2006 dataset contains the total population of all EU countries, with the exception of Cyprus (for further details, see: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Population_grids)
Detail of the road network		x	http://planet.openstreetmap.org/

1) ***Corine Land Cover Dataset :***

The land cover project is part of the CORINE programme and is intended to provide consistent localized geographical information on the land cover of the Member States of the European Community.
Temporal coverage: 2006
Geographic coverage : complete REFINEMENT coverage
Scale of the data set: 1:100,000.

2) **GMES* :**

The Urban Atlas is providing pan-European comparable land use and land cover data for Large Urban Zones with more than 100,000 inhabitants as defined by the Urban Audit. The GIS data can be downloaded together with a map for each urban area covered and a report with the metadata.
Temporal coverage: 2005-2007
Geographic Coverage: (Norway dataset not available)
Scale of the data set: 1:10,000.

*If GMES data are not available at the Study Area level, the data from the Corine Land Cover Dataset will be used.

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2. REFINEMENT GLOSSARY

THE REFINEMENT GLOSSARY

Terms and definitions concerning Mental Health Care Provision and Financing in Europe

WP6 REFINEMENT Mapping Service Tool

THE REFINEMENT PROJECT (No 261459)
2013

THE REFINEMENT GLOSSARY: Terms and definitions concerning Mental Health Care Provision and Financing in Europe

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PREFACE

Health information is expected to reach its target audience in a language they can understand (WHO, 2007). With this aim dictionaries and glossaries are officially provided in order to make health information more equitable and easier to use. For example, the Regional Office for the Eastern Mediterranean of the World Health Organization is engaged in bridging gaps and fostering understanding between people of different cultures and languages. It considers multilingual communication as an essential tool for improving health, strengthening health systems and providing essential health for all. Official definitions for health care are then provided through multilingual glossaries like the one by www.euro.who.int.

In line with the World Health Assembly's most recent resolution on multilingualism, adopted in 2008, with its five-year plan of action (2008-2013), the **REFINEMENT** project has produced its own glossary, i.e. a pragmatic and consistent way to define mental health care services. Actually, the **REFINEMENT** project had been developing from its very beginning a glossary of all terms used to identify the provision of services for mental health care across Europe. A specialist committee of experts from the **REFINEMENT** group has been collecting, verifying and adding nouns and definitions to a first draft of the glossary. Feedback, comments and information from all **REFINEMENT** partners have been taken into account to produce a final specific dictionary of terms referring to mental health services due at the end of the project. All definitions were based on official sources (existing glossaries, dictionaries, encyclopaedias, health reports and documents) which are reported in the References section. They were reformulated and adapted to the **REFINEMENT** context by a linguist, an English mother-tongue epidemiologist and the selected **REFINEMENT** glossary panel.

When preparing the initial version of the glossary, a preliminary discussion was whether its first aim was to be useful for the sole **REFINEMENT** project or whether it could also be addressed to take account of the needs of users from countries not included in **REFINEMENT**. If the first option would have made things apparently easier by choosing terms and definitions that only the nine **REFINEMENT** partners (Italy, Austria, Spain, England, Norway, Finland, France, Romania and Estonia) had to agree on, the second option gave us the chance to produce a linguistic tool of help for any future project in the psychiatric domain especially related to the costs of services (both health and social care) concerning mental health. The answer to this dilemma was that we wanted to prioritize usability for the project rather than global validity when conflicts may appear, and to try to reach only operational definitions of highly complex terms such as "Public/Private" where a final solution may be difficult.

During the different phases of the project (preparation of the tools, collection and analyses of the data etc.) different definitions were presented in order to start clarifying the meaning of each term and to find an agreement on its definition. A selected panel of experts from the **REFINEMENT** project produced the final version after a deep linguistic, as well as a practical/scientific discussion on the terms used in the **REFINEMENT** tools. This final official version is one element of the **“REFINEMENT decision support tool and manual”**.

GLOSSARY LAYOUT

Terms in bold are listed in alphabetical order. For some terms synonyms are reported after “or”. The correlated REFINEMENT tools are indicated by the acronyms in brackets: Fincento (F); *RM* (Remast); *RP* (Repato); and *RQ* (Requalit). When terms refer to the DESDE-LTC instrument (Salvador-Carulla et al., 2013) which is part of the REMAST tool, the combined acronym RM-DESDE-LTC is mentioned. Categories are added after the REFINEMENT tools acronyms and are: *Care and Treatment*; Payment Mechanisms; *Services Type*; and *Quality of Care*.

GLOSSARY

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24 hour acute (mobile or non-mobile) service (RM-DESDE-LTC, RQ; Services Types):

These are acute services which are available 24 hours a day, 7 days per week.

24 hour physician cover service (RM-DESDE-LTC, RQ; Services Types):

Facility within a hospital or within other residential **meso-organisation** or **service** (see definitions) where there is 24 hour cover by a registered physician (including medical residents). Services where cover is provided by medical pre-graduate students are excluded.

A

Acceptability (RQ; Quality of Care):

The way in which any service provider ensures that its services are adequate to satisfy the needs and the requirements of its users.

Access to Care (RQ; Quality of Care):

The perceptions and experiences of people as to their ease in having the opportunity to use a service in terms of location, time, and ease of approach.

Accessibility to care (RM-DESDE-LTC, RQ; Quality of Care):

Its main aim is to provide accessibility aids to users.

Accreditation System (RQ; Quality of Care):

A formal process by which a recognised body, usually a non-governmental organisation, assesses and recognises that a care organization meets applicable pre-determined and published standards. The accreditation follows a periodic on-site evaluation by a team of peer reviewers.

Activity Based Funding (ABF) System (F; Payment Mechanisms):

ABF is a financing mechanism that allocates funds to service providers (e.g. hospitals) according to the type and volume of activity they provide. Through ABF service providers are paid/reimbursed on the basis of the activity they undertake, i.e. payment varies according to the activity level. Usually ABF will make use of case-mix systems (see definition) to adjust the level of funding provided relative to clinical need. In other words ABF systems usually fund homogenous patients in the same way, with different levels of payment for different patient groups. One example of an ABF system is the Diagnose Related Group (DRG) (see definition) approach to funding.

Activity Based Costing System (F; Payment Mechanisms):
See **Activity Based System**

Activity Based Payment System (F; Payment Mechanisms):
See **Needs-linked/related System**.

Activity Based System (F; Payment Mechanisms):
Costing methodology which assigns the cost of all the activities of an organization to their actual utilization. Indirect costs are then assigned to products to help minimize waste.

Acute Care (F; Care and Treatment):
Health care in which a patient is treated for a brief but severe episode of illness, such as an emergency or other trauma, or during recovery from surgery. Acute care is usually provided in a hospital and it may involve intensive or emergency care. In terms of treatment and patient condition, it is the opposite of **chronic care** (see definition). For mental health, this type of care concerns all acute psychiatric illnesses.

Acute Psychiatric Hospitalisation (RP, RQ; Care and Treatment):
This term refers to all acute inpatient admissions in wards providing care with intensive medical and nursing support for patients in periods of acute psychiatric illness for a purpose related to the clinical and social management of their health condition. Patients are hospitalised when in crisis with a deterioration of their mental state, behavioural or social functioning which is related to their health condition. It encompasses treatment of illnesses and disorders in a relatively short amount of time.

Acute Psychiatric In-patient Admission (RP, RQ; Care and Treatment):
See **Acute Psychiatric Hospitalisation**.

Acute Psychiatric In-Patient Unit (RM; Services Type):
Psychiatric unit (or **BSIC**, see definition) where patients are admitted for mental health related care and/or treatment requiring the use of a bed overnight. The psychiatric unit is usually located within a hospital or clinic and provides acute care in emergency situations. There can be stand-alone acute psychiatric units as well.

Acute Psychiatric Service (RM-DESDE-LTC; Services Type):
Care that is generally provided because of a crisis, a deterioration of physical or mental state, behaviour or social functioning which is related to the user' health condition. This type of care may include treatment at home, short-term hospital stays, mobile care as well as emergency medical services.

Administrative Data (RQ; Other REFINEMENT terms):
Data primarily collected for the administration of a particular function.

Admission (RM, RQ; Care and Treatment):

The formal acceptance of a patient by a hospital or other inpatient healthcare facility. Room, board and continuous nursing service are provided and the patient generally resides at least over one night.

Aftercare (RP; Care and Treatment):

See **Follow-up Care.**

Anti-stigma Campaign (RQ; Quality of Care):

See **Stigma Campaign.**

Appropriateness (RQ; Quality of Care):

Services, care and treatment that meet the needs of patients, and have been demonstrated to be effective in the scientific literature.

Assessment of Housing Quality (RQ; Quality of Care):

The measurement of different indicators of the quality of housing where quality corresponds to a healthy and safe environment. These indicators are both tools evaluating the objective state of the house and the subjective views of the residents of the house.

Association (RM; Services Type):

A group of people organized for a joint purpose a legal entity.

Availability (RM; Quality of Care):

The presence, location and readiness for use of services or other organisational units in a care organisation or a catchment area at a given time. A service is available when it is operable or usable upon demand to perform its designated or required function. Opening times and placement and workforce capacity are some indicators of care availability. Placement Capacity is the maximum number of beds in residential care and of places in day care in a care delivery organisation or a catchment area at a given time. Finally, workforce capacity is the maximum number of staff available in a care delivery organisation or in a catchment area at a given time. Care workforce capacity usually refers to paid staff providing direct care (e.g. it excludes voluntary care providers and administrative staff). It is typically measured in Full Time Equivalents (FTE) (see definition).

Availability of care (RM; Quality of Care):

See **Availability**.

Availability of services (RM; Quality of Care):

See **Availability**.

Average Length of Stay (**ALoS**) (RP, RQ; Care and Treatment):

A measure of how many days a patient, on average, spends in an inpatient facility. Hence, this measure, when applied to individuals or specific groups of patients, may be an indicator of the severity of illness and resource use. It is often used as a comparison element to assess efficiency of resource usage between hospitals. It can be calculated by adding together the Length of Stay (LoS) of each patient and dividing this sum by the number of their admissions. Some computation methods are possible to help ensure comparability. For instance, date of discharge minus date of admission +1 (including day of admission) would be useful also in the calculation of bed occupancy with also use number of patient days (based on Los).

B

Basic Stable Input of Care (BSIC) (RM-DESDE-LTC; Other REFINEMENT terms):

Minimal set of inputs with temporal continuity and organisational stability for delivering health related care to a defined and identified group of users in a specific location. It is usually composed of an administrative unit with an organised set of structures and professionals. BSICs are the minimal micro-level functional systems of care organisation. Within the production model of health-related care (input-throughput-output), BSIC refers only to input functions of care that are stable and continuous over time and not to other organisational arrangements, tangible inputs (devices, facilities), or procedures (interventions)

Bed Occupancy (RM; Quality of Care):

The number of beds in hospital or other inpatient units occupied by patients in a specific period of time expressed as a percentage of the total beds available in the ward, specialty, hospital, area, or region. It is used to assess the demand for hospital beds and hence to gauge an appropriate balance between demand for health care and the number of beds. It can be calculated by dividing the sum of “inpatient days of care” (i.e. the sum of the total number of days in which each patient occupied a bed in a facility over a specific period of time) by the “bed days” (i.e. the multiplication of the number of available beds in the facility by the number of days in the period being analysed). For instance, as for the computation method, LoS is the date of discharge minus date of admission + 1.

Best-practice (core) Programmes (RQ; Quality of Care):

A whole program conferred either officially - by a government body, professional association, or other authoritative entity - or by published research results. A best practice program should be measurable (i.e. with clear goals whose progress can be easily measured), notably successful and replicable (i.e. it is structured and documented clearly enough so that it can be "replicated").

Block Contract System (F; Payment Mechanisms):

Under this system the provider has a contract to provide services for a defined population. The provider receives a defined funding and in return must meet the terms of the contract which often stipulates a defined set of services.

Block Grant (F; Payment Mechanisms):

A sum of money usually allocated by a statutory authority. It is given as a grant for discretionary use in funding programs, i.e. without major strict restriction on how the funds must be used (e.g. unrestricted grant in contrast to earmarked grants or categorical grants which may be spent only for specific purposes).

Bonus Payment (F; Payment Mechanisms):

An additional payment to the employees' and managers’ base fixed salary. The bonus payment is used according to predefined criteria.

Budget (F; Payment Mechanisms):

The total sum of money allocated for a particular purpose or period of time.

Burn-out (RM, RQ; Quality of Care):

Long-term exhaustion and diminished interest in work of individuals who are exposed to an intense emotional involvement and become completely exhausted through overwork, lack of support by management, role conflicts, injustice and other organizational causes as well as personal characteristics like perfectionism, low self-esteem etc. The main components of burn-out are exhaustion, cynicism, and inefficacy.

C

Capitation (**CAP**) (F; Payment Mechanisms):

A method that can be used to determine the level of resources allocated to service purchasers as well as to pay service providers. For instance in the case of service providers payment is made per head of a defined population. The provider is paid a specified sum of money for the care of this population for a specified period of time. Payment is independent of services used. Ideally payments to purchasers and service providers are risk adjusted (weighted to take account of factors such as age and geographical location). Capitation systems are often linked to geographical location, for instance in the case of some primary care systems which require registration with a particular.

Capitation Based Payment (F; Payment Mechanisms):

See **Capitation.**

Capitation Payments (F; Payment Mechanisms):

See **Capitation.**

Capitation - Risk Adjusted (**CAPR**) (F; Payment Mechanisms):

Risk adjusted capitation is a capitation payment method through which payment rates are adjusted for risk by taking into account factors like age, sex, health status and prior health care utilisation as well as socio-demographic factors such as residence, income etc.

Caregiver (RQ; Services Type):

See **Carer**.

Care Provider (RM; Services Type):

An individual or an institution helping in identifying or preventing or treating illness or disability in a systematic way. An individual health care provider is also known as a health worker and may be a health care professional within medicine, nursing or allied health professions. An institutional health care provider is also known as a health facility and includes hospitals, clinics, primary care centres and other service delivery points.

Carer (RQ; Services Type):

Here this term refers to non-professional carers who provide support to family or friends who need help with various activities in daily life. Typically carers are not paid, but in some circumstances they can receive some financial compensation for their caring time.

Casemix System (F; Payment Mechanisms):

Casemix systems provide a method of classifying patients and associated costs. System of describing and quantifying provider workload, i.e the expected cost of activity based on a classification of the mix of patient treated. Casemix systems are used in different countries for a variety of purposes – clinical review, funding, monitoring, comparison, management, hospital planning and national planning. It can be applied to all types of care and care setting. In the case of funding the motivation is to base funding on measured activity and expected costs, rather than on less objective systems of resource allocation and to fund hospitals based on their "mix" of cases.

Casemix Adjustment (F; Payment Mechanisms):

The method of taking into account differences in patient case-mix in determining provider payment based on a system for patient classification (casemix systems). Casemix adjustment can be used in different types of payment systems.

Catchment Area (RM, RP; Other REFINEMENT terms):

A geographical area which determines entitlement to localised services, usually based on residency. These services are usually provided within the catchment area, but in the case of more specialist services may be provided elsewhere. See also **Sectorisation**.

Chronic Care (F; Care and Treatment):

Long-term medical care lasting usually more than 6 months especially for individuals with chronic mental impairment.

Chronic Disease (RM, RQ; Care and Treatment):

This term can have both medical and administrative definitions (e.g. some countries have specific reimbursement systems for patients with chronic conditions), but the medical definition is here considered. Chronic disease or illness is a long-term condition, lasting more than 6 months, that is non-communicable and involves some functional impairment or disability and that is usually incurable.

Chronic Illness (RM, RQ; Care and Treatment):
See **Chronic Disease.**

Clinical Assessment (RQ; Quality of Care):
An evaluation of a patient's (mental) health condition and prognosis based on information gathered from multiple source of data including the patient's health and treatment history.

Clinical Record (RQ; Other REFINEMENT terms):
See **Record.**

Clubhouse (RM; Services Type):
A specific type of service modelled on a service first provided in New York in 1948. Clubhouse International, a multi-national non-profit organization helps communities around the world create sustainable solutions for mental illness by developing and nurturing new and existing Clubhouses. There are now over 300 clubhouses worldwide. They are community-based centres that offer members opportunities for friendship, employment, housing, education, and access to medical and psychiatric services through a single caring and safe environment, so members can achieve a sense of belonging and become productive members of society.

Coercive Treatment (RP, RQ; Care and Treatment):
See **Involuntary Status.**

Commissioning (F; Payment Mechanisms):
See **Commissioners**.

Commissioners (F; Payment Mechanisms):
Bodies at national or local level that hold a budget which they use to purchase services. Detailed contracts or service agreements may be drawn up with service providers as part of this process.

Common Mental Disorder (RP, RQ; Care and Treatment):
See **Common Mental Illness** (**CMI**).

Common Mental Illness (**CMI**) (RP, RQ; Care and Treatment):
A group of mental disorders that frequently occur in primary care patients. They include depression, anxiety and somatization. Common mental health disorders, such as depression, generalized anxiety disorder, panic disorder, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and social anxiety disorder, may affect up to 15% of the population at any one time. (EXAMPLE: To enable data collection and country comparison, in RP CMI is only defined by a diagnosis of affective or anxiety disorder).

Community Care (RM, RQ; Care and Treatment):

Services (including mainly social services) and support to help people with care needs to live as independently as possible in their communities.

Community Follow-up Care (RM, RQ; Care and Treatment):

See **Community Care**.

Community Mental Health Centre (**CMHC**) (F, RP; Services Type):

Found in some countries, a CMHC is a mental health treatment centre located in a catchment area close to the homes of mental health service users. It features a series of comprehensive services performed by mental health professionals and all aimed at providing a coordinated program of continuing mental health care. Psychotherapeutic services can be inpatient, outpatient, therapeutic rehabilitation, emergency, day treatment, screening and personal care home services.

Community Mental Health Team (RP; Services Type):

A multi-professional team offering outpatient and mobile services which is often located in a neighbourhood catchment area close to the homes of service users. It may be based in a community mental health centre. Services may be delivered in people's own homes. Features include offering a series of comprehensive services by one or more team members, provision of continuity of care, linkages to a variety of health and social services, etc.

Community Rated Insurance (F; Payment Mechanisms):

All members of an insurance pool pay the same insurance premium regardless of individual risk. Thus, risk is pooled across the whole community.

Community Tenure (RP; Services Type):

Average number of days patients lived in the community between inpatient admissions (days between hospital discharge and readmission).

Community-based Service (RM, RQ; Services Type):

It is a service targeting a group of individuals or a geographic community, i.e. only a short distance from the users' residence. It is centred in and around a particular community which can be represented by cities, municipalities, schools etc. Services may be delivered at facilities in the local area, in other local settings or in service users' homes.

Comorbidity (RP; Care and treatment):

The presence of at least one or more additional disorders (or diseases) in addition to a primary disease or disorder.

Competitive Paid Employment (RQ; Quality of Care):

Employment where employees received the market wage rate. The ability to obtain competitive paid employment can be used as one measure of the quality of care provided to service users to help them reintegrate into the community.

Comprehensive Care (RC, RP; Care and Treatment):

See **Integrated Care.**

Consultation/Liaison Service (**C/L Service**) (F; Services Type):

A specialist within psychiatry dealing with the overlap of physical and mental health care. It provides timely psychiatric consultation to patients in medical/surgery units and utilises a multi-disciplinary team approach (psychiatry, psychology and nursing) for assessment and treatment. It mainly consists of psychiatric or psychological management, liaison with the referring treatment team, ongoing monitoring of mental health status during hospitalisation and facilitation of transfer to other mental health services.

Consultation (RM, RQ, RP; Care and treatment):

Meeting with a medical doctor to assess one's physical and/or psychological health status. It refers to the number of contacts with service and may include also contacts with non-medical staff within health care premises.

Consumer Directed Payment (F, RM; Payment Mechanisms):

These are sums of money or cashless equivalents which are allocated to service users and/or their families. The service user can then choose what services to purchase. In some systems there are no restrictions on what can be purchased – they might buy a holiday or use money to pay a family carer. In other systems choice may be restricted to an approved list of services and/or service providers.

Contact (RM, RQ, RP; Care and treatment):

See **Consultation.**

Continuity of Mental Health Care (RP, RQ; Care and Treatment, Quality of Care):

The provision of barrier-free access to the necessary range of mental health care services over any given period of time, with the level of care varying according to individual needs. The concept of continuity of care is multi-axial and consists of several independent factors, like experiences, information, relations, context etc. It can be measured by the unplanned time lags during the treatment or lack of the appropriate treatment plan.

Convalescent Home (RM; Services Type):

See **Nursing Home.**

Co-occurring disorders (**COD**) (RQ; Care and Treatment):

See **Dual Diagnosis**.

Cooperative Care (RQ; Care and Treatment):

Especially used in health and social care in the UK, this term refers to cooperation between health and social care professionals and service users.

Coordinated Care (RC, RP; Care and Treatment):

See **Integrated Care.**

Coverage of Services (F; Payment Mechanisms):

Access to services for all at an affordable cost, where the majority of the costs of services are met by statutory authorities or social health insurance.

Crisis Intervention Team (RQ; Services Type):

See **Crisis Resolution Team**

Crisis Resolution Team (RQ; Services Type):

This team aims at responding to people in crisis by providing an assessment and treatment service. It is active 24 hours a day and it delivers acute mental health care in the community. The team is multi-professional (physicians, social workers, nurses staff etc.) and provide psychiatric assessment, outpatient psychotherapy, case management services and medication management services avoiding long waiting periods for patients.

Cultural Competence (RQ; Quality of Care):

The knowledge, attitudes and skills that a professional (including health and social care providers) require in order to provide appropriate care for people from minority population groups, including those with different languages and cultures.

Cultural Mediator (RQ; Services Type):

An individual, usually from a minority population group who is professionally qualified to act as a liaison and support between health and social care (and other) services and service users from the same minority population group.

D

Daily Fee (F; Payment Mechanisms):

A daily fee charged for the use of a service. In the case of health services it typically is charged in part to cover the hotel costs of inpatient care. In some cases these fees may have to be paid directly by service users; they may not always be reimbursed.

Daily Rate (F; Payment Mechanisms):

The service provider gets a fixed sum - regardless of the diagnosis - for each day on which a patient is in an institution -hospital, social care home. This fixed sum may depend on patient characteristics, not necessarily diagnosis, and may be graded according to length of stay, e.g. reduced daily rate after a certain length of stay. Unit of payment: Days.

Day Care (RM-DESDE-LTC, F; Services Type):

Care provision (i) is normally available to several consumers at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long-term care needs: e.g. providing a structured activity, or social contact and/or support; (iii) have regular opening hours during which they are normally available: and (iv) expect consumers to stay at the facilities beyond the periods during which they have face-to-face contact with staff (i.e. the service is not simply based on individuals coming for appointments with staff and then leaving immediately after their appointments). The care delivery is usually planned in advance.

Day Hospital (F; Services Type):

A specific type of day care provided in a special clinical facility or a hospital setting where structured treatments, occupational programmes and diagnostic procedures may be performed. Service users return home or go to their usual hospital ward at the end of the day.

Day Treatment (RM; Care and Treatment):

See **Psychiatric Day Care.**

Defined Benefit Package (F; Payment Mechanisms):

A list of medical benefits, services and treatments that are usually deemed medically necessary, where provision is usually guaranteed by the government. Defined benefit packages are most common in health systems where insurers are significant.

De-institutionalisation (RM, RQ; Quality of Care):

The policy of moving severely mentally ill people out of institutions (like a mental hospital or clinic) and then closing part or all of these institutions. Over the longer term fewer mental health treatments are delivered in hospitals and more services are provided by community-based mental health services. The process started in earnest in high income countries in the second half of the twentieth century and the shift towards greater use of community care is ongoing.

Diagnosis of co-occurring disorders (RQ; Care and Treatment):

See **Dual Diagnosis**.

Diagnosis Related Activity Based Payment (F; Payment Mechanisms):

Health care providers are reimbursed a set amount for each individual treated according to their primary diagnosis. Tariffs for each category are usually set centrally by government or health insurers. Two different applications of DRG based financing system can be found; i) Fixed price systems: Tariffs are set in advance (prices are fixed, the sum of payments to all providers are variable), ii) Point systems: Tariffs are determined retrospectively based on the total number DRG-points produced by all providers in relation to the total available budget (prices are variable, the sum of payment to all providers are fixed). Sometimes DRGs are also used in other ways e.g. as part of a case-mix adjustment process to help estimate the potential budgets of health care providers. See **Diagnosis Related Group**.

Diagnosis Related Group (F; Payment Mechanisms):

A system of classifying patients into medically meaningful and homogenous groups in terms of cost of treatment, i.e. group of patients who share similar clinical attributes and consume similar levels of resources. The grouping is based on primary diagnosis and may also take into account other factors such as different levels of severity of illness, length of stay, treatment on a day basis without overnight admission, or complicating factors including co-morbidities.

Direct Payment (F, RM; Payment Mechanisms):
See **Consumer Directed Payment.**

Disability (RM; Care and Treatment):
An umbrella term covering impairments (problems in body function or structure), activity limitations (difficulties in executing a task or action), and participation restrictions (problems in involvement in life situations). It is a complex phenomenon reflecting the interaction between features of a person's body and features of the society in which (s)he lives.

Disability Benefit (RM, RQ; Payment Mechanisms):
A financial payment made to individuals who have been assessed as having physical and/or mental health problems that lead to functional limitations.

Discharge Planning (RP, RQ; Care and Treatment):
A process by which an admitted inpatient's needs on discharge are anticipated, planned for or arranged in order to improve his/her engagement in outpatient aftercare.

Discrimination (RQ; Quality of Care):
Discrimination related to mental health has been defined as the behavioural consequences of stigma which act to the disadvantage of people who are stigmatised. Its importance can be seen in terms of impacts on personal relationships, parenting, childcare, health care utilisation, education, training, work and housing.

Disengagement from Mental Health Care (RP, RQ; Care and Treatment):
See **Dropout from Mental Health Care**.

Disincentive (F; Payment Mechanisms):
Defined as a factor, especially a financial disadvantage, that discourages a particular action.

Documented Discharge Plan (RP, RQ; Care and Treatment):
See **Discharge Planning**.

Domiciliary Care (RM, F; Services Type):
A home-based assessment and support service for people who need help with the activities of daily living. The service aims to help people live independently in their own homes and target groups covered can include people with disabilities, older people and all those with chronic physical and/or mental health problems.

DRG-based Payment (F; Payment Mechanisms):
See **Diagnosis Related Activity Based Payment**

Dropout from Mental Health Care (RP, RQ; Care and Treatment):

Inappropriate termination of mental health treatment after the initial contact or after further occasional contacts (EXAMPLE: In RP dropout from mental health care is defined as having no psychiatric outpatient contacts for at least 6 consecutive months).

Dual Diagnosis (RQ; Care and Treatment):

Dual diagnosis is a diagnostic term usually used to refer to an individual living with both a mental disorder and alcohol/substance abuse disorder.

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**.

Emergency Room (RQ; Services Type):

A medical treatment facility specializing in acute care of patients who present without prior appointment, either by their own means or by ambulance. The emergency department is usually found in a hospital or other primary care centre.

Emergency Service (RQ; Services Type):

Not to be confused with general emergency services, this refers to an organisation which ensure public safety and health. Staff responds to calls from police, healthcare professionals, clients, family members and the general public. Their job is to take quick action to deal with emergencies when they occur and with mental health crisis. Their services include mobile response for crisis assessment and resolution, referrals to mental health teams, healthcare professional or other agencies. They are normally active 24 hours a day.

Employee Morale (RM, RQ; Quality of Care):

See **Staff Morale.**

Employment Service (F; Services Type):

Employment services are usually funded and often provided by government. Their aim is to help people who are unemployed, or registered as unable to work because of disability, return to competitive employment. At a minimum services provided include information provision, employment guidance counselling and job searching. Perhaps less common are services related to employability or skills assessment, job coaching and supported employment, job matching and individualised career or job planning. Many employment services focus on the entire population, but there may also be specialist employment services may focus on the specific needs of people with mental health problems. See also **supported employment.**

Employment Support Services (F; Services Type):

See **Employment Service.**

Episode (RM, RQ; Care and Treatment):

A single noteworthy and critical event in the course of a prolonged illness.

Equity (RQ; Quality of Care):

The absence of systematic or potentially remediable differences in health status, access to healthcare and other services and health-enhancing environments, and treatment in one or more aspects of health across populations or population groups defined socially, economically, demographically or geographically within and across countries.

Evaluation Programmes (RQ; Quality of Care):

The systematic and objective assessment of the relevance, adequacy, progress, efficiency, effectiveness and impact of a course of actions, in relation to objectives and taking into account the resources and facilities that have been deployed.

Evidence Based Care (RQ; Care and Treatment):

The conscientious, explicit and judicious use of current best evidence in making decisions. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. The available evidence is often appraised and summarised in best practice recommendations or national guidelines for clinical practice.

Evidence Based Medicine (RQ; Care and Treatment):

See **Evidence Based Care.**

Evidence Based Practice (RQ; Care and Treatment):

See **Evidence Based Care.**

Examination of Physical Health (RQ; Care and Treatment):

See **Review of Physical Health.**

F

Facility (RM; Other REFINEMENT terms):

Something that is built, installed, or established to serve a particular purpose like a hospital.

Family Based Treatments (Care and Treatment):

Type of treatment aimed at solving problems and promoting health in the context of a family system.

Family Care (RM; Care and Treatment):

See **Informal Care**.

Family Doctor (F, RP; RQ; Services Type):

See **General Practitioner** (**GP**).

Family Medicine (F; Care and Treatment):

See **Primary Health Care** (**PC).**

Fee for Service (**FFS**) (F; Payment Mechanisms):

In fee for service systems payment is made for units of service or specific procedure performed. In the case for health care services for instance, for a physician consultation or MRI scan. Fee for service systems are usually based on fee schedules which classify service provider activities with varying degrees of precision (Unit of payment: Specific fee per unit of service received/procedure performed or per contact).

Fixed Fee Per Client (F; Payment Mechanisms):

A specified fixed fee for a service provided to a client for a specified period of time.

Flat Rate (F; Payment Mechanisms):

A fixed monetary fee received per case treated regardless of diagnostic group or severity of need. Flat rate fees can be used in different ways, per a fixed time period, per service user contact, per stay in an inpatient facility.

Follow-up Care (RP; Care and Treatment):

Care provided to individuals after discharge from hospital or other institutional care.

Forensic Inpatient Unit (RM; Services Type):

An inpatient unit that is exclusively maintained for the evaluation or treatment of people with mental disorders who are involved with the criminal justice system. These units can be located in mental hospitals, general hospitals, or elsewhere

Forensic Service (RM; RQ; Services Type):

A service providing assessment and treatment of people with a mental disorder and a history of criminal offending or at risk of offending. "Forensic" means related to or associated with legal issues. People may be referred for assessment by the police, courts, prison, other health or mental health services or justice agencies, and may have a mental illness or mental disorder. Treatment may be provided in the community, in hospital or in prison.

Formal Care (RM; Care and Treatment):

Professional paid help provided to people in need of health, social care and other support. Unpaid care is not usually considered to be formal care, even when provided by qualified individuals.

Formal Psychiatric Diagnosis (RQ; Care and Treatment):

The assessment by a psychiatrist of the presence of a mental health disorder in a patient. Such a mental health disorder is recognised and defined according to an official diagnostic manual like the DSM IV for instance.

Foundation (RM; Services Type):

An institution established with an initial large donation (endowment or legacy). It is often focused on charitable activities which can sometimes include research as well as the provision of services and other supports. The term is used in north America and continental Europe. In the UK and other British influenced countries the term charity is more common. See also **Registered Charity**.

Full-time Equivalent (**FTE**) (RM; Other REFINEMENT terms):

The workload expressed in terms of the number of days equivalent of one employee working full time, calculated as the ratio of the total number of paid hours during a specific period (part time, full time, contracted) by the number of working hours of full-time workers in that same period.

G

Gatekeeper (F, RP, RQ; Services Type):

A system whereby access to specialist and or hospital care is controlled by primary care or 'family' doctors. Such a system has two main aims: cost control and guidance to appropriate care providers. Individuals do not have direct access to secondary care and need a referral from their general practitioner to get access to a hospital or specialist health care.

In some cases gatekeeping systems are not mandatory, but voluntary and are often called soft gatekeeping systems. See also **Soft Gatekeeping.**

Gatekeeping (F, RP, RQ; Services Type):

See **Gatekeeper.**

Gate-keeping System (F, RP, RQ; Services Type):

See **Gatekeeper.**

General Health Care (RM; Care and Treatment):

Care provided in a hospital setting or within a community or at home. It includes all services and treatment aimed at improving a person's basic state of health, i.e. physical, mental and social well-being, without targeting specific diagnostic groups.

General Hospital (RP; Services Type):

A hospital not specialising in the treatment of particular illnesses or of patients of a particular sex or age group, but which is set up to deal with many kinds of disease and injury.

General Practice (F; Care and Treatment):

See **Primary Health Care** (**PC).**

General Practitioner (**GP**) (F, RP; RQ; Services Type):

Single-handed practice or group practice of one/several general doctors/physicians with no secondary care specialisation.

Global Budget (F; Payment Mechanisms):

The service provider receives a fixed lump sum for the whole service for a certain time period (usually one year). This may be based on past ("historical") budgets or it may be determined based on an assessment of community need. It might also include an element of case-mix adjustment to take account of differences in population and past activity in terms of severity of cases treated. There are usually limited or no restrictions on how this budget may be then allocated to different activities delivered by the service provider, unless this is specified in a contract.

Group Practice (RP; Services Type):

A medical practice, which is run by several physicians. Such medical groups are often for general practice.

Group Treatment (RP; Care and Treatment):

Type of treatment that involves one or more providers working with several people at the same time.

Guidelines for Referral and Treatment (RP; Quality of Care):

Clinical practice guidelines are systematically developed statements to assist practitioners and patients make decisions about appropriate health care in specific circumstances.

H

Health Care Centre (RP, RQ; Services Type):

A health centre is a facility which is used for the provision of primary care services and a range of community health services.

Health Care Provider (RM; Services Type):

See **Care Provider.**

Health Care Specialist (F, RQ; Services Type):

See **Specialist Physician**.

Health Care System (RP, RQ; Services Type):

The organization of people, institutions, and resources to deliver health care services to meet the health needs of target populations.

Health Centre (RP, RQ; Services Type):

See **Health Care Centre**.

Health Insurance (RM; Payment Mechanisms):

A contract between the insured and the insurer to the effect that when specified events (determined in the insurance contract) occur the insurer will pay compensation either to the insured person or to the health service provider. There are two major forms of health insurance. One is **social health insurance** which is mandatory for most residents of a country. The other is **voluntary health insurance**, which can act as a complement or alternative to social health insurance. See also **social health insurance** and **voluntary health insurance.**

Health Professional (RM; Services Type):

See **Care Provider.**

Health System (RP, RQ; Services Type):
See **Health Care System**.

Health Worker (RM; Services Type):
See **Care Provider.**

Home Care (RM, RP, RQ; Care and Treatment):
See **Domiciliary Care.**

Home Aid (RM, F; Services Type):
See **Domiciliary Care.**

Home Help (RM, F; Services Type):
See **Domiciliary Care.**

Homelessness (RQ; Quality of Care):
A person without a permanent home, and therefore typically living on the street. Homeless does also refer to people without a permanent home who are staying temporarily with friends or in other temporary accommodation, such as night shelters.

Hospital (RM, RQ; Services Type):
The neutral term "hospital" refers to any institution based in one or more buildings providing medical and surgical treatment and nursing care for sick and injured people. This institution can also provide more specific treatment like obstetric or psychiatric care. Basically; it is a place where people who are ill are looked after by doctors (general practitioners or specialists), nurses and other health professionals.

Hospital Discharge (RQ; Care and Treatment):
A patient's release from a hospital or other inpatient facility authorised by a named doctor once the patient is sufficiently recovered.

Hospital Discharge Against Medical Advice (RP; Care and Treatment):
A patient chooses to leave a hospital or other inpatient facility before the treating physician recommends discharge.

Hospital In-patient Treatment Care (F, RC; Services Type):
See **Inpatient Mental Health Care.**

Hospital Stay (RP, RQ; Care and Treatment):
See **Acute Psychiatric Hospitalisation**.

Housing Support (F; Services Type)
See **Supported Housing.**

I

Incentive (F; Payment Mechanisms):

Defined as a thing that motivated or encourages someone to do something. This can, for instance, include the use of financial rewards. See also **Disincentive.**

Income from Sales (F; Payment Mechanisms):

This source of funding describes the revenues raised from sales of goods and services, for example in sheltered workshops and enterprises.

Independent Variable (RP; Quality of Care):

See **Influencing Factor**.

Indicator of Quality of Care (RQ; Quality of Care):

A measure of performance of care. It describes one or more aspects of the quality of care of a service or a provider at one particular point in time or over a series of points in time

Individual Budget (F; Payment Mechanisms):

See **Consumer Directed Payment.**

Individual Placement and Support (**IPS**) (RQ; Quality of Care):

Individual placement and support (frequently abbreviated to IPS, and also known as evidence-based supported employment) is a variant of supported employment developed by Robert Drake & Gary Becker. Its overriding philosophy is that anyone is capable of working competitively in the community if the right kind of job and work environment can be found and the right kind of support provided. Thus, the primary goal is not to change the individual, but to find a natural match between the individual's strengths and experiences and a job in the community. Unlike traditional approaches to vocational rehabilitation, supported employment programmes do not undertake lengthy assessments or screen people for work readiness. People are not excluded because they are not 'ready' or because of prior work history, substance use or psychiatric symptoms. Individuals obtain employment and then have access to ongoing support from employment specialists and other professionals to help them maintain their employment for as long as they want. Employment specialists tend not to be mental health professionals by training: they are usually people who have skills and experience in vocational rehabilitation, human resources, marketing or occupational psychology and they may have personal experience of mental health problems. See also **Vocational Rehabilitation.**

Infirmary (RM, RQ; Services Type):

See **Hospital.**

Influencing Factor (RP; Quality of Care):

A factor that precedes, influences or predicts an incident or a result.

Influencing Variable (RP; Quality of Care): See **Influencing Factor**.

Informal Care (RM; Care and Treatment):

Help and support (usually unpaid) that is provided to people who need help with activities of daily living by family, friends or neighbours. Informal carers often live in the same residence as the individual they are supporting.

Informal Payment (F; Payment Mechanisms):

Additional unofficial payment (in cash or goods) to obtain a good or service in addition to any formal payment that must be made. Informal payments have been most common in countries where the wages of professionals are very low; making an informal payment may mean that the service is received more rapidly.

Information on Care (RM-DESDE-LTC; Services Type):

Its main aim is to provide information and assessment to users. This care does not entail a subsequent monitoring/follow-up of the user.

Inpatient Care (RM; Care and Treatment):

Care provided with the use of a bed overnight.

Inpatient Care in Hospitals (F, RC; Services Type):

See **Inpatient Mental Health Care.**

Inpatient Episode at an Acute Psychiatric Ward or Department/Facility (either at a mental or a general hospital) (RP, RQ; Care and Treatment):

See **Acute Psychiatric Hospitalisation**.

Inpatient Mental Health Care (F, RC; Services Type):

Delivery of mental health care services on an inpatient basis, where at least one night is spent in the health care facility.

Inpatient Mental Health Service (F, RC; Services Type):

See **Inpatient Mental Health Care.**

Input Level (RQ; Quality of Care):

An indicator related to the structures, personnel and budget of a service, i.e. the structural characteristics of a healthcare organisation. In mental health, inputs consist of visible (mainly staff, facilities and budget) and invisible (experience, qualification and skills of staff, working relationship, legal and policy framework) resources.

Institution (RM; Services Type):

Facility which provides health care and related services mostly to individuals that are living in the facility (see also **Institutional Care**).

Institutional Care (RM-DESDE-LTC; Care and Treatment):

Residential care in a health or social care facility, like large residential **BSIC**s (see definition) characterised by long-term stay for a defined population group, which usually have over 100 beds.

Institutionalisation (RM, RQ; Quality of Care):

The compulsory or voluntary commitment of an individual or a group to an institution such as a mental hospital, social care institution or other residential facility.

Integrated Care (RC, RP; Care and Treatment):

The management and delivery of health and social care services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health and social care systems.

Intensity of Care (RQ; Care and Treatment):

The levels of care received by a patient when hospitalised. It is calculated on the basis of the total time and staff mix of health care resources consumed by an individual patient during a specific episode of care.

Interdisciplinary Team (RP, RM; Services Type):

See **Multidisciplinary Team.**

Internist (F, RQ; Services Type):

See **Specialist Physician**.

Intervention (RQ; Care and Treatment):

An activity or set of activities aimed at modifying a process, course of action or sequence of events, in order to change one or several of their characteristics, such as performance or expected outcome.

Involuntary Outpatient Treatment (RP, RQ; Care and Treatment):

See **Involuntary Status.**

Involuntary Placement (RP, RQ; Care and Treatment):

See **Involuntary Status.**

Involuntary Status (RP, RQ; Care and Treatment):

Treatment and/or care of an individual with a mental disorder without obtaining their consent. This usually has to be determined by a quasi-legal process This involuntary care is usually justified on rounds that an individual health status can be of harm for him/herself and the others.

Involuntary Stay (RQ; Care and Treatment):

Hospitalisation for a minimum of 24 hours without obtaining the consent of the service user.

K

Keyworker (RP; Services Type):

A person with defined responsibility towards a specific service user, usually with responsibility for service provision and the monitoring of care. Usually the first point of contact for an individual.

L

Legal System (RM; Other REFINEMENT terms):

The legal status of a service.

Length of Stay (**LoS**) (RM; Other REFINEMENT terms):

Date of discharge minus date of admission + 1 (if admission day is included which is logic in the calculation of bed occupancy rate)

Line Item Budget (F; Payment Mechanisms):

The service provider gets a fixed lump sum for the whole service for a certain time period, usually one year, without flexibility for the service to transfer money between cost groups.

List System with a Gatekeeper Function (F; Payment Mechanisms):

A cost-containment system through which primary care physicians assume responsibility for managing the health needs of members of the population registered with their practice.

Living Independently (RQ; Quality of Care):

Living in a private residence being in charge of one's life for daily activities, including personal life, accommodation or employment. For living independently self-determination, self-respect and equal opportunities are key concepts.

Living Skills (RQ; Quality of Care):

The skills needed to perform everyday tasks and maintain one's independence.

Local Area (RM, RP; Other REFINEMENT terms):

See **Catchment Area**.

Local Authority(RM, Other REFINEMENT terms):

Local tier of government that has responsibility for ensuring the provision of publicly funded services in a specified geographical area. It may also have the power to collect taxes.

Local Health Authority (RM; Other REFINEMENT terms):

An organisation that is officially responsible for ensuring the provision of publicly funded health services and facilities (in a specified geographical area).

Long Term Care (RM-DESDE-LTC; Care and Treatment):

This is a blanket term that brings together a range of services for persons who are dependent on help with basic activities of daily living (ADLs) over an extended period of time. This range includes medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short or long-term and may be provided in a person's home, in the community, or in residential facilities.

Long Term Residential Care (F, Services Type):

This type of care is provided in a residential setting such as a nursing home where service users live rather than living in their own home or family home. Paid staff or volunteers (families and friends are usually not involved in this type of care) help service users with everyday activities.

M

Macro Area (Other REFINEMENT terms):

It is a geographical area selected as a reference area in terms of representativeness. It must include the study area and it is recommended to choose a macro area with a population between 1,500.000 and 10,000,000 inhabitants, this could be identified as a NUTS1 or NUTS2.

Main Type of Care (**MTC)** (RM-DESDE-LTC; Other REFINEMENT terms):

It is the major descriptor of the **BSIC** (see definition) in relation to its more relevant, general and meaningful activity or 'generic care function'. Six descriptor levels define the MTC according to the health status of the user (acute/non acute), the category, intensity and other specification of the care activity

Management (RM; Other REFINEMENT terms):

The term refers to the responsibility for and control of a company or organisation.

Meals on Wheels (RM; Services Type):

A service which provides nutritious meals usually at a nominal fee to people in their own homes who are homebound and/or disabled who otherwise would be unable to maintain their dietary needs.

Medical Institution (RM, RQ; Services Type):

See **Hospital.**

Medical Office (F, RP; RQ; Services Type): See
General Practitioner (**GP**).

Medication Management (RQ; Quality of Care):
The monitoring of the medications patients take to make sure the pharmacological therapy is appropriate and well followed. It is essential to ensure the patient avoids potentially dangerous drug interactions and other complications of his/her medication regimen.

Medium Intensity 24 Hours Physician Cover Hospital Service (RM-DESDE-LTC; Services Type):
Acute care facility with 24-hour physician cover in a health care facility where users are admitted due to a deterioration of their physical or mental state, behaviour or social functioning which is related to their health condition. Admissions are usually available within 24 hours and service users usually retain their own accommodation while admitted. This type of facility includes at least some secure beds and routine surveillance.

Mental Disorder (RP; Care and Treatment):
This is an umbrella term referring to many different disorders that affect the mind. These illnesses can be either non-psychotic (e.g. depression and anxiety) or psychotic (e.g. schizophrenia and bipolar disorder) or an organic brain disorder (i.e. a damage to brain tissue caused by diseases like dementia or alcoholism), a personality disorder (i.e. an enduring disturbance in the way a person interact with others) or an intellectual disability (e.g. a disability caused by problems with brain development).Generally speaking, a mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning.

Mental Health (RM; Other REFINEMENT terms):
The WHO defines mental health as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community. The positive dimension of mental health is stressed in WHO's definition of health as contained in its constitution: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

Mental Health Care (RM; Care and Treatment):
The provision of services, treatments, medications, programmes and all other health related actions aimed at maintaining and improving the emotional and mental wellbeing of people.

Mental Health Nurse (RQ; Services Type):
See **Psychiatric Nurse**.

Mental Health Outpatient Service (RP, F, RQ, RM; Services Type):
See **Outpatient Mental Health Service.**

Mental Health Patient (RP; Care and Treatment):
See **Mental Health Service User.**

Mental Health Plan (RM, RQ; Quality of Care):
The orderly process of defining mental health problems, identifying unmet needs and surveying the resources to meet them, establishing priority goals that are realistic and feasible, and projecting administrative action, concerned not only with the adequacy, efficacy and efficiency of mental health services but also with those factors of ecology and of social and individual behaviour that affect the mental health of the individual and the community.

Mental Health Policy (RM; Quality of Care):
A set of decisions or commitments, usually by national or local government, to pursue courses of action aimed at achieving defined goals for improving mental health, stating or inferring the values that underpin these decisions.

Mental Health Problem (RP; Care and Treatment):
See **Mental Disorder.**

Mental Health Service User (RP; Care and Treatment):
A person in contact with (mental) health services for a mental health problem.

Mental Health Specialist (RP; Services Type):
A mental health specialist is a person who has advanced training to work with those with mental illnesses and psychological issues. Examples are: Psychiatrist, psychologist, psychotherapist, clinical social worker, psychiatric nurse, etc.

Mental Hospital (RP, RQ; Services Type):
A specialist hospital for the care and treatment of people with acute or chronic mental illness.

Mental Illness (RP; Care and Treatment):
See **Mental Disorder.**

Mental Inpatient Care (F, RC; Services Type):
See **Inpatient Mental Health Care.**

Meso-organisation (RM; Services Type):
A care organisation which includes several services within the same location (i.e. a general hospital).

Met/Unmet Needs (RQ; Quality of Care):
Unmet need is defined as the lack of use of any formal health, social care and other appropriate services among individuals defining as having a need for care. Met need is the appropriate use of these services.

Mobile Care (F, RP; Care and Treatment):
See **Psychiatric Mobile Care**.

Mobile Clinic (F, RM-DESDE-LTC, RQ, RP; Services Type):
See **Mobile Mental Health Service.**

Mobile Mental Health Care (F, RP; Care and Treatment):
See **Psychiatric Mobile Care**.

Mobile Mental Health Service (F, RM-DESDE-LTC, RQ, RP; Services Type):
Health care and non-health care services that are delivered outside of hospitals or other ambulatory care facilities. Instead services may interact with patients in their own homes or in other settings in the areas in which they live. This for instance includes assertive outreach teams, social care provided at home and the like (EXAMPLES: Mobile outpatient service delivered at a patient home; Assertive outreach team (assertive community treatment); Home treatment team; Crisis resolution team, etc.).

Mobile Outpatient Service (F, RM-DESDE-LTC, RQ, RP; Services Type):
See **Mobile Mental Health Service.**

Monitoring Mechanism (RQ; Quality of Care):
The continuous oversight of an activity to assist in its supervision and to see that it proceeds according to plan. Monitoring involves the specification of methods to measure activity, use of resources, and response to services against agreed criteria.

Mortality Rate (RQ; Quality of Care):
The frequency of occurrence of death in a defined population over a specified time period. See also **Standardised Mortality Rate.**

Multidisciplinary Team (RP, RM; Services Type):
A group of health, social care and other professionals who work in a coordinated fashion toward a common goal for people with mental health needs.

Multi-modal Treatment (RP, RQ; Care and Treatment):
Type of treatment which combines multiple techniques or co-operation between multiple organisations providing different services.

Multiprofessional Team (RP, RM; Services Type):
See **Multidisciplinary Team.**

Municipality (RM; Other REFINEMENT terms):
A political unit like a city, a town or a district with its own local government.

N

National Health System (RM; Other REFINEMENT terms):

The publicly funded health care system of a nation.

Need (RQ; Quality of Care):

Need is based on the population's ability to benefit from care including broad domains of health and social functioning, which are necessary to survive and prosper in the community. A need covers all aspects of an individual's life and mental wellbeing – for example accommodation, daytime activities, management of physical and mental health symptoms of poor health, childcare, money, psychosocial distress, and personal relationships.

Needs-linked/related System (F; Payment Mechanisms):

As with diagnosis related activity based payment except that payments are made usually for patients with similar levels of need, even though they may have different primary diagnoses.

Negative List (of pharmaceuticals) (F; Payment Mechanisms):

A specified list of drugs, technologies and health care procedures which in normal circumstances are not covered by the publicly funded health care system. This might for instance cover some forms of cosmetic surgery or in vitro fertilisation. These products are usually only available privately. They may be covered by voluntary health insurance.

Neuromodulation Treatment (Care and Treatment):

Biological, non-pharmacological therapies that involve the stimulation of various nerves in the central nervous system, such as electroconvulsive therapy (ECT), transcranial magnetic stimulation (TMS), transcranial direct current stimulation (tDCS), deep brain stimulation (DBS), and vagus nerve stimulation (VNS).

Non Acute Psychiatric Care (RQ; Care and Treatment):

All types of psychiatric care (home health care, hospice, extended care, respite, rehabilitation, nursing facility, residential care, long-term care, geriatric care, adult day care etc.) which are addressed to patients with chronic mental health conditions.

Non-Governmental Organisation (**NGO**) (RM; Other REFINEMENT terms):

Any non-profit organisation that is recognised within local law. Many NGOs provide health and social care services; some advocate or lobby policymakers and other actors to improve service of provision and outcomes for their interest groups.

Non-health Care Service (F, RM; Services Type):

Services that are not funded or provided by public health care systems.

Non-health Service (F, RM; Services Type):

See **Non-health Care Service.**

Non-medical Service (F, RM; Services Type):

See **Non-health Care Service.**

Non-specialist Health Care (RM; Care and Treatment):

See **General Health Care.**

Nursing Home (RM; Services Type):

An institution providing residential care to people requiring continual (usually 24 h) nursing care and having significant difficulties in managing their daily living activities. Physical, occupational and other rehabilitation activities are provided within this setting which can be run publicly and/or privately.

O

Occupancy Rate (RQ; Quality of Care):

The average rate of bed occupancy in a hospital or residential service. This is usually calculated by multiplying the total number of beds available by the number of days in the year that these beds are available (usually between 300 and 350 days a year).

Occupational Health Care (RM; Care and Treatment):

Medical discipline focused on sustaining and promoting the health and ability to work of the population.

Occupational Medicine (RM; Care and Treatment):

See **Occupational Health Care.**

Occupational Health Services (RM; Care and Treatment):

See **Occupational Health Care.**

Occupational Therapy (**OT**) (RM, RQ; Services Type):

Occupational therapy is defined in the English National Health Service as the assessment and treatment of physical and psychiatric conditions using specific activities to prevent disability and promote independent function in all aspects of daily life. Occupational therapists work with people of all ages to help them overcome the effects of disability caused by physical or psychological illness, ageing or accident.

On-site Mental Health Worker (RP; Services Type):

Mental health specialists working in primary health care settings. Examples: Psychologists, counsellors, psychotherapists, mental health nurses, etc.

Other health or mental health worker (RM; Services Type):

Health or mental health worker possessing some training in health care or mental health care but not fitting in any of the defined professional categories (e.g. medical doctors, nurses, psychologists, social workers, occupational therapists). This definition includes non-doctor/non-nurse primary care workers, professional and paraprofessional psychosocial counselors, special mental health educators and auxiliary staff. It excludes general staff for support services within health or mental health care settings (e.g. cooking, cleaning staff, security).

Outcome Assessment (RM; Quality of Care):

The formal process of evaluation - preferably quantitative, but sometimes necessarily qualitative of interventions to achieve health and/or other outcomes. In the case of mental health, for example, it could evaluate the impact of interventions provided by the mental health system, the facilities and personnel that recommend them and the actions of those who are the targets of the interventions.

Outpatient Care (RM-DESDE-LTC, RP, RQ; Care and Treatment):

Care provision typically (i) involves contact between staff and consumers for some purpose related to management of their condition and its associated clinical and social difficulties and (ii) are not provided as a part of delivery of residential or day services.

Outpatient Facility (RP, F, RQ, RM; Services Type):

See **Outpatient Mental Health Service.**

Outpatient Mental Health Service (RP, F, RQ, RM; Services Type):

Setting in which mental health services are provided on an outpatient basis, without overnight stay - either mobile (when the facility is capable of being moved to different locations) or fixed (when the person seeking care must travel to a fixed service site). There is contact between staff and service users for some purpose related to management of their condition and its associated clinical and social difficulties. These services are not provided as a part of delivery of day care services; and they have at least some qualified health care professionals as staff members.

Outpatient Mental Health Visit (RQ; Services Type):

A meeting for treatment between a mental health care professional and a service user either on the premises of an outpatient service or another location, including a service user’s home, in the case of mobile services.

Outpatient Service Contact (RQ; Services Type):

The count of the times a patient comes into contact with an outpatient service. Each contact is differentiated, i.e. counted once, which means that the same user of a service can report a higher number of contacts to that same service.

Out of pocket payment (F, Payment Mechanisms):

A charge that individuals must pay personally for the use of a service sometimes at the point of service and sometimes at a later point in time. In some cases a proportion or all of the out of pocket payment can be reimbursed. Out of pocket payments can take different forms, they can be a fixed fee or proportional to the total costs of the service received. There may also be ceiling on the maximum level of out of pocket payments in a defined time period**.** In the case of long stay residential care, especially care provided outside of the health sector, there may be substantial regular out of pocket payments for care, often charged by the week or month.

Owner of the Service (RM; Services Type):

The company, person or organisation that possesses the exclusive right to hold, use, convey, transfer and dispose of a service. This party can be either public or private.

P

Pathway of Care (RP; Care and Treatment):

A pattern of service utilisation with at least two service contacts in an observable sequence.

Patient Turnover (RP, Care and Treatment):

The number of hospital discharges from the ward, specialty, hospital, area, or region expressed as a percentage of the total beds available over a specified time period (often one year).

Patient Centredness (RQ; Quality of Care):

The degree to which the patient/user is placed at the centre of the delivery of services.

Payment Mechanism (RM, RP; Payment Mechanisms):

Different approaches to paying for goods and services.

Performance Assessment (RQ; Quality of Care):

A procedure to evaluate the quality of a service along one or more dimensions.

Performance Related Payment (RP; Payment Mechanisms):

This term covers a number of different payment mechanisms that reward service providers for the achievement of specific goals . These tend to be related more to the level of throughput rather than to achievement of specific clinical (or broader) quality related outcomes. It is rarely the dominant payment mechanism but a supplementary payment mechanism. Performance related payment mechanisms can include target payments; i.e. models where income is (partly) related to the provider reaching certain predefined targets and relative target payment; i.e. models where providers compete for a limited reward based on their internal rank. Some performance related payment schemes will also impose penalties for “underachievement”; i.e. models where payment is withheld or even deducted when providers do not meet specific performance targets.

Period of Involuntary Status (RP, RQ; Care and Treatment):
See **Involuntary Status.**

Personal Budget (F, RM; Payment Mechanisms):
See **Consumer Directed Payment.**

Phase Level (RQ; Quality of Care):
It defines at which stage an indicator of mental health is: input or process or outcome. It is useful to measure the quality of care.

PHC Doctor (F; Services Type):
See **General Practitioner.**

Physical Health Review (RQ; Care and Treatment):
See **Review of Physical Health.**

Pooling (F; Payment Mechanisms):
Accumulation of prepaid revenues on behalf of a defined population. In most EU countries publicly collected funds for health tend to be pooled at national level, but there may be multiple pools when funds are also collected at sub-national level. Social health insurance funds may also have to pool their resources or participate in risk equalisation procedures to transfer money to those insurance funds whose members may have more risky profiles or who have lower levels of income due to the lower income of their members.

Positive list (of pharmaceuticals) (F; Payment Mechanisms):
Specified list of drugs, technologies and health care procedures that will be covered by publicly funded health care systems. Products not on the list in some cases will not be reimbursed by tax or social insurance funded systems. They might though be covered by voluntary health insurance. Positive lists are most often seen in countries with social health insurance schemes.

Postgraduate Medical Education RP; Services Type):
See **Postgraduate Medical Training.**

Postgraduate Medical Internship (RP; Services Type):
See **Postgraduate Medical Training.**

Postgraduate Medical Residency (RP; Services Type):
See **Postgraduate Medical Training.**

Postgraduate Medical Training (RP; Services Type):
Period of supervised practice which newly graduated doctors are required to undertake

before full registration is granted.

Practical Aid (RM, F; Services Type):
See **Domiciliary Care.**

Preauthorisation Requirement (RP; Payment Mechanisms):
Individuals must obtain prior authorisation from the relevant national or regional authority before they can guarantee that they can receive public funds for the utilisation of certain services.

Predictor Variable (RP; Quality of Care):
See **Influencing Factor**.

Prevention, primary (Services Type):
Actions both within and outside of health care systems that are designed to prevent the occurrence of disease and to promote health. These interventions often are targeted at the general population.

Prevention, secondary (Services Type):
Preventive actions both within and outside of the health care system that are targeted at individuals already identified to be at high risk of injury or disease.

Prevention, tertiary (Services Type):
Preventive actions, mostly delivered within the health care system, that are targeted at individuals already living with a health problem or injury. The objective is to reduce the risk of further disease related deterioration.

Primary Care Doctor (F; Services Type):
See **General Practitioner.**

Primary Care Physician (F; Services Type):
See **General Practitioner.**

Primary Health Care (F; Care and Treatment):
While used in different ways in different health care systems health medical care is often the first level of contact people have with the health system in relation to their health. In many countries it is used to refer to primary medical services such as general practitioner or family practice services provided by primary care physicians, nurse-practitioners (nurses with some prescribing powers) and practice-based colleagues such as nurses and physiotherapists. More broadly it can also refer to other community based services such as dentists, opticians and podiatrists.

Primary Medical Care (F; Care and Treatment):
See **Primary Health Care** (**PC).**

Private Health Insurance (Payment Mechanisms): See **Voluntary Health Insurance.**

Private for Profit (RM; Other REFINEMENT terms):
Established by an individual or a private association with the intention of making a profit, i.e. making money.

Private not for Profit (RM; Other REFINEMENT terms):
Legal entities that do not make profits; they are usually not subject to corporation tax and all financial surpluses of their activities are either reinvested in the service or used for charitable activities.

Process Level (RQ; Quality of Care):
Level of care such as the consumer's interaction with the healthcare system which includes technical and interpersonal components of care. It represents a range of actions which take place in the delivery of mental health care.

Prospective Payment (F; Payment Mechanisms):
Any system of providing funds to health care service providers in advance of any services being delivered.

Provider of Care (RM; Services Type):
See **Care Provider.**

Protection from Discrimination (RQ; Quality of Care):
A legislative provision to avoid any dismissal or lower wages or lack of success in obtaining a job, as well as participation in other activities, such as education or politics for people living with health problems or other risk categories for discrimination such as age, gender or ethnicity.

Psychiatric Ambulatory Care (RM; Services Type):
Same day care and support that does not involve an overnight stay.

Psychiatric Centre (F; Services Type):
A legal entity where mental health care services are concentrated. In this place a psychiatrist is usually available for medication management and a psychologist for testing and oversight. Other mental health professionals also provide help for service users.

Psychiatric Day Care (RM; Care and Treatment):
Day care specifically focused on people with mental health needs. See **Day Care** and **Day Hospital** for more on these services.

Psychiatric Department (F, RM ; Services Type):
A psychiatric department or ward which is an integral part of a general hospital that provides

services for people with many different physical and mental health needs. The department or ward can be a division or floor or room inside a hospital or attached to it. Some of these hospitals will be part of universities and will provide clinical education and training as routine; non-university hospitals may not provide education and training.

Psychiatric Hospital (RP, RQ; Services Type):

See **Mental Hospital**.

Psychiatric Mobile Care (F, RP; Care and Treatment):

Mental health services which are not delivered at a mental health centre but instead delivered in many other locations in the community, including in a service user's home.

Psychiatric Mobile Service (F, RM-DESDE-LTC, RQ, RP; Services Type):

See **Mobile Mental Health Service.**

Psychiatric Nurse (RQ; Services Type):

A professional with at least a diploma in psychiatric nursing who caters to the needs of patients with learning or mental disorders. (S)he evaluates the needs of the patients, assisting and coordinating with doctors to ascertain the best treatment.

Psychiatric Outpatient Service (RP, F, RQ, RM; Services Type):

See **Outpatient Mental Health Service.**

Psychiatric Patient (RP; Care and Treatment):

See **Mental Health Service User.**

Psychiatric Practice (RP; Services Type):

Single-handed practice or group practice of one/several physician/s that are registered to practice psychiatry.

Psychiatric Service (FB; Services Type):

Any service providing approved programmes designed to assist recovery and manage mental illnesses. A psychiatric service can be mobile or not mobile, inpatient or outpatient, for emergencies or residential, long- or short-term. It can be provided in a person's home, in the community, in a hospital etc.

Psychiatrist (RM; Services Type):

A medical doctor who has received a university post-graduation in psychiatry with at least two years training in psychiatry.

Psychiatrist in Training (RM; Services Type):

A graduated physician spending at least two additional years in psychiatry residency learning the diagnosis and treatment of mental health.

Psychologist (RC; Services Type):

Generally, a graduate professional having received education and training from a university-level school of psychology. That of psychologist is a broader concept than clinical or therapist since a psychologist can be trained in organizational, occupational, educational, social, developmental etc. Whereas psychologists especially trained in clinical psychology are called clinical psychologists. However, in some countries, like Austria, psychologists are not allowed to practice psychotherapy without special training and psychotherapists do not need a degree in psychology.

Psychopharmacological Therapy (RP; Services Type):

Use of psychoactive drugs in the treatment of mental illness.

Psychosocial Problem (RQ; Care and Treatment):

Any problem related to one's psychological development in and interaction with a social environment. It could refer to the lack of development or atrophy of the psychosocial self, often occurring alongside other physical, emotional or cognitive dysfunctions.

Psychotherapist (RC; Services Type):

Either a psychiatrist, a psychologist, a psychiatric nurse or a psychiatric social worker practicing psychotherapy, i.e. the treatment of mental health problems through talking and counselling and other psychological techniques designed to encourage communication of conflicts and insight into problems. In some countries, e.g. Austria, psychotherapists do not need a degree in psychology.

Public (RM; Other REFINEMENT terms):

Services that are funded through taxes or other public financing resources like social health insurance.

Public Corporation (RM; Services Type):

A company where the majority of shares are owned by national or local government.

Publicly Funded Health and Social Care Services (F; Payment Mechanisms):

Services that are paid for by government from taxes or by funds collected by social health insurance.

Q

Quality Dimension (RQ; Quality of Care):

A feature of the mental health system, i.e. a measure to be used as an indicator of the quality of care in mental health services.

Quality of Care (RQ; Quality of Care):

A multidimensional construction described as the structural characteristics of healthcare organisation inputs; processes of care and outcomes of care. Quality of care is then the balance across input-process-outcome.

Quality of Life (**QoL**) (RQ; Quality of Care):

A multidimensional concept given by physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity. It is influenced by the interaction of objective life conditions, subjective feeling of wellbeing, and personal values and aspirations.

R

Readmission (RP, RQ; Care and Treatment):

A hospital admission that occurs within a specified time frame after discharge from the first admission.

Real Potential Users (RM; Other REFINEMENT terms):

The total population in the Study Area, excluding those who cannot benefit from specific services for reasons of age, gender, residence etc.

Re-approval of Involuntary Status (RQ; Care and Treatment):

The re-confirmation of the detention of a patient in a mental health facility according to the state law and procedures for a further period of time.

Recommendation (RQ; Quality of Care):

Any formal advice like regulations or protocols by health authorities for best practice and improved provision of care.

Record (RQ; Other REFINEMENT terms):

An account of a specific event (like, for instance, admission to a hospital) written in official registers.

Recovery (RM; Care and Treatment):

In mental health it is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is defined by 8 fundamental components: hope; medication/treatment; empowerment; support; education/knowledge; self-help; spirituality; employment/meaningful activity.

Referral (RP, RQ; Care and Treatment):

An authorisation from a medical profession to another medical facility or professional in the health and /or social care system. In gatekeeping system a referral is usually required from primary care doctors in order to access publicly funded specialist services.

Registered Charity (RM; Services Type)

A registered charity is a not for profit organisation, usually exempt from taxation, which may have been established by endowment, but which also raises revenue from ongoing donations, the sale of merchandise and the provision of services for public authorities. The term is most commonly used in the UK and Ireland, as well as in countries that have close connections to the UK. See also **Foundation.**

Rehabilitation (RQ; Care and Treatment):

It refers to all services which are a part of a programme aimed at enhancing social skills, facilitating integration into working life and developing independent living skills after an illness or an injury.

Rehabilitation Plan (RQ; Quality of Care):

An individual plan developed by a mental health care professional together with the patient to enhance her/his rehabilitation processes and personal recovery. It can include coordinated approaches by both government and non-government agencies and encompass clinical, psychosocial, vocational, physical and substance addiction aspects, according to patients' need.

Rehabilitative Care (RM; Care and Treatment):

The recovery from an illness or brain damage through specialised healthcare dedicated to improving, maintaining or restoring cognition to full, normal functions.

Rehospitalisation (RP, RQ; Care and Treatment):

See **Readmission.**

Reimbursement (RP; Payment Mechanisms):

Act of compensating someone for an expense incurred. Health care service providers may for instance be reimbursed by government or social health insurers for services providers. In some cases out of pocket payments by service users may also be reimbursed by government or insurance companies.

Relapse (RQ; Care and Treatment):

Regression after partial recovery from illness.

Remuneration (RP; Payment Mechanisms):

Payment or compensation received for the provision of a service.

Rescue Service (RQ; Services Type):

See **Emergency Service**.

Residential Care (RM-DESDE-LTC, RP, RQ; Care and Treatment):

Care provision of beds overnight for patients for a purpose related to the clinical and social management of their care needs -patients are not intended to sleep there solely because they have no home or are unable to reach home.

Residential Facility (F, RQ; Services Type):

A place where a group of people with mental health problems reside in a community setting. This live-in institution is licensed by or under an official authority and includes: room and board, supervision, support services and nursing care. Custodial care is also provided and a professional trained staff supervise the facility at least once a day.

Resource Allocation Formula (F, RM; Payment Mechanisms):

An approach to the distribution of pooled funds to service commissioners taking account of different potential indicators of need. For instance a formula might include weighted capitation payments adjusted for additional needs including morbidity, social deprivation and the unavoidable excess costs of providing health services in different geographical areas.

Resource Allocation Mechanism (F, RM; Payment Mechanisms):

See **Resource Allocation Formula.**

Responsiveness (RQ; Quality of Care):

The way a health system facilitates people to meet their legitimate non-health expectations.

Retrospective Payment System (F; Payment Mechanisms):

A cost reimbursement contract where the provider's own real costs are fully or partially reimbursed some time after the service has been delivered.

Review of Physical Health (RQ; Care and Treatment):

A review of mental health patients taking into account physiological conditions and lifestyle choices (smoking, diet and physical activity). This examination is aimed at excluding or stabilising problems which are physical in origin.

Risk Equalisation (F; Payment Mechanisms):

It involves payments by health insurers with lower risk members to health insurers with higher risk members. In broad terms, this is a mechanism to spread some of the claims costs of high risk members amongst all health insurers in the market in proportion to their market share. Risk equalisation is a common mechanism in countries with community rated health insurance systems. See also **Community Rated Insurance.**

Risk Rated Insurance (FA; Payment Mechanisms):

The calculation of insurance premiums according to the risk profile of an individual. This can take into account several factors such as age, gender and pre-existing medical conditions.

S

Safety (RQ; Quality of Care):

Dimension where the system has the right structure, renders services and obtains results in ways that prevent harm to the user, provider or environment.

Salary (F, RC; Payment Mechanisms):

Employees are paid a set wage for working for a set period of time. Remuneration is independent of volume of work done. Employees work within defined hours specified in contracts. Salaries may be negotiated at local level, but often are negotiated at a national level by budget holders. Overtime payments may also be made. In some cases contracts allow extra income to be earned through second jobs and private work after hours work.

Satisfaction of Care (RQ; Quality of Care):

See **Service User Satisfaction**.

Satisfaction with Services (RQ; Quality of Care):

See **Service User Satisfaction**.

Seamless Care (RC, RP; Care and Treatment):

See **Integrated Care.**

Seclusion (RQ; Quality of Care):

The supervised confinement of a mental health service user in a room, which may be locked. Its sole aim is to contain severely disturbed behaviour which is likely to cause harm to others.

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

See **Secondary Health Care.**

Secondary Care Service (F, RC; Services Type):

See **Secondary Mental Health Care Service.**

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

Medical care provided by a specialist or facility that requires more specialist knowledge, skill, or equipment than available in primary care.

Secondary Mental Health Care Service (F, RC; Services Type):

A specialist mental health service including psychiatric hospitals, psychiatric wards within general hospitals and community mental health services based more locally. These services can provide any combination of inpatient and outpatient care offering a range of treatments like psychiatric drugs but also therapy and counselling. Their staff include psychiatrists, psychiatric nurses, clinical psychologists, social workers, therapists and counsellors.

Sectorisation (RM; Other REFINEMENT terms):

Establishment of a catchment area where services are provided for all residents. For instance, there will be specific mental health service structures responsible for providing mental health services to everyone in the catchment area.

Self-help & Voluntary Care (RM-DESDE-LTC; Services Type):

Its main aim is to provide users with self-help or contact, with unpaid staff that offers **accessibility**, **information**, **day**, **outpatient** and **residential care** (see definitions).

Self-referral (RP; Services Type):

Individuals who refer themselves directly to a facility, institution or specialist in the health and social care system.

Serious Mental Illness (RP, RQ, RM; Care and Treatment):

See **Severe Mental Illness** (**SMI**).

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.

Service outside the Health Care System (F, RM; Services Type):

See **Non-health Care Service.**

Service User (RM, RQ; Other REFINEMENT terms):

The term ‘service user’ is often used as an alternative to the use of the word patient when speaking about people with mental health problems who are in receipt of services. The term patient is seen as too ‘passive’, implying that individuals do not have a say over any treatment and support they receive. It has there been seen to be politically inappropriate by service user groups and many mental health professionals.

Service User Engagement (RP; Quality of Care):

Different mechanisms that facilitate discussions between services users and professional services. This may for instance help service users to have a greater say over any planned care.

Service User Satisfaction (RQ; Quality of Care):

The level of satisfaction expressed by the users of a service.

Services Inventory (RM ; Services Type):

A list of services, organised into BSICs by their MTCs, for a specified geographical area. The inventory includes address, number of staff, opening times, users and contacts registered in a year, type of care provided etc. Services are coded through a specific classification tool. See also **BSICs** and **MTC.**

Service Mapping (RM; Services Type):

Service mapping is an instrument for a standardised description and classification of services within a defined geographical area. When mapping services, the different levels of service provision are also categorised. A visual representation of results can be given by plotting services on a map to indicate their spatial distribution.

Severe Mental Illness (**SMI**) (RP, RQ, RM; Care and Treatment):

SMI is usually defined as a psychotic or major affective disorder. It can also cover other disorders that lead to chronic disability. It can include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD) and borderline personality disorder. SMI have recurrent functional limitations on major life activities. The definition of SMI may take account of duration of illness and intensity of service utilisation (EXAMPLE: To enable data collection and country comparison, in RP SMI is only defined by the diagnosis of schizophrenia or bipolar disorder).

Shared Care (RQ; Care and Treatment):

See **Cooperative Care**.

Sheltered Employment (F, RQ; Services Type):

See **Vocational Rehabilitation Service.**

Single-handed (F, RC, RP; Services Type):

A service that is run by just one physician, although it may have other medical professionals, e.g. a single-handed GP practice would have just one primary care doctor, but could also have several practice nurses etc.

Social Care (RM, F; Care and Treatment):

Social care covers a wide range of services to help people live independently. It can include services provided in people's homes to help them with everyday activities of daily living as well as the provision of day services that individuals can choose to attend. Services are often funded and provided by local government or contracted to not for profit or for-profit organisations. See also **Social Welfare** and **Social Services.**

Social Services (RM; Services Type):

A wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable situations and manage complex relationships. This covers social care services, but also other activities such as providing support to local communities and monitoring the safety of vulnerable people, such as children and older people. In some situations social services will be synonymous with social welfare services also providing final support, help with accommodation and education etc. See also **Social Care** and **Social Welfare.**

Social Firm (RM; Services Type):

A business created for the employment of people with a disability or disadvantage in the labour market.

Social Functioning (RQ; Quality of Care):

The ability to interact in the normal or usual way in society.

Social Health Insurance (F; Payment Mechanisms):

A social health insurance system is one where the policy-holder is obliged or encouraged to insure by the intervention of a third party (usually government). Social health insurance has two crucial characteristics. Firstly, the insured pay regular, usually wage-based (i.e. not related to risk) contributions. Secondly, independent quasi-public bodies usually act as the main managers of the system and as third party payers. Under certain conditions non-employed or self-employed people may also be covered.

Social Welfare Services (F; Services Type):

This term can cover many different services that provide financial and other support to individuals usually on the basis of entitlement (e.g. unemployment benefit) or need (housing assistance, help to find employment, rehabilitation etc). It can be provided directly by national or local government, but may be provided by the for profit and not-for-profit sectors under contract to the statutory authorities. Social care services can be considered as one type of social welfare service. See also **Social Care.**

Social Worker (RM, RQ; Services Type):

A professional with a graduate level qualification in the field of social work.

Soft Gatekeeping (F; Services Type):

Soft gatekeeping restricts the choice of specialists by voluntarily encouraging individuals to register with a primary care doctor or practice. 'Soft' gatekeeping is a term that has arisen within the context largely of some countries (France, Germany) where insurance systems are significant and where traditionally there has been a large degree of freedom of choice of providers. 'Soft' gatekeeping has been seen as providing the possibility for individuals to voluntarily choose to be subject to gatekeeping arrangements. There are usually financial or other incentives for the individual to make this choice. This is the case in France where voluntarily choosing a general practitioner (although in theory it could be a specialist rather than a GP). If an individual does not choose soft gatekeeping the rate of reimbursement is lower. In the French example there are also financial penalties if an individual who has chosen the soft gatekeeping option decides to visit a specialist without a referral. Well over 90% of the public have now chosen this option since the French scheme was introduced in 2005. See also **Gatekeeping.**

Single-handed (F, RC, RP; Services Type):

See **Single-handed.**

Specialist (F, RQ; Services Type):

See **Specialist Physician**.

Specialist Outpatient Service (RP, F, RQ, RM; Services Type):

See **Outpatient Mental Health Service.**

Specialist Stand-alone Outpatient Centre (F, RC; Services Type):

See **Stand-alone Outpatient Service**.

Specialized Outpatient Service (RP, F, RQ, RM; Services Type):

See **Outpatient Mental Health Service.**

Specialized Psychiatric Outpatient Service (RP, F, RQ, RM; Services Type):

See **Outpatient Mental Health Service.**

Staff Continuing Education (RQ; Quality of Care):

Education and training of staff to maintain the currency of their skills and qualifications. Local entities generally provide assistance in support of lifelong learning and continuing professional development.

Staff Morale (RM, RQ; Quality of Care):

The tone or spirit of mood of employees in any workplace. Good employee morale refers to a situation when most employees are well motivated and happy with the job that they do.

Stakeholder (RM; Other REFINEMENT terms):

Individuals or organisations that are affected by the actions of an organisation in which they have an interest. For example, the local community are stakeholders affected by the performance of their local health system. Other stakeholders can include service users and their families, service funders, the government, insurers, health and social welfare professionals etc.

Standardised Mortality Rate (RQ; Quality of Care);

The **Standardised Mortality Rate** can be expressed as the ratio of observed deaths in a specified population to expected deaths if the mortality was equal to that of the general population.

Stand-alone Outpatient Centre (F, RC; Services Type):

See **Stand-alone Outpatient Service**.

Stand-alone Outpatient Service (F, RC; Services Type):

An outpatient service which operates independently from other services and facilities. See also **Outpatient care**.

Stand-alone Psychiatric Facility (F; Services Type):

Establishment devoted firstly to the treatment and care of inpatients and outpatients with both acute and long term psychiatric disorders.

Stigma (RP, RQ; Quality of Care):

The assignment of negative perceptions to an individual because of perceived difference from the population at large; it may occur on the basis of many factors including race, age, disability or disfigurement, gender, sexual orientation, religion, mental or physical illness.

Stigma Campaigns (RQ; Quality of Care):

A campaign promoted to address the social stigma associated with mental illness. It can include many different activities such as different types of advertising campaigns, public events, radio and television programmes, sponsorship activities at sporting events etc, better inclusion of people with mental health problems, lobbying of politicians and arguing for anti-discrimination measures.

Stigmatisation (RP, RQ; Quality of Care):

See **Stigma**.

Study Area (Other REFINEMENT terms):

A discrete area within a project boundary in which mapping of services actually takes place. Study Areas should be delineated to logically group samples together, generally based on habitat or population stratification and/or logistical concerns. It preferably has a population between 200,000 and 1,500,000 inhabitants and should cover health district or a municipality (or have other administrative boundaries) served by a defined range of health services.

Substance Misuse (RQ; Care and Treatment):

The harmful use of substances (like drugs and alcohol) for non-medical purposes.

Suicide (RQ; Quality of Care):

It is defined as a death caused directly by intentional self-harm, including purposely self-inflicted poisoning or injury. It is sometimes used as an indicator of outcome of the quality of care of a health system or as one indicator of population health. The suicide rate may in particular be used as an indicator of the performance of mental health systems.

Support Model (RQ; Quality of Care):

A model to support people with mental health problems to return to employment. It is based on the concept that before it is necessary to be carefully trained on a range of skills so that people with mental health problems can handle real-world situations and afterwards be placed in work.

Supported Employment (FA, RQ; Services Type):

It refers to both the development of employment opportunities and on-going support for those individuals to maintain employment on the open labour market. It can provide assistance such as job coaches, assistive technology, specialist job training and individually tailored supervision (EXAMPLE: Supported employment programs).

Supported Housing (RQ, RM; Services Type):

Support for independent housing can take different forms including houses or flats for one or more people without any on-site support, or blocks of houses or flats for single or shared use with an on-site manager or support worker providing support. In some cases residence will be time limited while in other instances it will be seen as a potential permanent dwelling.

Survey Data (RQ; Other REFINEMENT terms):

Data collected through survey methods and especially used for statistical analyses. They can be either personal or general, referring to individuals or to services for example.

Symptom (RQ; Care and Treatment):

A symptom is a subjective evidence of a disease whereas a sign is objective evidence. Only the patient can perceive it whereas a sign is apparent to the patient, the doctor and all the others.

T

Target Payment (**TAR**) (F; Payment Mechanisms):

See **Performance Related Payment**.

Tax Generated Revenue (F; Payment Mechanisms):

Income received by national and/or local government from any form of taxation of individuals or business.

Tax Revenue (F; Payment Mechanisms):

See **Tax Generated Revenue**.

Tele-assistance (RM; Services Type):

A service supporting people in their own home by using information technology systems, for instance to monitor their health status It can be used to allow professionals to remotely assist each other, e.g. when a doctor remotely assists another doctor carrying out a medical or surgical act, or in assessing images, even within the framework of an emergency. Other examples include remotely assisting a first-aid worker or any person providing medical assistance to someone in danger while waiting for the arrival of the doctor.

Telecare (RM; Services Type):

See **Tele-assistance**.

Telehealth (RM; Services Type):

See **Tele-assistance**.

Tertiary Health Care (RP; Care and Treatment):

Tertiary care is specialised consultative health care, usually for inpatients and on referral from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment.

Timeliness (RQ; Quality of Care):

The degree to which care is provided within the most beneficial or necessary time window.

Tool (Other REFINEMENT terms):

Any device or instrument to help perform an activity.

Toolkit (Other REFINEMENT terms):

A set of tools, such as a collection of information, resources, and advice for a specific subject area or activity, designed to be used together or in isolation for a particular purpose.

Train-and-Place Model (RQ; Quality of Care):

See **Support Model**.

Training Activity (RQ; Quality of Care):

Training of professionals according to evidence-based practices and the needs of the target population. In the case of REFINEMENT the focus has been on mental health-related training activities.

Trans-institutionalization (RM; Quality of Care):

Process through which the mentally ill are alternately and repeatedly routed between the mental health and criminal justice systems, i.e. from psychiatric hospitals to penal institutions. This process sees the increase of mentally ill in prisons followed by the reduction of mental hospital beds. It may also refer to the transfer of patients previously found in large mental hospitals to other "institutionalized" settings.

Travel Time to Service (RP; Quality of Care):

One-way travelling time by car between place of residence and place of service delivery.

U

"Under the table" Payment (F; Payment Mechanisms):

See **Informal Payment.**

Undetermined Intent (RQ; Quality of Care):

An indicator for cause of death used in mortality statistics for deaths from events where it is not clear if death was self-intentional. A proportion of these deaths will be from suicide.

User Charge (F; Payment Mechanisms):

See **Out of pocket payment.**

User Involvement (RP; Quality of Care):

See **Service User Engagement**.

Utilisation Rate (RQ, Quality of Care):

The percentage of the capacity (in terms of maximum number of potential users) of a service that is actually used (in terms of total real users) over a specific period of time. This percentage shows the relationship between the potential output of a service and its actual use.

V

Vocational Rehabilitation Service (F, RQ; Services Type):

A service to enhance and support people with long term health problems and disabilities to prepare for, obtain or return to employment. It can take many different forms. For example, a vocational rehabilitation counsellor helps the user throughout all this process by understanding the abilities, strengths, priorities and capabilities of the user.

Vocational Care (F, RQ; Services Type):

See **Vocational Rehabilitation Service.**

Voluntary Care (RM; Care and Treatment):

Unpaid services which are nonetheless provided by a non-profit and non-governmental organisation. Service provider does not receive public funding for the several social activities provided (e.g. visiting inpatients, working alongside the emergency services and providing support for disabled and sick people). Staff are unpaid and on a free voluntary basis. The aim of voluntary care facilities is to provide users with mental health need, with support, self-help or contact. There could exist in some countries voluntary organisations which are contracted and paid to provide services.

Voluntary Health Insurance (**VHI**) (F; Payment Mechanisms):

Health insurance that is taken up and paid for at the discretion of individuals or employers on behalf of individuals. VHI can be offered by public and quasi-public bodies and by for profit (commercial) organisations and non-profit private organisations. VHI may substitute for cover that would otherwise be available from the state, provide complementary cover for services excluded or not fully covered by the state (e.g. cover for co-payments) or provide supplementary cover for faster access and increased consumer choice.

Voucher (F; Payment Mechanisms):

A virtual or physical bond with a defined monetary value that can be exchanged for specific goods and services. Examples include vouchers that can be used to pay for training courses or for additional help at home.

W

Waitingtime for regular service appointment (RP; Quality of Care):

Time between appointment scheduling and service provision.

Ward in General Hospital (F, RM ; Services Type):

See **Psychiatric Department.**

Work Integration Social Enterprise (**WISE)** (RM; Services Type):

See **Social Firm**.

Worker Morale (RM, RQ; Quality of Care):

See **Staff Morale.**

Work-related activity (RM-DESDE-LTC; Quality of Care):

A facility 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.

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INDEX

3. FIL SANTE JEUNES QUESTIONNAIRE

Des infos SANTE pour les jeunes • Enquêtes • Ta santé et ton bien être sur in

Ta santé et ton bien être sur internet

Jeudi, 07 Mars 2013 16:57

Ta santé et ton bien-être sur Internet

Internet est-il pour toi un outil pour obtenir des informations ou des conseils sur ta Santé et ton bien-être ? Préfères-tu lire des documents ou des pages pour te renseigner ou recherches-tu plutôt un soutien dans les forums ou en parlant avec les autres ?

En répondant aux questions suivantes, tu nous aideras à comprendre quels sont les instruments les plus efficaces pour donner une solution à tes questions sur la santé et le bien-être.

Merci pour ta participation !

✱1. Age :

✱2. Sexe :

○ Fille
○ Garçon

✱3. Tu es :

○ Ecolier
○ Collégien
○ Lycéen
○ Etudiant
○ Apprenti /Stagiaire
○ Salarié

Mise à jour le Lundi, 11 Mars 2013 11:27

Ta Santé et ton bien-être sur Internet

Internet est-il pour toi un bon outil pour obtenir des informations ou des conseils sur ta Santé et ton bien-être ? Préfères-tu consulter Internet plutôt que voir un médecin ? Préfères-tu lire des documents ou des pages pour te renseigner ou recherches-tu plutôt un soutien dans les forums ou en parlant avec les autres ?

En répondant aux questions suivantes, tu nous aideras à comprendre quels sont les instruments les plus efficaces pour donner une solution à tes questions sur la santé et le bien-être.

Questions :

1) **Age :**

2) **Sexe :**
   - Fille
   - Garçon

3) **Tu es :**
   - Ecolier
   - Collégien
   - Lycéen
   - Etudiant
   - Apprenti /Stagiaire
   - Salarié
   - Auto-entrepreneur ou en Profession libérale
   - Inactif

4) **Où habites-tu ?**
   a. Dans une grande ville
   b. Dans une ville moyenne
   c. Dans une petite ville ou en milieu rural

5) **Est-ce la première fois que vous venez sur le site Fil Santé Jeunes ?**
   - Oui
   - Non

6) **As-tu personnellement un ordinateur, un Smartphone ou une tablette qui t'appartient et avec lequel tu peux aller sur internet ?**
   - Oui
   - Non

7) **Au cours des 12 derniers mois, as-tu/tu as utilisé Internet pour rechercher des conseils ou des informations de santé qui concernait…**

	voir un médecin	être aidé(e) par un expert contacté sur Internet (e-mail, forum, chat…)	parler avec ta famille ou des amis	échanger sur Internet avec d'autres personnes (forum, réseaux sociaux…)	lire sur Internet des informations	appeler un service d'aide par téléphone	je n'ai pas recherché ce type d'informations ou conseils
Bien-être (sport, alimentation, détente…)							
Santé en général (maladies, allergies, médicaments…)							
Santé sexuelle (sexualité et contraception…)							
Troubles alimentaires (anorexie, boulimie, prise du poids…)							
Dépression, panique, anxiété							
Addictions (alcool, tabac, cannabis ou autres drogues)							

8) **Au cours des 12 derniers mois, pour chacun de ces thèmes, est-ce qu'il t'est arrivé de…**

	OUI	NON
Toi-même		
Un membre de ta famille ou de ton entourage		
Un ami		
Personne en particulier, par curiosité		

9) **Sur le site Fil Santé Jeunes où recherches tu en priorité les réponses à tes questions concernant chacun de ces thèmes ?**

	Forum	Boîte à questions	Foire à questions	Articles	Quizz	Je ne recherche pas ce type d'information
Bien-être (sport, alimentation, détente…)						
Santé en générale (maladies, allergies, médicaments…)						
Santé sexuelle (sexualité et contraception…)						
Troubles alimentaires (anorexie, boulimie, prise du poids…)						
Dépression, panique, anxiété						
Addictions (alcool, tabac, cannabis ou autres drogues)						

10) **Comment procèdes-tu lorsque tu vas sur Internet pour des informations ou des conseils dans le domaine de la santé ou du bien-être ?**

	La plupart du temps	Assez souvent	Rarement	Jamais
Tu recherches par mot clé à partir d'un moteur de recherche, un portail ou un fournisseur d'accès (Google, Yahoo…)				
Tu vas directement sur un site santé ou un portail santé que tu connais déjà				
Tu regardes la date de mise à jour de l'information				
Tu regardes quelle personne ou quelle institution diffuse l'information				

11) Sur le site Fil Santé Jeunes où recherches tu en priorité les réponses à tes questions ?

	Forum	Boîte à questions	Foire à questions	Articles	Quizz
Bien-être (sport, alimentation, détente…)					
Santé en générale (maladies, allergies, médicaments…)					
Santé sexuelle (sexualité et contraception…)					
Troubles alimentaires (anorexie, boulimie, prise du poids…)					
Dépression, panique, anxiété					
Addictions (alcool, tabac, cannabis ou autres drogues)					

12) T'arrive-t-il de chercher des informations de santé sur Internet…

	Très souvent	Assez souvent	Rarement	Jamais	NSP
… au lieu d'aller chez le médecin					
… avant d'aller consulter un médecin					
… après une consultation médicale					
… sans liens avec une consultation médicale					

13) Selon toi, en général l'information que tu obtiens sur internet est-elle crédible ?

- Tout à fait crédible
- Plutôt
- Plutôt pas
- Pas du tout crédible

14) Sais-tu ce qu'est un site sur la santé labellisé ?

- Oui
- Non

15) Comment est ton état de santé physique ?

- Très bon
- Bon
- Assez bon
- Mauvais
- Très mauvais
- Ne sais pas

16) Comment est ton état de santé psychique et émotionnel ?

- Très bon
- Bon
- Assez bon
- Mauvais
- Très mauvais
- Ne sais pas

17) Au cours des douze derniers mois, as-tu consulté…

	OUI	NON
Un médecin généraliste, un médecin de famille ou un pédiatre		
Un gynécologue		
Un psychologue ou un psychiatre		
Un autre médecin spécialiste		
Un(e) infirmier(e) scolaire		
Un autre professionnel de la santé		

4. E-MENTH QUESTIONNAIRES

a) ENGLISH QUESTIONNAIRE

Survey of Internet Usage for Mental Health Information Seeking

General Information

1. Age: ☐

2. Gender: Male ☐ Female ☐

3. What is your area of study?

a	Arts, Letters, Social Studies	
b	Science, Engineering, IT	
c	Business, Law	
d	Medicine, Health	

4. Where are you currently living?

a	Living with parents/family	
b	Living in rented accommodation with other people (not members of your family)	
c	Living alone	
d	Living in college accommodation	
e	Other	

5. Where is your accommodation located?

a	City, big town	
b	Middle-sized town	
c	Small town, village, in the country	

6. Are you currently in paid employment? (tick one box only)

a	Not working	
b	Working part time (1-30 hours per week)	
c	Working full time (more than 30 hours per week)	

7. What is your state of physical health? (tick one box only)

a	Very good	
b	Good	
c	Quite good	
d	Bad	
e	Very bad	

8. What is your psychological and emotional state? (tick one box only)

a	Very good	
b	Good	
c	Quite good	
d	Bad	
e	Very bad	

9. In the last 12 months have you seen one of the following health professionals?

		Yes	No
a	General Practitioner		
b	Gynaecologist		
c	Psychologist /Psychiatrist or Counsellor		
d	Another Medical Specialist		
e	School Nurse		
f	Another health professional		

General Usage of Internet

10. How often do you use the Internet? (tick one box only)

a	Several times a day	
b	Once a day	
c	Several times a week	
d	Once a week	
e	Less than once a week	

11. Do you personally own a computer, a smartphone or a tablet to access the Internet?

Yes No

12. Where do you access the Internet? (tick all that apply)

a	At home	
b	At college	
c	At work	
d	At friends/family’s house	
e	In a public place (internet café, library etc.)	
f	Wherever I can get internet access on my smartphone	

13. For what purpose do you use the Internet? (tick all that apply)

		Several times a day	Once a day	Several times a week	Once a week	Once a month	Less often	Never
a	Sending emails							
b	Finding information for college							
c	Getting news updates							
d	Getting information on movies, music or TV							
e	Looking for health information							
f	Downloading music							
g	Playing games							
h	Shopping							
I	Participating in chat rooms							
L	Participating in discussion or message boards (forums)							
m	Social networks (Facebook, Twitter etc.)							
n	Watching videos (YouTube, Vimeo etc.)							

Use of Internet for Health and Mental Health

14. Have you ever looked for general health information on the Internet?

Yes ☐ No ☐

15. Have you ever looked for mental health information on the Internet?

Yes ☐ No ☐

16. In the last 12 months have you used the Internet to look for information and advice about health issues concerning… (tick all that apply)

a	Yourself	
b	A member of your family or entourage	
c	None in particular	

17. In the last 12 months how often have you looked for the following types of information?

		Once a week or more	Once or few times a month	Several times a year	Once or few times a year	Never
a	Wellbeing (sport, nutrition, relaxation…)					
b	General Health (illnesses, allergies, treatments)					
c	Sexual Health (sexuality and contraception)					
d	Eating disorders (anorexia, bulimia, weight gain…)					
e	Depression, panic, anxiety					
f	Addictions (alcohol, smoking, cannabis…)					

18. In the last 12 months have you looked for information or advice on the internet about the following ?

		YES	NO
a	General information on mental health		
b	Depression		
c	Bipolar disorder		
d	Anxiety problems		
e	Obsessive compulsive disorder		
f	Panic attacks		
g	Eating disorders		
h	Suicide and self-harm		
i	Schizophrenia		
l	Stress (also post-traumatic)		
m	Dementia		
n	Personality Disorders		
o	Addictions		
p	Post-natal depression		

19. What are for you the 3 main <u>advantages</u> for using the Internet for mental health information seeking and support? <u>(tick 3 boxes)</u>

a	Anonymous, private and confidential	
b	Vast amount of valuable information available	
c	Easily accessible 24h a day	
d	Easy to find and ask for information	
e	Fast and time saving	
f	Cheap	
g	Convenient	
h	Easy to communicate with other people in the same situation	
i	A good place to start and to find out where to go for further assistance	
l	Less embarrassing than talking to a professional	
m	Less embarrassing than talking to a friend or family member	
n	Knowing who produced the information	
o	Opportunity to find real experiences of people	

20. What are for you the 3 main <u>disadvantages</u> for using the Internet for mental health information seeking and support? <u>(tick 3 boxes)</u>

a	Too anonymous	
b	Unreliable information	
c	Not easy to find information	
d	Inconvenient and complicated tool	
e	Not knowing who produced the information	
f	Impersonal information not fitting your own experience	
g	Alarming information	
h	Distrust the information in comparison with medical advice	
i	Difficult to access an internet connection	
l	It complicates the relationship with one's doctor	
m	No filters in forums or chat rooms	
n	It is less trustworthy than talking with family and/or friends	
o	Risk of being traceable	

21. In the last 12 months have you ever used the following for support on the internet for a mental health related difficulty?

		Yes	No
a	Online therapy		
b	Chat rooms		
c	Forums/discussion boards		

22. When looking for mental health information on the internet, how do you proceed? <u>(tick all that apply)</u>

		Very often	Quite often	Rarely	Never	Don't know
a	You enter key words into a search engine, portal or ISP such as Google or Yahoo					
b	You directly visit one health website or portal you already know					
c	You pay attention to the date of the information					
d	You pay attention to the person and/or institution providing the information					

23. When you review information for mental health on the internet, do you do so… <u>(tick one box for each item)</u>

		Very often	Quite often	Rarely	Never	Don’t know
a	…instead of going to a doctor					
b	…before going to a doctor					
c	…after a medical consultation					
d	…independently from any medical consultation					

24. Do you think in general that mental health information in the Internet is credible? <u>(tick one box only)</u>

a	Absolutely yes	
b	Quite so	
c	Not quite so	
d	Absolutely not	

25. Do you know what certified health websites are?

Yes No

b) FRENCH QUESTIONNAIRE

Questionnaire sur l'utilisation d'Internet pour la recherche d'informations et conseils sur la santé mentale

Merci de bien vouloir répondre à ce court questionnaire en cochant les cases qui correspondent à votre situation.

<u>Informations générales</u>

1. Âge : ……….. ans

2. Sexe :

a	Homme	
b	Femme	

3. Quelle est la filière du diplôme que vous préparez ?

a	Arts, Lettres, Sciences Sociales	
b	Sciences, Génie, Informatique	
c	Sciences économiques, Droit	
d	Médicale	

4. Où habitez vous à présent actuellement?

a	Avec mes parents / ma famille	
b	En location avec d'autres personnes (qui ne sont pas membres de ma famille)	
c	Seul(e)	
d	Dans une résidence universitaire	
e	Autre résidence	

5. Où se trouve votre résidence ?

a	Dans une grande ville	
b	Dans une ville moyenne	
c	Dans une petite ville ou en milieu rural	

6. Quelle est actuellement votre situation professionnelle ? (1 seule réponse possible)

a	Vous ne travaillez pas	
b	Vous travaillez à temps partiel (1-30 heures par semaine)	
c	Vous travaillez à temps plein (plus de 30 heures par semaine)	

7. Comment est votre état de santé physique ? (1 seule réponse possible)

a	Très bon	
b	Bon	
c	Assez bon	
d	Mauvais	
e	Très mauvais	

8. Comment est votre état de santé psychique et émotionnel ? (1 seule réponse possible)

a	Très bon	
b	Bon	
c	Assez bon	
d	Mauvais	
e	Très mauvais	

9. Au cours des 12 derniers mois, avez vous consulté l'un de ces professionnels de santé ? (Cocher une case par ligne)

	oui	non
Un médecin généraliste, un médecin de famille		
Un gynécologue		
Un psychologue ou un psychiatre		
Un autre médecin spécialiste		
Un(e) infirmier(e) scolaire ou universitaire		
Un autre professionnel de la santé		

Utilisation générale d'Internet

10. À quelle fréquence allez-vous sur Internet? (1 seule réponse possible)

a	Plusieurs fois par jour	
b	Une fois par jour	
c	Plusieurs fois par semaine	
d	Une fois par semaine	
e	Moins d'une fois par semaine	

11. Avez-vous personnellement un ordinateur, un Smartphone ou une tablette qui vous appartient et avec lequel vous pouvez aller sur internet ?

a	oui	
b	non	

12. Où accédez-vous à Internet ? (Indiquer toutes les réponses qui vous concernent)

a	Chez vous	
b	A l'université	
c	Au travail	
d	Chez votre famille / vos amis	
e	Dans un lieu public (cyber-café, bibliothèque etc.)	
f	N'importe où il y a une connection pour mon smartphone	

13. À quelles fins utilisez-vous Internet ? (Cocher une case par ligne)

	Plusieurs fois par jour	Une fois par jour	Plusieurs fois par semaine	Une fois par semaine	Une fois par mois	Moins souvent	Jamais
Envoyer des e-mails							
Trouver des informations pour l'université							
Obtenir des informations sur divers sujets							
Obtenir des informations sur films, musique ou télé							
Rechercher des informations sur la santé							
Télécharger de la musique							
Jouer aux vidéo-games							
Faire des achats							
Participer à des chats							
Participer à des discussions sur les forums							
Réseaux Sociaux (Facebook, Twitter etc.)							
Regarder des vidéos (YouTube, Vimeo etc.)							

Utilisation d'Internet pour la Santé et pour la Santé Mentale

14. Avez-vous déjà cherché des informations sur la santé en général sur Internet ?

a	oui	
b	non	

15. Avez-vous déjà cherché des informations sur la santé mentale sur Internet ?

a	oui	
b	non	

16. Au cours des 12 derniers mois, avez-vous utilisé Internet pour rechercher des conseils ou des informations de santé qui concernait…… (Cocher toutes les réponses qui vous concernent)

a	Vous-même	
b	Un membre de votre famille ou de votre entourage	
c	Personne en particulier	

17. Au cours des 12 derniers mois, à quelle fréquence avez-vous cherché des informations sur les thèmes suivants ?

	Une ou plusieurs fois par semaine	Une ou peu de fois par mois	Plusieurs fois par an	Une fois ou peu de fois par an	Jamais
Bien-être (sport, alimentation, détente…)					
Santé en général (maladies, allergies, médicaments…)					
Santé sexuelle (sexualité et contraception…)					
Troubles alimentaires (anorexie, boulimie, prise du poids…)					
Dépression, panique, anxiété					
Addictions (alcool, tabac, cannabis ou autres drogues)					

18. Au cours des 12 derniers mois, est-ce qu'il vous est arrivé de chercher des informations ou des conseils sur les sujets suivants ? (Cocher une case par ligne)

	oui	non
Informations sur la santé mentale en général		
Dépression		
Trouble bipolaire		
Troubles anxieux		
Trouble obsessionnel compulsif		
Attaques de panique		
Troubles alimentaires		
Suicide et automutilation		
Schizophrénie		
Stress (même post-traumatique)		
Démence		
Troubles de la personnalité		
Addictions		
Dépression post-natale		

19. Quels sont d'après vous les 3 <u>avantages</u> principaux d'utiliser Internet pour obtenir des informations et des conseils sur la santé mentale ? (Donner 3 réponses)

a	C'est anonyme et confidentiel	
b	Cela offre une grande quantité d'informations de bonne qualité	
c	C'est accessible 24 heures sur 24	
d	C'est un moyen simple pour demander et trouver des informations	
e	C'est rapide et permet de gagner du temps	
f	C'est économique	
g	C'est pratique	
h	C'est un instrument simple pour communiquer avec des personnes dans la même situation que soi	
i	C'est un moyen pratique pour trouver des informations sur les services auxquels s'adresser pour obtenir un soutien	
l	C'est moins embarrassant de demander des conseils sur Internet qu'à un professionnel de santé	
m	C'est moins embarrassant de demander des conseils sur Internet qu'à un ami ou à quelqu'un de la famille	
n	On peut savoir qui a produit l'information	
o	Cela permet de trouver des témoignages sur les expériences réelles des personnes	

20. Quels sont, à votre avis, les 3 principaux <u>inconvénients</u> de l'emploi d'Internet comme instrument pour obtenir des informations et du soutien à propos de la santé mentale ? (Indiquer 3 réponses)

a	C'est trop anonyme	
b	Les informations sont peu fiables	
c	Il n'est pas facile de trouver les informations	
d	C'est un moyen trop compliqué et peu pratique	
e	Cela ne permet pas de connaître la source des informations	
f	Les informations sont impersonnelles et ne correspondent pas à ma propre expérience	
g	C'est source d'inquiétudes	
h	Vous faites moins confiance aux informations sur Internet qu'à l'avis des médecins	
i	Il vous est difficile de vous connecter à Internet	
l	Cela complique le rapport avec son médecin	
m	Dans les forums et les chats, les gens peuvent dire n'importe quoi	
n	C'est moins rassurant que de parler à des amis ou quelqu'un de la famille	
o	On risque d'être tracés avec Internet	

21. Au cours des 12 derniers mois, avez-vous utilisé l'un de ces supports en ligne pour un problème lié à la santé mentale ?

	Oui	Non
Thérapie en ligne		
Chats		
Forums		

22. Comment procédez-vous (et à quelle fréquence) lorsque vous allez sur Internet pour des informations ou des conseils dans le domaine de la santé mentale ? (Cocher une case par ligne)

	Très souvent	Assez souvent	Rarement	Jamais	NSP
Vous cherchez par mot clé à partir d'un moteur de recherche, un portail ou un fournisseur d'accès (Google, Yahoo…)					
Vous allez directement sur un site santé ou un portail santé que vous connaissez déjà					
Vous regardez la date de mise à jour de l'information					
Vous regardez quelle personne ou quelle institution diffuse l'information					

23. Vous arrive-t-il de chercher des informations sur la santé mentale sur internet… (Cocher une case par ligne)

	Très souvent	Assez souvent	Rarement	Jamais	NSP
…au lieu d'aller chez le médecin					
…avant d'aller consulter un médecin					
…après une consultation médicale					
…sans lien avec une consultation médicale					

24. Selon vous, en général l'information que vous obtenez sur internet est-elle crédible ? (1 seule réponse possible)

a	Tout à fait crédible	
b	Plutôt	
c	Plutôt pas	
d	Pas du tout crédible	

25. Savez-vous ce qu'est un site sur la santé labellisé ?

a	oui	
b	non	

MERCI !

c) ITALIAN QUESTIONNAIRE

Questionario sull’uso di Internet per la Salute Mentale

Informazioni di base

1. Età: ☐

2. Sesso: ☐ Uomo ☐ Donna

3. Quale è la tua area di studio?

a	Arte, Lettere, Scienze Sociali	☐
b	Scienze, Ingegneria, Informatica	☐
c	Economia, Legge	☐
d	Medicina e discipline medico-sanitarie	☐

4. Dove risiedi attualmente?

a	Con i miei genitori/in famiglia	☐
b	Con altre persone (non membri della mia famiglia) in affitto	☐
c	Da solo	☐
d	Con altri studenti in una residenza universitaria	☐
e	Altro	☐

5. Dove si trova la tua abitazione?

a	In una metropoli, in una grande città	☐
b	In una città di media grandezza	☐
c	In una città piccola, in un paese, in campagna	☐

6. Quale è la tua situazione lavorativa attuale? (una sola risposta possibile)

a	Non sto lavorando	☐
b	Lavoro part-time (1-30 ore a settimana)	☐
c	Lavoro a tempo pieno (più di 30 ore a settimana)	☐

7. Come consideri il tuo stato di salute fisico? (una sola risposta possibile)

a	Ottimo	
b	Buono	
c	Nella media	
d	Cattivo	
e	Pessimo	

8. Come consideri il tuo stato di salute psicologico ed emotivo? (una sola risposta possibile)

a	Ottimo	
b	Buono	
c	Nella media	
d	Cattivo	
e	Pessimo	

9. Negli ultimi 12 mesi hai consultato uno di questi professionisti della salute?

		Sì	No
a	Medico di base		
b	Ginecologo		
c	Psicologo o Psichiatra		
d	Un altro medico specialista		
e	Sportello di supporto psicologico alle attività formative in Università		
f	Un altro professionista della salute		

Uso generale di Internet

10. Quanto ti connetti a Internet? (una sola risposta possibile)

a	Più volte al giorno	
b	Una volta al giorno	
c	Più volte a settimana	
d	Una volta a settimana	
e	Meno di una volta a settimana	

11. Possiedi un computer, uno smartphone o un tablet personali da cui accedi a Internet?

☐ Sì ☐ No

12. Da dove ti connetti? (indica tutte le risposte possibili)

a	Casa	
b	Università	
c	Lavoro	
d	Casa di amici/familiari	
e	In un luogo pubblico (internet café, biblioteca etc.)	
f	Ovunque riesca a connettermi con il mio smartphone	

13. Quali attività svolgi su Internet? (indica tutte le risposte possibili)

		Più volte al giorno	Una volta al giorno	Più volte a settimana	Una volta a settimana	Una volta al mese	Con minore frequenza	Mai
a	Inviare e-mail							
b	Trovare informazioni per l'università							
c	Seguire l'attualità							
d	Ottenere informazioni su film, musica, TV							
e	Cercare informazioni sulla salute							
f	Scaricare musica							
g	Giocare online							
h	Fare acquisti							
i	Chattare							
l	Partecipare a discussioni nei forum							
m	Social networks (Facebook, Twitter ecc.)							
n	Guardare video (YouTube, Vimeo ecc.)							

Uso di Internet per la Salute e per la Salute Mentale

14. Hai mai cercato su Internet informazioni sulla Salute in generale?

☐ Sì ☐ No

15. Hai mai cercato su Internet informazioni sulla Salute Mentale?

☐ Sì ☐ No

16. Nel corso degli ultimi 12 mesi hai utilizzato Internet per cercare delle informazioni su un problema o una domanda sulla salute che riguardava… (indica tutte le risposte possibili)

a	Te stesso	☐
b	Un membro della tua famiglia o un amico	☐
c	Nessuno in particolare	☐

17. Nel corso degli ultimi 12 mesi quante volte hai cercato informazioni sui seguenti argomenti?

		Una o più volte a settimana	Una o poche volte al mese	Più volte all'anno	Una o poche volte all'anno	Mai
a	Benessere (sport, alimentazione, relax…)					
b	Salute in generale (malattie, allergie, medicinali, prevenzioni)					
c	Salute sessuale (sessualità e contraccezione)					
d	Disturbi alimentari (anoressia, bulimia…)					
e	Depressione, attacchi di panico, ansia					
f	Dipendenze (alcol, fumo, droghe, gioco, internet…)					

18. Nel corso degli ultimi 12 mesi hai cercato informazioni o richiesto aiuto su Internet in merito a questi argomenti?

		Sì	No
a	Informazioni generali sui problemi e sulle malattie mentali		
b	Depressione		
c	Disturbo bipolare		
d	Problemi d'ansia		
e	Disturbo ossessivo compulsivo		
f	Attacchi di Panico		
g	Disturbi alimentari		
h	Suicidio e autolesionismo		
i	Schizofrenia		
l	Stress (anche stress post-traumatico)		
m	Demenza		
n	Disturbi della personalità		
o	Dipendenze		
p	Depressione post-partum		

19. Quali sono secondo te i 3 vantaggi principali dell'uso di Internet come strumento per ottenere informazioni e supporto in merito alla salute mentale? (indica 3 risposte)

a	Anonimo, privato e confidenziale	
b	Disponibilità di una grande quantità di informazioni di buona qualità	
c	Facilmente accessibile 24 ore su 24	
d	Uno strumento semplice per chiedere e trovare informazioni	
e	Veloce, permette di risparmiare tempo	
f	A basso costo	
g	Pratico	
h	Uno strumento semplice per comunicare con persone con lo stesso problema	
i	Un modo pratico per sapere a chi rivolgersi per un ulteriore supporto	
l	Meno imbarazzante che chiedere consigli a un professionista della salute	
m	Meno imbarazzante che chiedere consigli a un amico o a un familiare	
n	Possibilità di sapere chi ha fornito le informazioni	
o	Possibilità di trovare delle testimonianze sulle esperienze reali delle persone	

20. Quali sono secondo te i 3 svantaggi principali dell’uso di Internet come strumento per ottenere informazioni e supporto in merito alla salute mentale? (indica 3 risposte)

a	Troppo anonimo	
b	Informazioni poco affidabili	
c	Non è facile trovare le informazioni	
d	È uno strumento troppo complicato e poco pratico	
e	Non è possibile risalire alla fonte delle informazioni	
f	Informazioni impersonali che non corrispondono alla tua esperienza personale	
g	Informazioni che aumentano invece che diminuire le proprie preoccupazioni	
h	Poca fiducia nelle informazioni fornite rispetto al parere di un medico	
i	È difficile trovare una connessione internet	
l	Rende più complicato il rapporto con il proprio medico	
m	Non esistono filtri nei forum o nelle chat	
n	È meno rassicurante di un consiglio di parenti o amici	
o	Rischio di essere rintracciabili	

21. Nel corso degli ultimi 12 mesi hai mai usato uno di questi strumenti di supporto online per un problema di salute mentale?

		Sì	No
a	Terapia online		
b	Chat		
c	Forum		

22. Quando navighi su Internet per rispondere alle tue domande sulla salute, come cerchi le informazioni ? (indica tutte le risposte possibili)

		Molto spesso	Abbastanza spesso	Raramente	Mai	Non so
a	Inserisci una parole chiave in un motore di ricerca, un portale o un internet provider (Google, Yahoo…)					
b	Vai direttamente in un sito o in un portale sulla salute che conosci già					
c	Controlli la data di aggiornamento della pagina/sito					
d	Controlli chi o quale istituto/ente diffonde le informazioni che stai leggendo					

23. Ricerchi su Internet informazioni sulla salute mentale… (fornisci una risposta per ciascuna riga)

		Molto spesso	Abbastanza spesso	Raramente	Mai	Non so
a	…invece di andare dal dottore					
b	…prima di andare dal dottore					
c	…dopo essere andato/a dal dottore					
d	…indipendentemente da qualsiasi consulto medico					

24. Secondo te, in generale, le informazioni che ottieni su internet sono attendibili? (una sola risposta possibile)

a	Assolutamente sì	
b	Più sì che no	
c	Più no che sì	
d	Niente affatto	

25. Sai cosa sono i siti sulla salute certificati?

☐ Sì ☐ No

d) SPANISH QUESTIONNAIRE

Encuesta sobre el uso de Internet para búsquedas de información sobre Salud Mental

Información general

1. Edad: ☐

2. Género: ☐ Masculino ☐ Femenino

3. ¿Cuál es tu área de estudio?

a	Arte, letras, Estudios sociales	
b	Ciencia, ingeniería, IT	
c	Empresa, ley	
d	Medicina, salud	

4. ¿Dónde vives actualmente?

a	Vivo con mis padres/ familia	
b	Vivo en una casa de alquiler con otras personas (no de la familia)	
c	Vivo solo	
d	Vivo en una residencia	
e	Otros	

5. ¿Dónde está situada tu vivienda?

a	Ciudad, gran ciudad	
b	Ciudad de tamaño medio	
c	Pequeña ciudad, pueblos, en el campo	

6. ¿Tienes actualmente trabajo remunerado? (Señala una única respuesta)

a	No tengo trabajo.	
b	Trabajo a tiempo parcial (de 1-30 horas semanales)	
c	Trabajo a tiempo completo (más de 30 horas por semana)	

7. ¿Cuál es tu estado de salud? (Señala una única respuesta)

a	Muy bueno	
b	Bueno	
c	Bastante bueno	
d	Malo	
e	Muy malo	

8. ¿Cuáles son las condiciones de su estado de Salud Mental? (Señala una única respuesta)

a	Muy buena	
b	Buena	
c	No demasiado buena	
d	Mala	
e	Muy mala	

9. ¿En los últimos 12 meses has visitado alguno de los siguientes profesionales de la salud?

		Sí	No
a	Médico		
b	Ginecólogo		
c	Psicólogo/ Psiquiatra o consejero		
d	Otro especialista médico		
e	Enfermera de la escuela		
f	Otro profesional de la salud		

Uso general de Internet

10. ¿Con qué frecuencia usas Internet? (Señala una única respuesta)

a	Varias veces al día	
b	Una vez al día	
c	Varias veces por semana	
d	Una vez por semana	
e	Menos de una vez por semana	

11. ¿Tienes ordenador, smartphone ó tablet para acceder a Internet?

Sí No

12. ¿Dónde accedes a Internet? (Señala todas las opciones que se den en tu caso)

a	En casa	
b	En la facultad	
c	En el trabajo	
d	En casa de familiares/amigos	
e	En lugares públicos (cybercafé, biblioteca, etc.)	
f	En cualquier lugar que tenga conexión a Internet desde mi smartphone	

13. ¿Con qué propósito utilizas Internet? (Señala todas las opciones que se den en tu caso)

		Varias veces al día	Una vez al día	Varias veces a la semana	Una vez a la semana	Una vez al mes	Con menos frecuencia	Nunca
a	Enviar correos							
b	Encontrar información para la universidad							
c	Conocer nuevas noticias							
d	Obtener información sobre películas, música o televisión							
e	Buscar información sobre salud							
f	Descargar música							
g	Jugar							
h	Comprar algo							
i	Participar en chats							
l	Participar en debates o tablones de mensajes (foros)							
m	Redes sociales (Facebook, Twitter, etc.)							
n	Ver videos (YouTube, Vimeo, etc.)							

Uso de Internet para la Salud y la Salud Mental

14. ¿Alguna vez has buscado información sobre salud en Internet?

Sí No

15. ¿Alguna vez has buscado información sobre Salud Mental en Internet?

Sí No

16. En los últimos 12 meses, ¿has utilizado Internet para buscar información y consejo sobre aspectos relacionados con… (Señala todas las opciones que se den en tu caso)

a	Contigo mismo	
b	Un miembro de tu familia o entorno	
c	Nadie en particular	

17. En los últimos 12 meses, ¿con qué frecuencia has buscado información sobre los siguientes temas?

		Una vez a la semana o más	Una o más veces al mes	Varias veces al año	Una o más veces al año	Nunca
a	Bienestar (deporte, nutrición, sueño…)					
b	Salud en general (enfermedades, alergias, tratamientos)					
c	Salud sexual (sexo and métodos anticonceptivos)					
d	Trastornos del comportamiento alimentario (Anorexia, bulimia, aumento de peso…)					
e	Depresión, ataques de pánico, ansiedad					
f	Adicciones (alcohol, tabaco, cannabis…)					

18. En los últimos 12 meses, ¿has buscado información en Internet sobre los siguientes aspectos?

		SÍ	NO
a	Información general sobre problemas de salud y enfermedades		
b	Depresión		
c	Trastorno bipolar		
d	Problemas de ansiedad		
e	Trastorno obsesivo compulsivo		
f	Ataques de pánico		
g	Trastornos del comportamiento alimentario		
h	Suicidio y autolesiones		
i	Esquizofrenia		
l	Estrés (también post-traumático)		
m	Demencia		
n	Trastornos personales		
o	Adicciones		
p	Depresión post-parto		

19. Para ti, ¿cuáles son las tres ventajas principales que aporta el uso de Internet para la búsqueda de información sobre Salud Mental? (Señala tres opciones)

a	Anónimo, privado y confidencial	
b	Disponibilidad de una gran cantidad de información útil.	
c	Fácilmente accesible las 24 horas del día	
d	Fácil para buscar y encontrar información	
e	Es rápido y ahorra tiempo	
f	Barato	
g	Adecuado	
h	Es fácil comunicarse con otras personas que estén en nuestra misma situación	
i	Buen lugar para empezar y descubrir adónde ir para una asistencia más personalizada	
l	Menos vergonzoso que hablar con un profesional	
m	Menos vergonzoso que hablar con un amigo o miembro de la familia	
n	Saber de quién proviene la información	
o	Experiencias reales de otras personas	

20. ¿Qué tres principales desventajas ves en el uso de Internet para la búsqueda de información y soporte de Salud Mental? (Señala tres opciones)

a	Demasiado anónimo	
b	Información poco fiable	
c	No es fácil encontrar información	
d	Herramienta inadecuada y compleja	
e	Desconocimiento de la identidad de la persona que remite dicha información	
f	Información impersonal sin ajustarse a tu propia experiencia	
g	Información alarmante	
h	Desconfianza de la información con respecto al consejo médico	
i	Dificultad para acceder a una conexión de Internet	
l	Complica la relación con el médico	
m	No existen filtros en foros o chats	
n	Es de menos confianza que hablar con la familia y/o los amigos	
o	Riesgo de ser localizado	

21. En los últimos 12 meses, ¿has usado alguno de los siguientes soportes de Internet para un problema relacionado con la Salud Mental?

		Sí	No
a	Terapia online		
b	Chats		
c	Foros de discusión		

22. Cuando buscas información sobre Salud Mental en Internet, ¿cómo lo haces? (Señala todas las opciones que se den en tu caso)

		Muchas veces	A menudo	Rara vez	Nunca	No lo sé
a	Pones palabras claves en el buscador de Internet, como Google o Yahoo					
b	Directamente, buscas una página o portal sobre salud que ya conoces					
c	Te fijas en la fecha de publicación de la información					
d	Te fijas en la persona y/o institución que publica dicha información					

23. Cuando revisas información sobre Salud Mental en Internet, lo haces… (Señala una única respuesta por cada apartado)

		Muchas veces	A menudo	Rara vez	Nunca	No lo sé
a	…en lugar de ir al médico					
b	…antes de ir al médico					
c	…después de una consulta médica					
d	…independientemente de cualquier consulta médica					

24. ¿Piensas en general que la información sobre Salud Mental de Internet es fiable? (Señala una única respuesta)

a	Sí, completamente	
b	Bastante	
c	No demasiado	
d	En absoluto	

25. ¿Sabes qué páginas de salud están certificadas?

☐ Sí ☐ No