MINDFUL - Mental health information and determinants for the European level

Final technical implementation report

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Executive Summary

This report summarizes the main activities and results of the project, 'Mental health information and determinants for the European level (MINDFUL)' conducted under STAKES leadership from 15 March 2004 to 15 June 2006. The project was co-sponsored by the EC DG SANCO in the framework of its Community action programme in the field of public health.

Aims
The goals of MINDFUL were to improve the level of mental health information within the EU and to produce a proposal for a comprehensive mental health information system for the EU. A core vision was to widen the scope of the mental health monitoring systems to cover - not only mental ill-health - but also positive mental health and mental health promotion and prevention of mental disorders.

Background
The project built on the previous project 'Establishment of the indicators for mental health monitoring in Europe', co-ordinated by STAKES in the period 1998-2001[1]. The project established a list of 36 mental indicators for use in Europe, covering the domains of mental health status, mental health determinants and mental health systems. These indicators were then incorporated by the European Community Health Indicators 2 (ECHI-2) project[2] in a comprehensive European health monitoring system.

Partners
The MINDFUL project consisted of seven partnership projects each with an independent leader and collaborators in different EU Member States. STAKES co-ordinated the project, developed the mental health indicators, defined metadata, and retrieved public mental health data for the freely available MINDFUL database (http://info.stakes.fi/mindful/EN/database/indicators.htm). University of Leicester contributed to the MINDFUL with an analysis of the determinants of mental health and mental ill-health from existing sources. The Public Health Institute of the Republic of Slovenia was responsible for examination and development of the mental health monitoring systems in the new Member States. University of Deusto (Bilbao, Spain) elaborated monitoring of positive mental health. Radboud University Nijmegen (The Netherlands) established a training system on mental health promotion and prevention of mental ill-health. Ludwig Boltzmann Institute for Social Psychiatry (Vienna, Austria) contributed with assessment and development of monitoring of mental health services utilisation. MGEN, Foundation for Public Health (Paris, France) was responsible for a subproject to improve currently available mental health survey and reporting methods.

Support for the Mental Health Working Party
The MINDFUL project co-ordinated also activities of the Mental Health Working Party of DG SANCO. The working party mainly consisted of leaders of current and past mental health projects in the public health programmes, and the overall aim was to co-ordinate development of mental health monitoring within Europe. On behalf of the working party, MINDFUL produced recommendations for improvement of the mental health indicator set in the health indicator list of ECHI-2.

MINDFUL mental health indicators
The MINDFUL project recommends a final set of 35 mental health indicators. After thorough survey of validity, psychometric properties, availability and policy relevance, three new indicators were added to the existing list of indicators: self-esteem (an indicator of positive mental health);

childhood adversities (a strong mental health determinant); and mental disorders and adjustment of children and adolescents (an important population group). Several indicators recommended in previous projects were dropped due to psychometric problems or lack of availability. To facilitate implementation, a shortlist of 20 prioritised mental health indicators was developed (MINDFUL-20).

MINDFUL database
The MINDFUL database, consisting of indicator metadata and numerical data for each of the 35 MINDFUL mental health indicators, is freely available for researchers, developers, and the public, through the project website http://www.stakes.fi/mindful. The database covers the period from 1990 onwards. Available data were retrieved from international databases, national statistical offices, survey reports and published scientific articles. Availability varied considerably between indicators. In addition to national total population data, the MINDFUL database also contains breakdowns by sex, age and NUTS2 regions where available.

MINDFUL Recommendations
Based on the MINDFUL indicator list, a recommendation on five items to include in the European Health Interview Survey (EHIS) module on health determinants was developed. MINDFUL strongly recommends a modern view on health determinants and expansion of the determinants module to encompass the following population measures of psychosocial determinants of mental health (presented in priority order): Sense of mastery, social support, life events, self-esteem, and childhood adversities.

The MINDFUL also produced a set of recommendations to improve the mental health monitoring abilities of the ECHI-2 indicator set. These recommendations were delivered to the Health Indicators Working Party and the ECHIM (European Community Health Indicators Monitoring) Project.

MINDFUL subprojects produced recommendations for indicators on childhood determinants of adult mental health, mental health systems, structural indicators of positive mental health, indicators of promotion and prevention actions in mental health, and mental health survey indicators. Special recommendations were developed for the new Member States.

[1] Korkeila J, Lehtinen V, Bijl R, Dalgaard OS, Kovess V, Morgan A, Salize HJ. Establishing a set of mental health indicators for Europe. Scand J Publ Health 2003;31:451-9
[2] Kramers PGN and the ECHI team. Public health indicators for the European Union: Context, selection, definition. RIVM Report 271558006. Bilthoven, the Netherlands: RIVM National Institute for Public Health and the Environment, 2005.

1. AIMS AND OBJECTIVES

Health information is essential to ensure a high level of human health protection in the Community. Mental health is an integral and important part of population health: it is estimated that one fourth of the population burden of disease is due to mental ill health. Mental ill health costs at the EU level are 3-4 % of GDP, mainly through lost productivity. Good mental health is increasingly important for the economic growth and population wellbeing in Europe. The transition of Europe into an information society and advances in working life cannot successfully be achieved without giving population mental health a special consideration.

MINDFUL (Mental health information and determinants for the European level) was a collaborative European project, co-funded by the European Commission from the health information and knowledge strand of the Community action programme in the field of public health and by the partners. MINDFUL was functional between 15 March 2004 and 15 June 2006.

The goals of MINDFUL were
- to improve the level of mental health information within the EU and
- to produce a proposal for a comprehensive mental health information system for the EU.

The project consisted of seven **partnership projects** each with an independent leader and collaborators in different EU Member States.

The work is firmly based on previous projects (funded from the Health Monitoring Programme of the EC), and it also links with many of the ongoing projects (co-financed from the EC Public Health Programme 2003-2008).

The seven partnership projects focused on:
(1) analysing determinants of mental health and mental ill-health from existing sources;
(2) exploring and develop the relevant information systems in the new Member States;
(3) establishing a system for monitoring the impact of policies and programmes promoting mental health;
(4) offering a training programme for the implementation of mental health promotion and prevention interventions;
(5) establishing a system to monitor service utilisation data;
(6) developing the contemporary survey and reporting methods; and
(7) refining the set of mental health indicators and setting up the MINDFUL database.

The partnership projects 1-6 have produced separate technical implementation reports of (Annex 1-6). However, the proposal for a comprehensive mental health monitoring system outlined in this technical report can be regarded as the main outcome of MINDFUL. This proposal will be presented in more detail in what is tentatively entitled the "MINDFUL Book" (draft contents outlined in Annex 7), to be published in late 2006. This book will summarise and bring together all of the work conducted in MINDFUL and pave the way for further development in this area.

2. CO-ORDINATION OF THE PROJECT

2.1. General issues

The official starting date of the project was 15th of March 2004 with a duration of 27 months.

STAKES, as a main beneficiary of MINDFUL, has been responsible for the co-ordination (including the general administration and financial issues) of the project.

This work has included the budget negotiations[1], contract preparation (with the six associated beneficiaries) and communicating the relevant information to the partnership project leaders. Preparation of the project leader meetings (including practical arrangements) has been the task of STAKES. Furthermore, STAKES has been responsible for preparing the final technical implementation and financial reports. STAKES will also compile and publish the full MINDFUL Book in printed version and electronically.

All associated beneficiaries have been responsible for the work that has been carried out within the partnership projects. They have worked rather independently with their partners and reported on the progress in the meetings.

As an integral part of the dissemination of information of the project, STAKES operated and maintained a public project website (http://www.stakes.fi/mindful).

2.2. Partnership projects

2.2.1. Childhood determinants of adult mental illness (University of Leicester, England)

The aim of this study was to review the evidence currently available linking childhood factors to the frequency of mental illness in adults. This project largely used evidence from prospective cohort studies, focusing mainly on factors that might be amenable to individual or population intervention to prevent mental disorder and promote mental health, with an emphasis on relevance to European populations.

2.2.2. Exploring and developing the relevant mental health information systems in the new Member States (Public Health Institute of the Republic of Slovenia)

This project intended to investigate and provide an overview on presence of main mental public health concerns (suicide behaviour, alcohol misuse and unemployment, all in relation to mental health), and to carry out a systematic review of mental health policies and systems in the new Member States.

2.2.3. Structural indicators of positive mental health (University of Deusto, Spain)

This project devised and promoted a system of indicators of positive mental health for different levels of social systems. It also planned a system for monitoring the impact of policies and programmes promoting mental health, with a specific view on exploring the barriers to implementation.

[1] Due to a derogation, the project was able to start before there was a signed agreement between the Commission and STAKES.

2.2.4. Quality indicators for mental health promotion and prevention (Radboud University Nijmegen, The Netherlands)

This project developed and implemented a training package to develop capacity in Europe on strategies, development and implementation of mental health promotion and mental disorder prevention interventions such as those aiming to reduce depression, anxiety or suicide. The training was built on the evidence provided by reviews of existing best practices and on the science of programme development and implementation.

2.2.5. Monitoring service utilisation (Ludwig Boltzmann Institute for Social Psychiatry, Austria)

This project analysed the existing systems of collecting and reporting mental health service use data on different levels: a) the institutional level of the services, b) the organisational level of health service providers and financiers, c) the regional level within one country, d) the country level, and e) the international level

2.2.6. Mental health survey instruments and methods (MGEN, Foundation for Public Health, France)

This project aimed at setting up a survey system across EU Member States, which allows monitoring of mental health on a regular basis using suitable methodologies and instruments for the whole population.

2.3. Meetings

Five meetings of the project leaders have been organized during the whole period of the project:

(1) Helsinki	26.-27.3.2004
(2) Barcelona	19.-20.11.2004
(3) Helsinki	10.-11.6.2005
(4) Vienna	18.-19.11.2005
(5) Paris	1.-2. 6. 2006

The **Helsinki** inaugural meeting concentrated on outlining and refining the contents of the project in general, and on discussing in detail the contents and work plans of all partnership projects. Considerable time was also spent on discussing and defining the obvious synergistic nature between the partnership projects. At the end, this meeting resulted in major reallocation of the budget between the partners.

Hence, the first meeting provided a timely chance to still sharpen the focus of the project with regard to the past achievements as well as in view of ongoing and future developments.

The second meeting in **Barcelona** (annex 10) was used as a checkpoint for monitoring the progress of MINDFUL. The meeting also offered an opportunity to introduce corrective measures with a view of some of the projects involved.

The focus of the third meeting in **Helsink**i (annex 11) was the indicators. The choice of several indicators and their contents were discussed. In the end, it was decided that the list is still flexible as to inclusion of feasible new indicators originating from the partnership projects. The beta version of the MINDFUL database was presented. It was also decided that a prolongation of three month will

be sought for from the Commission. Finally, the MINDFUL report, later called MINDFUL Book, was discussed and decided to be the principal outcome of the project.

In the fourth meeting in **Vienna** (annex 12) questions related to indicators and the MINDFUL Book were further discussed. It was also stressed that there is a real need to integrate MINDFUL with general EC health information systems development and individual projects, such as ECHIM and EUPHIX, and with the Working Party on Health Indicators. In addition, the Book contents and structure were clarified. The partnership project all reported to make progress. Based on the presentation of the MINDFUL database, a progress could also be report in relation to its data and metadata content and structure.

The final MINDFUL meeting was held in **Paris** on June 1-2, 2006 (annex 13). First, the new MINDFUL webpages were demonstrated. Based on the discussion and the comments, some details of the pages were decided to be revised. The deadlines and other details regarding the Book were discussed. The current status of each partner project, of the MINDFUL indicators and of the use of the indicators in EUROSTAT were presented.

A short list (MINDFUL-20, annex 14) in order of priority was adopted by the meeting. It also finalized suggestions for the ECHI short and long list of mental health indicators. Moreover, a list of five indicators of psychosocial determinants of mental health for the Determinants Module of the European Health Interview Survey was approved (Annex 15).

2.4. Mental health working party

Besides the co-ordination task and carrying out one of the partnership projects, the personnel in STAKES has also been active in operating the Working Party on Mental Health, established under the auspices of the Health information and knowledge strand of the Public Health Programme. The project leader, Prof. Kristian Wahlbeck was elected the leader of the Working Party and the project manager, Dr. Juha Lavikainen has acted as the secretary of this body.

3. OUTCOMES

3.1. Results

3.1.1. Mental health indicators

The MINDFUL project recommends a final set of 35 mental health indicators (Annex 8). After thorough survey of validity, psychometric properties, availability and policy relevance, three new indicators were added to the existing list of indicators: self-esteem (an indicator of positive mental health); childhood adversities (a mental health determinant); and mental disorders and adjustment of children and adolescents. Several indicators recommended in previous projects were dropped due to psychometric problems or lack of availability. The rationale and properties of each survey instrument was scrutinised (Annex 9) before the final inclusion recommendation was taken.

Table 1. The MINDFUL list of mental health indicators for Europe:

GROUP	DOMAIN	INDICATOR
Health status	*Cause specific mortality*	1a. Suicide
		2a. Deaths of undetermined intent
		3. Drug related deaths
		4. Alcohol related deaths
	Morbidity, disease specific	5. Any anxiety disorder
		6. Major depression
		7. Hazardous and harmful drinking
		8. Suicide attempts
	Morbidity, generic	9. Psychological distress
		10. Mental disorders and adjustment among children and adolescents
		11. Energy, vitality
		12. Happiness
		13. Psychological impairment
Determinants of health	*Personal conditions*	14. Sense of mastery
		15. Self-Esteem
	Social and cultural environment	16. Social support
		17. Negative life events
		18. Childhood adversities
Health systems	*Prevention, health protection and promotion*	19. Suicide prevention
		20. Mental health promotion
	Health resources	21. Number of psychiatric beds
		22. Number of psychiatrists
		23. Number of child (and adolescent) psychiatrists
	Health care utilisation; psychiatric care and social services	24. Number of in-patient episodes due to mental health conditions
		25. Number of long-stay patients
		26. Involuntary placements
		27. Use of outpatient services
		28. Self-reported use of mental health services
		29. Use of antidepressants
		30. Use of antipsychotics
		31. Use of anxiolytics
		32. Use of hypnotics
		33. Disability pensions due to mental disorders
		34. Sickness allowance spells due to mental disorders
	Expenditure	35. Expenditure on mental health services

To facilitate implementation, a shortlist of 20 prioritised mental health indicators was developed (MINDFUL-20) (Annex 14).

Based on the MINDFUL indicator list, a recommendation on five items to include in the European Health Interview Survey (EHIS) module on health determinants was developed (Annex 15). MINDFUL strongly recommends a modern view on health determinants and expansion of the determinants module to encompass the following population measures of psychosocial determinants of mental health (presented in priority order): Sense of mastery, social support, life events, self-esteem, and childhood adversities.

The MINDFUL database, consisting of indicator metadata and numerical data for each of the 35 MINDFUL mental health indicators, is freely available for researchers, developers, and the public, through the project website http://www.stakes.fi/mindful. The database covers the period from 1990 onwards. Available data were retrieved from international databases, national statistical offices, survey reports and published scientific articles. Availability varied considerably between indicators. In addition to national total population data, the MINDFUL database also contains breakdowns by sex, age and NUTS2 regions where available.

The MINDFUL also produced a set of recommendations to improve the mental health monitoring abilities of the ECHI-2 indicator set. These recommendations were delivered to the Health Indicators Working Party and the ECHIM (European Community Health Indicators Monitoring) Project.

3.1.2. Childhood determinants of adult mental illness (Annex 1)

An extensive literature review resulted in more than 2500 references that were scrutinised for relevance. Identified childhood determinants include psychological disturbance and psychiatric illness in childhood, genetic factors, early brain damage or neurological deviance, neuroticism, behavioural disturbance, childhood adversity, childhood abuse or neglect, poor parenting and dysfunctional families. Indicators for these determinants are suggested, and the final consensus of the partners was to include two indicators covering childhood and adolescent determinants in the MINDFUL indicator list: negative life events and childhood adversities. The recommended instrument for measuring negative life events is the List of Threatening Experiences (LTE) questionnaire. For childhood adversities the recommended instrument are the four items inquiring sexual abuse (rape and sexual molestation), physical abuse and serious neglect before the respondent was 18 years old from the life events section of the National Comorbidity Survey.

3.1.3. Mental health information systems in the new Member States (Annex 2)

Availability of the MINDFUL indicators varied to great extent between the 10 new Member States. The majority of available mental health indicators represented part of the routine data collection related to morbidity, mortality and health care system, and were mostly used for administrative purposes. Data on mental health determinants and representative survey data on population mental health is largely missing in the new Member States. With the exception of two new Member States (Estonia and Czech Republic), no real epidemiological survey on mental health has been carried out so far.

Definitions of the indicators varied considerably between Member States, compromising comparability. It is recommended that the indicators' elements should be more exclusively operationalized in order to provide better comparability of the data (e.g. the age interval used for establishing prevalence figures needs to be unified across countries). It is suggested that common mental health monitoring recommendations from the EU level for all the EU states and future

applicant countries would be given, because some new Member States are currently developing and establishing mental health monitoring systems.

Availability of data is compromised by problems in reporting and accessibility. Poor reporting needs to be addressed by measures to improve level and quality. In the process of privatisation, governments should ensure that access to certain data, important for policy development, stay in the public domain and that data remains available for research analysis.

Available mental health indicator data from the new Member States was entered in the MINDFUL database and is now freely available at www.stakes.fi/mindful.

3.1.4. Structural indicators of positive mental health (Annex 3)

This project has compiled experiences and bibliographical references relating to structural indicators of Positive Mental Health and Mental Health Prevention and Promotion produced in Europe over the past 20 years. The partnership project has constructed a robust questionnaire of structural indicators of Positive Mental Health to be used in the analysis of mental health policy. Using the Delphi methodology, 100 European mental health experts and stakeholders were consulted about the set of structural indicators which were compiled.

The two main objectives were:
1) to establish a system for monitoring the impact of policies and programmes promoting mental health; 2) to devise and promote a system of structural indicators of environmental factors having an impact on positive mental health at different levels defined as domains.

As a final result of the work, a set of 31 indicators of social and environmental factors that have a positive impact on mental health has been proposed. This impact has been described with scientific evidence in the selected bibliography.

3.1.5. Quality indicators for mental health promotion and prevention (Annex 4)

A review of the literature and expert consultations to identify key quality indicators of mental health promotion and mental disorder prevention programme development, evaluation and implementation were undertaken. Data were collected through an iterative process using a triangulation approach. Through the extensive literature searches, it appeared that quantitative studies in Europe relating to the development, implementation, evaluation and quality of mental health promotion and mental disorder prevention programmes were not widely available. A paper outlining some of the key principles of intervention success across different settings has been prepared and accepted for publication in a peer-reviewed journal.

A training module was developed on programme development, training, implementation and evaluation of mental health promotion and mental disorder prevention interventions and on improving their efficacy through the development and application of quality standards for implementation. The training manual "Programme Planning, Evaluation and Implementation" was developed and piloted in a 3-day European course organised by the partner.

This project showed that easily available indicators that can quantify mental health promotion and mental disorder prevention programmes, policies and infrastructures are scarce. More time, resources and research should be used for identifying these indicators and to make them widely available. Based on these findings, only two indicators covering the field of promotion and prevention in mental health are included in the MINDFUL indicator set. These are "suicide

prevention", defined as the existence of a national suicide prevention activity, and "mental health promotion among minors", defined as activities targeting e.g. bullying in school or parenting and social skills training programmes. The availability of these indicators is severely hampered by the lack of a sustained system for monitoring the implementation of mental health promotion and mental disorder prevention programmes.

3.1.6. Establishing a system to monitor service utilisation data (Annex 5)

Six EU Member States, three “old” ones (Austria, Greece and Spain) and three “new” ones (the Czech Republic, Latvia and Slovakia), representing a wide range of mental health service systems, have participated in this project. The results indicate that a loss of data occurs when data are aggregated on higher levels (i.e. provincial or national level). Furthermore, the appropriateness of the data is questionable; because it covers mostly hospital services, in spite of the fact that a majority of mental health care is provided in the community. An additional challenge is posed by mental health services offered by non-health sectors (e.g. the social and educational sectors, as well as NGOs, may offer services such as residential facilities, day centres, counselling services).

Comparability of many mental health systems indicators is very low. For example, figures on number of inpatient episodes due to a psychiatric diagnosis as well as number of psychiatric beds differ largely between EU countries. The variation is largely due to variation in definitions and inclusion or exclusion of certain services.

It can be concluded that data on mental health service use which are published or made accessible regularly on an international level provide only a distorted picture of the actual pattern of mental health service use. Based on this factual state and on ongoing developments in the field, the following recommendations for improving the present international monitoring systems for mental health service use are proposed here:
•the relevance and meaningfulness of the data, and not only their availability, should be the leading criterion for defining a monitoring system for mental health service use
•the existing hospital focused systems of monitoring mental health services utilization should be supplemented by reporting systems on day care, outpatient, residential and other types of care
•the definitions of the reported variables should be consolidated across EU member states
•reporting to the international data bases should be made obligatory (including deadlines) with sanctions in case of non-compliance
•the development of e-health systems in terms of introducing e-cards and electronic patient records should be furthered (possibly also covering social care services) in order to provide the possibility of linking data on mental health service use for obtaining a realistic picture of what is going on in the field of mental health service use and identifying sections of the patient population who are “heavy users” - data protection aspects would have to be taken into account.
•general population self-report surveys might be a relevant source for information about mental health service use, if questions and answers are formulated in a less ambiguous way than they have been up until now.

Based on the findings in this subproject, several improvements were made in the definitions of MINDFUL mental health system indicators. Improved definitions were also proposed to ECHI-list (Annex 16).

3.1.7. Mental health survey methods and instruments (Annex 6)

A validation study, performed at GP practices in five EU Member States, concluded that the interview instrument CIDI-SF (Composite International Diagnostic Interview, Short Form) seems to work better than the alternative instrument CIS-R (Clinical Interview Schedule – Revised) for measuring anxiety and mood disorder diagnoses (according to the Diagnostic and Statistical Manual of Mental Disorders DSM-IV). The results support the MINDFUL recommendation to use the CIDI-SF-instrument in mental health surveys in the indicators "Any anxiety disorder" and "Major depression".

The first results from the pilot telephone survey in five EU Member States show an important difficulty in obtaining participation. For example, in Romania a sizable portion of interruption is reported mainly due to questions on alcohol and drugs to which people were reluctant to answer. These findings indicate that implementation of the survey items of the MINDFUL indicator list needs careful planning.

3.2. Way forward

Mental health has individual, social, ethical, economic and societal precursors and consequences that should be addressed in all Member States. Adequate and comparable information on mental health at a population level will be an indispensable prerequisite for tackling these problems, in targeting measures effectively towards required priorities and in monitoring progress to jointly agreed goals.

MINDFUL clearly demonstrated the need to further develop policy-relevant European mental health monitoring, to support the aims of the Commission's Green Paper on Mental Health, the implementation of the WHO Mental Health Action Plan for Europe, and major EC policies, such as the Lisbon Agenda.

MINDFUL also shows that in many cases mental health data is non-comparable across Member States, due to differences in data collection, indicator definitions and health systems. However, the project also proposes solutions to increase comparability. Even if valid international cross-sectional comparisons are difficult to implement, progress in public mental health can still be monitored by analysing time trends using a longitudinal set of population based mental health indicators.

Any future work should build on the ECHI-2 indicator set and previous Commission-funded work on mental health indicators. Work is needed to support further harmonisation of mental health indicators and to secure the development and retrieval of data on determinants of mental health. It is necessary to make full use of and create synergy between existing EC and non-EC data collection activities, such as e.g. the EC Labour Force Survey, the Survey of Health, Ageing and Retirement (SHARE), the WHO Health Behaviour in School-Aged Children survey, the OECD social indicators, the OECD health care quality indicators, and the WHO -AIMS mental health system indicators.

Special emphasis should be put on policy-relevant indicators, such as gender-specific determinants of mental health, indicators of positive mental health, and data on vulnerable groups at risk of developing mental ill-health.

4. LIST OF ANNEXES

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