Mental Health and the 2nd EU Health Programme 2008 – 2013 Project Abstracts
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Mental Health and the 2nd EU Health Programme 2008 – 2013
Project Abstracts
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Introduction

The objective of the Commission’s work in the field of mental health is to support Member States in their actions to improve the mental health and well-being of their populations and to help them in reducing the burden of mental disorders.

The European Pact for Mental health and Well-being was launched by a high-level European conference of 2008 as an informal instrument to work towards this objective, through cooperation between Member States’ Governmental experts, EU-health and non-health policies, stakeholder organisations from the health field and others and from civil society.

The policy dialogue between Member States takes places through a Group Governmental Experts on mental health and Well-being, which meets up to two times per year.

The conference “Mental health: Challenges and Possibilities”, which the Lithuanian Presidency is organising on 10-11 October 2013 in Vilnius, only two weeks after the adoption of the new WHO European Mental Health Action Plan 2013-2020, shows that investing in mental health is now seen as an important political priority.

Early 2013 saw the launch of a Joint Action on Mental Health and Well-being with financial support from the EU-Health Programme. This Joint Action is led by Portugal, and involves 25 Member States plus Norway and Iceland. It will run over three years. The objectives of the Joint Action are to, firstly, develop recommendations guiding Member States in the five fields addressed by the work packages of the Joint Action, and secondly, to agree on a proposal for a common framework of action on mental health and well-being.

The Joint Action is funded under the 2008 – 2013 EU Health Programme which provides funding to innovative initiatives promoting health development. This includes:

- projects,
- conferences,
- joint actions (actions conducted by national competent authorities and other public bodies or non-governmental organisations nominated by the EU Member States and other participating countries) and
- operating grants (financial support covering some of the core operating costs for organisations promoting a health agenda in line with the EU Health Programme) promoting health development.

The EU Health Programme supports the implementation of the EU health strategy and the Commission’s initiatives in the field of public health. This brochure provides examples and information on initiatives on mental health and Alzheimer funded under this programme.
I. Mental health
Summary

General objectives

The main objective of this joint action is to contribute to the promotion of mental health and well-being, the prevention of mental disorders and the improvement of care and social inclusion of people with mental disorders in Europe. This objective will be attained by establishing a process for structured collaborative work on mental health and well-being involving Member States, stakeholders in the health and other relevant sectors, and international organizations, in particular the WHO and the OECD, leading to the development of a common endorsed framework for action addressing issues related to a) promotion of mental health at the workplaces and schools; b) promoting action against depression and suicide; c) developing community mental health care; and (f) promoting the integration of mental health in all policies.

Strategic relevance and contribution to the public health programme

The strategic relevance of the JA and its contribution to the Health Programme is ensured by the attention dedicated to mental health and well-being as a public health area which has in the past not always received a level of priority in proportion with its weight in the burden of disease. It is also ensured by the attention dedicated to the promotion of partnerships at EU level and in Member States between health policies and other public policy areas, namely social, educational and economic policies. The JA will therefore contribute to sustainable development and the Europe 2020 vision of smart, sustainable and productive growth. The JA will create EU added value, because of its contribution to realizing EU policy objectives in public health and other fields.

Methods and means

National and European working groups will evaluate progress made in EU and MS in mental health through SWOT analysis, review of literature, questionnaires, and interviews. Recommendations for action to improve the effectiveness of mental health policies implementation will be made in collaboration with EU agencies, WHO and other international organizations based on analysis of implementation research and review of literature. To support engagement and commitment in effective action, a dissemination plan will be developed. Meetings of national and European networks will be used to build consensus and promote engagement. A final JA conference will be organized to support the endorsement of the recommendations by Member States and the EU, and promote their commitment for follow-up actions. A close collaboration will be established with other European mental health initiatives, and a strategy will be developed to create a structured cooperation in mental health policy in Europe in the future.
Expected outcomes

1. A more rigorous and comprehensive knowledge on the situation of mental health and well-being in EU countries, particularly on prevention of depression and suicide, development of community based approaches and social inclusion, mental health at the workplace, mental health and schools, and integration of mental health in all policies.
2. Creation of an inventory of existing evidence, best practices and available resources.
3. Strengthening of national and European networks;
4. Recommendations for action;
5. Building capacity of national mental health leaders and other stakeholders in mental health policy development;
6. Endorsement of a framework for action by MS and EU agencies, as well as their commitment for follow-up action;
7. Establishment of a structured cooperation between MH WB and networks from other European projects, and the creation of mechanisms supporting a structured collaboration between key actors in the implementation of mental health policies in Europe.

Keywords and portfolio

**Keywords**
suicide within Mood anxiety disorders within Mental diseases and disorders within Non communicables diseases
Mood anxiety disorders within Mental diseases and disorders within Non communicables diseases
Mental diseases and disorders within Non communicables diseases
Health promotion within Methods

**Portfolio**
Mental health within Fostering good health

**Reports & deliverables**

**Final Report**
Final Report

**Assessment Report**
Internal Assessment

**Deliverables**
Report with situation analysis and recommendations for action against depression/suicide, including use of e-health
Report with situation analysis and recommendations for action to develop community-based approaches at EU and MS level
Report with situation analysis and recommendations for action to promote mental health at the workplace in EU and MS
Report with situation analysis and recommendations for action to promote mental health of children/adolescents in EU and MS
Report with situation analysis and recommendations for action to integrate mental health in other policies in EU and MS
Workshops aiming at building capacity of national mental health leaders and other stakeholders
JA web site
JA evaluation report
JA dissemination report

Maximum EC Contribution: 1 492 188,00 €

Duration: 2013/02/01 - 2016/01/31
European regions enforcing actions against suicide (EUREGENAS)

Summary

General objectives

Mental ill health has a unique impact on all aspects of life at individual and community levels and represents a major economic burden. Suicide is never the consequence of a single cause or stressor and its rate can vary between regions and local communities as well as over time and within various risk groups. Given the existing discrepancies in suicide rates within Member States and regions, this project brings together 11 regions with different experiences in suicide prevention, with the objective of undertaking a bottom-up approach for largescale interventions so as to lower rates of suicide in diverse populations. The development of large-scale and evidence-based programmes has a three-fold aim: 1) strengthening community-based systems of early detection, support and referral of suicidal behaviour 2) creating sustainable networks within each participating region that should ensure continuity of prevention programmes, 3) reduction of suicide rates in risks groups by improving the efficacy of care and support.

Strategic relevance and contribution to the public health programme

The project is focused on implementing evidence-based and culturally adequate suicide prevention programmes. According to the second programme of Community action in the field of public health, the project promotes the use of regional cluster management as an innovative method to improve the existing services. Special attention will be given to tailored-made solutions that would be developed by taking into account target groups, social trends and the contextual needs of each participating region. For instance, the e-conceptual framework, integrating different levels of care, will be developed by involving youngsters in the definition of online services that are addressed to them. By encouraging regional interventions and campaigns dedicated to both target groups and lay people, the project aims to implement the Mental Health Pact in relation to: 1) prevention of suicide, 2) de-stigmatisation of mental health disorders, 3) promotion of health in youth. Furthermore, the project aims to develop guidelines and promote evidence-based best practices to be included in the Mental Health Compass.

Methods and means

It is clear that suicide prevention requires an innovative, comprehensive multisectoral approach, including both health and non-health sectors. Our aim is to achieve sustainability through a bottom-up approach focusing on GP training, media campaigns, community events and intervention with risk groups. A crucial aspect is the creation of sustainable networks connecting the new and existing community players in suicide prevention on a routine basis. However due to budget limitations, the evaluation of the work will be piloted for each type of intervention in at least 5 regions. Tailored interventions will be adopted to reach risk groups such as the so-called survivors, namely persons bereaving the loss of a relative or friend due to suicide. A key aspect of the project will be to increase scientific and clinical knowledge on efficacy of support groups for suicide survivors.
Expected outcomes

The project aims to promote evidence-based suicide prevention interventions through pilot interventions. Expected qualitative and quantitative outcomes include:

- An increased level of awareness and change in attitude towards mental ill health in lay people and other stakeholders.
- An improved understanding of the health and socio-economic causes of suicide in the general population and in specific target groups.
- Establishment of stable networks between multipliers, namely local players and GPs and mental health providers.
- Increased scientific and clinical knowledge on the efficacy of support groups for suicide survivors, overcoming the gap in this field.
- Finally assessing the benefits of this approach with respect to other more structural and expensive therapeutic options.
- Decreased suicides rates in the general population of the regions involved in the project. This objective cannot be assessed during the life-cycle of the project but represents a long-term outcome.

Keywords and portfolio

Keywords

Poverty & social exclusion within Socio economic factors
Vulnerable groups within Target groups
Mental diseases and disorders within Non communicables diseases
Collection of Best Practices within Methods
HIA within Methods

Portfolio

Mental health within Fostering good health
Health in all policies within Steering EU Public Health

Reports & deliverables

Final Report
Final Report

Assessment Report
Internal Assessment

Deliverables

Communication and dissemination strategy
Evaluation framework
On-line library
Assessment of needs
Technical specifications for e-conceptual mode
Guidelines and toolkits for prevention
Training module for GP-s
Evaluation tool for survivor support groups
Preventing Depression and Improving Awareness through Networking in the EU (PREDI-NU)

Summary

General objectives

The objectives of PREDI-NU are:

1) To use more systematically the possibilities offered by information and communication technologies (ICT) for mild depression. This enables reaching many male patients with mild depression who are reluctant to seek medical help. Such interventions consistently show positive effects among adult populations and adolescents (Vant Hof et al, 2009).

2) To improve early identification of depression and related mental health difficulties. Therefore, a depression awareness training programme will be developed combining training materials for implementation of an internet-based self-management intervention with depression awareness elements, that have been proven to be effective among health care professionals, in particular general practitioners (GPs) and community facilitators working with young people and adults. This programme will be sustained by a Train-The-Trainer (TTT) model.

3) To develop a European Mental Health website, comprising modules on E-Awareness and E-Self-management to enhance wider implementation and sustainability of the PREDI-NU intervention.

Strategic relevance and contribution to the public health programme

PREDI-NU contributes to the EC’s Health Programme for the implementation of the second programme of community action in the field of health (2008-2013), supporting the strand 3.3.2.5 “Mental health”. Key objectives of the PREDINU intervention programme are in line with key priorities of the EC Health Programme. PREDI-NU will focus on the implementation of an internet-based guided self-management intervention for young people and adults with mild depression, which will increase the likelihood for depressed people who are reluctant to seek treatment from traditional mental health services, to receive adequate treatment. A TTT model to implement the intervention and increase awareness, and establishment of a multi-lingual European Mental Health website will assure wider implementation and sustainability of the internet-based guided self-management intervention. PREDI-NU builds upon networks established by the European Alliance Against Depression (EAAD) and aims to further develop and strengthen multidisciplinary networks to enhance depression awareness and prevent attempted suicide and suicide.

Methods and means

The PREDI-NU intervention programme will be developed, implemented and evaluated according to the following steps:

Prior to implementation an intervention for self-management of mild depression using ICTs with a version for adults (25 and over) and a version for young people aged 15-24 years will
be developed. Also modules of evidence based depression awareness sessions for health care professionals, in particular GPs and community facilitators working with young people and adults will be developed.

These awareness modules will be implemented along with the materials for the self-help package, using a TTT model. In order to ensure sustainability, modules on E-Depression Awareness and E-Self-management will be integrated in a European Mental Health website and made available in eight languages. Six European intervention regions in Austria, Spain, Hungary, Ireland, Estonia and Germany have been selected for a two-phase implementation plan of the PREDINU intervention programme. Independent process and outcome evaluation will be conducted by the WP03 partners.

Expected outcomes

The PREDI-NU intervention programme is expected to contribute to increased uptake of treatment by young people and adults with mild forms of depression. It is expected that a larger population of men, who otherwise would not receive any help, will be reached. By increasing awareness of depression among health professionals and community facilitators, PREDI-NU will contribute to early identification of depression and help to prevent attempted and completed suicides. These expected outcomes are initially expected to be observed in the six PREDI-NU intervention regions. However, by making the PREDI-NU intervention materials available in eight languages through the European Mental Health website, it is expected that the predicted outcomes will expand to other European countries. Considering that the intervention will be implemented according to a TTT model, it is expected that implementation of the PREDI-NU interventions will be sustained within and across European countries beyond completion of the PREDI-NU project after three years.

Keywords and portfolio

Keywords

Portfolio
Mental health within Fostering good health

Reports & deliverables

Final Report
Final Report

Assessment Report
Internal Assessment

Deliverables
Protocols for guided self-management of depression
Design and Upload of a European Mental Health Website
Leaflet promoting PREDI-NU, a material catalogue and a laymen´s version of the final report
PREDI-NU News Bulletins every 12 months
Report on recommendations from PREDI-NU for politicians and policy makers involved in mental health policy in the EU
Evaluation report

Maximum EC Contribution:
1 099 032,00 €

Duration:
2011/09/01 - 2014/08/31
Suicide Prevention by Internet and Media Based Mental Health Promotion (SUPREME)

Summary

General objectives

General objective of the SUPREME project is to organize a partnership of expert organizations for the development of an internet and media based, multi-language, culturally adapted, mental health promotion and suicide prevention interventions. The intervention will comprise a sustainable, highly interactive website targeted at adolescents and young adults in the age group 14-24. A media dissemination campaign on best-practices will be aimed at newspapers and magazines with a young audience. On the basis of the results, guidelines for best practices in the field of internet and media usage for mental health promotion interventions will be issued.

Strategic relevance and contribution to the public health programme

This project meets the priorities of the Second Programme of Community Action in the field of health (2008-2013) in numerous key areas: it contributes towards the attainment of high level of mental health through a comprehensive suicide prevention programme; there is an emphasis on improving the health condition of young people; the activities will coordinate with other relevant Community Programmes including FP7, e-Health, Safer Internet Programme and the Youth programme; non-governmental bodies and specialised networks will be involved in the activities; the WHO will be involved as a collaborating centre (para 34). Moreover, the European Pact for Mental Health and Well-Being, launched in 2008 identified 5 priority areas, which included prevention of suicide and mental health youth, themes which are central to this project.

Methods and means

The intervention will be multi-culturally adapted through translation but also adaptation of the intervention tools according to the specific local cultural context. The partnership comprising countries from different regions of Europe has been developed in order to cover culturally diverse regions of Europe. The multi-language Internet based prevention program will be a series of highly interactive websites accessible to all but aimed at adolescents and young adults.

The websites will be monitored by adults in order to prevent harmful behaviors.

The program will use peer as well as adult referral to the intervention website.

The disseminated information and activities performed by users will focus on raising awareness about mental health and suicide, combating stigma, and stimulate peer help as well as make professional help available. The media-based intervention will build on an assessment of the evidence from literature-based studies with input from focus groups, on the basis of which guidelines for best practices will be drafted.
Expected outcomes

The main expected outcome of the project is to improve mental health among European adolescents and young adults. Conclusions will be reached about best practices to promote mental health through the internet and the media: these will include evidence based information about the overall effectiveness of the intervention, the most effective way to involve large numbers of adolescents and young adults in the intervention, the capacity of the intervention to include subjects in need who suffer of social exclusion. Best practices for mental health promotion will be available for European stakeholders, the scientific community, the media, and the general public. The dissemination plan included in the project will ensure proper knowledge translation.

Reports & deliverables

Final Report
Final Report

Assessment Report
Internal Assessment

Deliverables
First Plan and Final Management and Communication Report.
Dissemination Plan and Project Website
Project Brochure, Project Website and Bi-monthly newsletters
First, Interim and Final Evaluation procedure Reports
Protocol for translation and cultural adaptation and project materials in different languages
Report on mapping of internet based health promotion programmes
Partnerships for action: Workshop and Development Review

1. Interactive Website
2. Report on outcomes of the use of Internet Based Mental Health Promotion Intervention

Reports on mapping of media based health promotion intervention on young people and suicide prevention no name - Report on best practices for internet and media on the basis of the available literature and the internet intervention
Mental Health Promotion Handbooks (MHPHands)

Summary

General objectives

The general objective of this project is to equip staff in various settings (schools, workplaces, older peoples' living environment) with the resources required to enhance the mental wellbeing of young people, the labour force and older people. This project will enable professionals working in these areas to acquire the appropriate skills and knowledge to address these issues through effective mental health promotion.

The main thrust of the project is to build upon existing expertise; to transform this expertise into usable and useful manuals for people working in the field; and to use existing networks and resources to ensure that the project outputs are used as widely as possible in as many countries and languages as possible.

The project aims to:

• Produce MHP manuals targeted at the three settings
• Develop a MHP training specification
• Create an e-learning course
• Field test the manuals and training
• Amend the manuals and training
• Valorise the manuals and training through mental health networks and multiplier organisations

Strategic relevance and contribution to the public health programme

The project addresses the second objective of the Health Programme - promoting health - as the core of the project is concerned mental health promotion for vulnerable groups such as young and older people. One of the target settings of the project is older people's homes.

One objective is to address the mental wellbeing of older people thus tackling the objective of increasing healthy life years and promoting healthy ageing. Furthermore, the project targets schools and workplaces.

The project concentrates on the priority action of Public health capacity building of the Work Plan 2009 and specifically, on developing handbooks to support the integration of mental health promotion and mental disorder prevention into the training and work practice of professionals in youth, social, school and workplace environments, taking account of the activities under the 'European Pact for mental health and wellbeing'.

Methods and means

The project will proceed through 4 stages:

1. Development of MHP manuals and training, which includes needs analysis of target groups, scientific and grey literature review, producing a training specification for MHP, producing 1st version of manuals, face to face training and e-learning in 7 languages.
2. Testing: this includes developing an evaluation protocol, field testing of manuals and training, analysis of field testing data, and development of a final product specification.

3. Final production of MHP manuals and training, which includes amendment of each project product in 7 languages, production of final versions of project outputs.

4. Dissemination and implementation: this includes production of publicity materials, development of links with professional bodies and training agencies to ensure widespread implementation through Continuing Professional development programmes, development of (electronic) links with appropriate websites, integration of products within the service offers of partners and others, publications and presentations on the project.

**Expected outcomes**

The project aims to boost the level of mental health promotion taking place in schools, workplaces and older people’s settings. It will provide resources to professionals to enable them to undertake MHP projects, thereby maintaining and promoting mental wellbeing.

The outputs of the project are a set of MHP manuals, face to face training courses and a website/e-learning/web based toolkit. These will be disseminated by the implementing the training courses and manuals and through a dissemination campaign using web-based methods, more traditional methods such as networking (e.g., the European Network for Mental Health Promotion), publications and conferences and the endorsement of courses by professional bodies.

The project outcomes will be increased awareness of project outputs amongst target groups, increased skill/knowledge levels in the target groups, increased implementation of MHP projects, improvements in mental health of beneficiaries, ongoing provision of training manuals and training by professional groups and endorsement of the project outputs by professional bodies.

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**Keywords and portfolio**

**Keywords**

**Portfolio**
Mental health within Fostering good health

**Reports & deliverables**

**Final Report**
Final Report (EN) (C)

**Assessment Report**
Internal Assessment

**Deliverables**
Dissemination plan (3)
Project evaluation framework (3)
Specifications for MHP manuals and training (7)
Mental health promotion manual version 1 (7)
Field trial protocol (7)
Mental health promotion manual version 2 (7)
Final technical and management report (Month 36+2) (3)
Promotional brochure and publishable final report (7)
Summary

General objectives

The project aims to develop and disseminate guidelines for generic training and education with respect to Mental Health Promotion and Illness Reduction, and in addition implement specific applications with respect to the prevention of suicide, depression, and alcohol and drug abuse.

Strategic relevance and contribution to the public health programme

With the implementation of the European Green Paper on Mental Health, and the development of the Mental Health Pact, the strategic importance of Mental Health Promotion and Illness Reduction as keystones of Europe-wide mental health policy and practice has never been greater. The recent implementation of the Mental Health Pact has strengthened the significance of this initiative. Added value is supplied through collaboration with European level health and social service professional bodies, university networks, civil society organisations and non-traditional actors.

Methods and means

Project actions include consensus finding stakeholder consultations, achieved through the development of a carefully selected set of scientific committees. These will be systematically evaluated through goal attainment scaling. A specific innovation is the involvement of mental health service users as nontraditional actors who will build on previous work by developing multidisciplinary training guidelines and training programmes with a special emphasis on positive mental health, healthy living, diet and exercise.

Expected outcomes

The European health inequalities agenda is addressed through ensuring a dissemination focus which embraces Southern Eastern and Baltic European areas. Outcomes are an integrated and comprehensive set of training guidelines and model training programmes accessed through an interactive website, endorsed by European level professional body and university networks.

Keywords and portfolio

Keywords

Poverty & social exclusion within Socio economic factors
Vulnerable groups within Target groups
Mental diseases and disorders within Non communicables diseases
Primary care within Health system within Healthcare
Health education within Methods
Portfolio
Mental health within Fostering good health

Reports & deliverables

Final Report
Final Report (EN) (C)

Assessment Report
Internal Assessment

Deliverables
Dissemination plan
Guidelines (EN) (P)
Evaluation plan
Project website
Critical review of current training guidelines and training programmes in mental health promotion in the context of mental health pact and current EU mental health promotion policy
Overview of progress: obtaining agreement and commitment of European professional body and university commitment to adopting training guidelines and programmes
Guidelines for inclusion of service users in mental health promotion training including package designed to promote healthy living and positive mental health
Comprehensive guidelines and model programmes for prevention of suicide and depression
Comprehensive guidelines and model programmes for prevention alcohol and drug abuse
Guidelines for health and social care professions including Psychiatry, Clinical Psychology, Nursing and Social Work, in the area of mental health promotion
Case studies of effective methods for local implementation of guidelines and in using positive role models with the media
Two final peer review publications
Final summative conference
Final evaluation report: a systematic analysis of the levels of success achieved by the project in achieving its objectives using the goal attainment scaling methodology

Maximum EC Contribution: 699 909,43 €

Duration: 2009/10/09 - 2012/10/31
Summary

General objectives

The European Network for Traumatic Stress - Training and Practice (TENTS-TP) aims to widely disseminate and implement evidence based practice for those affected by traumatic events to promote social inclusion throughout the entire European region. This will be achieved by developing guidelines that effectively integrate mental health promotion and disorder prevention into the training and practice of professionals in mental health and social services. TENTS-TP will integrate the work of other European projects in the field.

The final aim is to raise levels of knowledge and expertise of the end users of this project (mental health and social service professionals) which will result in improved services to those affected by traumatic events. Professionals responsible for teaching and training in this field will be identified, provided with evidence based practice teaching package and equipped to implement this in a sustainable manner in partner countries.

Strategic relevance and contribution to the public health programme

The strategic relevance of TENTS-TP lies in the added value that integrated guidelines on post-trauma psychosocial care will bring to the existing knowledge and practice of mental health. As a result, TENTS-TP will improve resiliency within member and partner countries by enabling them to appropriately manage the psychosocial consequences of traumatic events.

Methods and means

The project will achieve its aims by developing guidelines that effectively integrate mental health promotion and disorder prevention into the training and practice of professionals in mental health and social services. Methods include systematically reviewing the field to establish the evidence base, the Delphi process to achieve consensus, and mapping and needs analysis to inform the development of comprehensive educational resources.

Expected outcomes

The expected outcomes include: 1) training and practice guidelines for professionals based on the previous TENTS project’s evidence based psychosocial care guidelines; 2) a core TENTS-TP curriculum; 3) high-standard educational materials (e.g. DVD’s, workbooks), tailored to different cultures and languages across Europe; 4) best practice guidance for combating social exclusion of people with mental health problems secondary to type 1 trauma; 5) an e-learning platform on the TENTS website; 6) A ‘Teach the Teachers’ workshop disseminated in all participant countries; 7) An established European network of ‘teachers’.
Keywords and portfolio

Keywords
Intentional within Injuries within Lifestyle
Poverty & social exclusion within Socio economic factors
Vulnerable groups within Target groups
Mental diseases and disorders within Non communicables diseases
Primary care within Health system within Healthcare

Portfolio
Mental health within Fostering good health

Reports & deliverables

Final Report
Final Report

Assessment Report
Internal Assessment

Deliverables
TENTS-TP Website facilities
Report 1d: Information on existing training and teaching courses
Report 1a: Training and practice guidelines
Report 1b: combating social exclusion
Report 1c: core curriculum
Report 1e: Training and teaching needs analysis
Teaching and training materials
Local teaching networks
Teaching the teachers workshops
Evaluation of effectiveness of dissemination
The Forgotten Children – Children of Parents with Mental Illness (COPMEN)

Summary

General objectives

The general objective of the two day conference was to develop further on previous work which has been carried out, such as the EU funded CAMHEE project and by organisations such as the WHO, UNICEF and various family support associations in Europe. Throughout the two days, delegates discussed what was happening across Europe in order to examine and review actions and programmes that are aimed at improving the outlook children who have parents with mental illness. The conference was also a platform to expose the plight of these children. Another objective was to address the need to protect the rights of these children and to raise and discuss various related issues.

Expected achievements

- Early identification and prevention of the problems associated with children who have parents with mental illness
- Support in parenting - education of parents with emphasis on the role of the extended family
- Child protection
- Increased awareness of the problems and issues surrounding this young group

The conference also aimed to

- Initiate a process through the national member organisations of EUFAMI to translate the results (identified best practices) of the conference into tangible actions in Europe, in line with EU/WHO initiatives and through better understanding of the issues.
- Agree actions among all stakeholders to promote and support the Commission's Pact for Mental Health and Well-being
- Gain widespread publicity for a consensus paper through pan-European and national media relations activities and thereby help to raise awareness
- Use the conference to initiate a virtual ‘Action Network’ of stakeholders.

Target audience

The conference programme was devised to reflect an integrated and coordinated approach to the subject matter and encapsulate a total European perspective in terms of content and speaker/workshop. Invitations were sent to target delegates in all of the European countries as well as in the US, Canada, Australia, New Zealand, India, Japan and China. The main reason for sending invitations to countries outside Europe was to extend the catchment area for expertise and knowledge gathering.

We also targeted European representatives from the various teaching, child and school psychologist and psychiatric organisations. Delegates from European Youth Organisations, European Psychiatric Nurses, the European Psychiatrists Associations and Magistrates and Judges working in the area of youth and young adults, other professionals, who through the course of their every day work come into contact with these children (such as General Practitioners, Social and Health workers) and representatives from Child Protection agencies in the EU attended. Delegates from the WHO, UNICEF and the EU also attended.
### Conference programme

The conference programme included a number of plenary sessions and a series of parallel workshops.

During the first plenary session, delegates heard first hand accounts and experiences from both a child of a parent with mental illness and a mother who has suffered with mental illness for many years. Then the scene was set by Professor Tytti Solantaus, from the National Institute for Health and Welfare Finland. The second plenary session had two distinct sections. The first section focused on the rights from three different view points. The second section was devoted to the topic of developing the child and parent supporting services in Europe and the speaker was Dr Dainius Puras from Vilnius University. The third plenary session was the wrap up session and included reports back, with recommendations, from the various workshops. There were 4 parallel workshops on each of the two days. A Poster exhibition was also held.

For further information about the final conference programme, please consult the links below.

### Reports & deliverables

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II. Alzheimer
ALzheimer COoperative Valuation in Europe (ALCOVE)

Summary

General objectives

The Joint Action contributes to public health programmes in Europe and develop Alzheimer’s disease (AD) and dementia prevention and care models in different European countries. The aim is to contribute to improvements in health by supporting and facilitating quality and efficiency of public health and healthcare policies and interventions. Synergy and avoidance of duplication with other health and research programs will be ensured.

The aim is to build a sustainable European platform. The objectives of ALCOVE are to accomplish the following during the 2 year project duration:

1. Establish a European statement on Alzheimer’s disease: Propose a synthesis regarding AD information and practices in Europe which could be the basis for further implementation at the European level
2. Ability of the JA to support the implementation of good practices in the field of risk prevention with measured results for patients: a focus on the overuse of psychotropics.

Strategic relevance and contribution to the public health programme

ALCOVE is a response to an explicit request by the EU and MS and covers a number of EU MS, incl. CZ, BE, GR, FI, IT, LV, LT, SK, ES, SE, UK and FR, pooling different competences across Europe with diverse experiences for the prevention and care of AD and dementia. Strategic relevance is enhanced by the involvement of various types organisations to provide scientific excellence and develop links for future collaborations between institutions involved in AD and dementia in EU countries. Due to the nature of AD and its impact on ageing and the aged as well as to national health systems (in terms of both social and economic impact) the ALCOVE JA corresponds to the approach outlined in the white paper: Together for Health: A Strategic Approach for the EU 2008-2013. The diagnosis and treatment of AD developpe several of the identified priority areas for 2010, including: Sustainability of health systems in the face of challenges such as the ageing population; Inequalities in health within and between MS; and Health security, surveillance and response to health threats.

Methods and means

The JA builds on methods and tools developed by international EuroCode and Dementia in Europe Yearbook (Alzheimer Europe) and relevant collaborations. It comprises four fields and share a common question on risk reduction in population with AD, i.e. the overuse of psychotropics. WPs are devoted to: 1 Improvement of knowledge, using existing epidemiological collection data and connecting of these studies with other national info systems. 2 Improvement of risk prevention and diagnosis, based on better knowledge of effectiveness of preventive strategies, using an assessment of implementation of these strategies. Improvement of diagnosis: improvement of operational criteria of diagnosis and assessment of health care systems in order to formulate recommendations. 3 Improvement of existing practices and care models, based on assessment of info about care practices, training practices and evaluation of the rights of the persons with dementia (concerning professional and family carers). 4 Autonomy and dignity of people with dementia from an ethical and legal perspective (incl. ADW, competence assessment w/ overview of good practices.)
Expected outcomes

ALCOVE will support effective collaboration for improving the AD public health problem in Europe that brings added value at the European, national and regional levels. The JA aims to bring better knowledge and development of risk prevention and care recommendations to facilitate policy and health care decision making in EU MS. The main outcome will be the establishment of a network for risk prevention and care of dementia in EU, with the hope that EU MS not yet involved in this JA will, in the future, join the network. Exchange of information among agencies will be increased, avoiding duplication of work in the field of AD and other dementia in EU. Availability of information allows MS to adapt recommendations to each situation, allowing better efficacy. Finally, emerging and future developments in the domains of risk prevention and care improvement, will be more easily disseminated and implemented.

Keywords and portfolio

Keywords
Patients rights within Socio economic factors  
Vulnerable groups within Target groups  
Mental diseases and disorders within Non communicables diseases  
Intellectual disability within Disabilities  
Secondary care within Health system within Healthcare

Portfolio
Population groups within Health in Society  
Ageing within Health in Society  
Major and chronic diseases within Taking Action against Diseases  
Mental health within Fostering good health

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Workplan & Communications toolsReport from final conference (WP2) (7)  
Plan for Evaluation of the JA (WP3) (6)  
Interim Technical and Financial Reports from the JA (6)  
Interim Technical and Financial Reports from the JA (EN) (C)  
Recommendations to improve epidemiological data on AD & dementia w/ overview data & def. of best practices for data collection (7)  
Recommendations to improve ED & care w/ assessment of MS recommendations & diagnostic HC systems & their implementation (WP5)(cf Ib) (7)  
Recommendations to improve practices in ambulatory & nursing home settings w/an assessment of practices & training focusing on PBD (7)  
Recommendations to improve rights & dignity of people w/ dementia (ADW & good practices in assessing the CAD)(WP7)(cf Ib) (7)
**Alzheimer Europe (AE)**

**Summary**

Mission and vision of the operating grant holder

Alzheimer Europe (AE) defines its mission as «changing perceptions, practice and policy in order to improve the access of people with dementia and their carers to treatment options and care services». In addition, the organisation has defined its guiding philosophy as «promoting the autonomy and self-determination of people with dementia and their carers throughout the course of the disease».

To achieve its mission and accomplish its vision, Alzheimer Europe has developed four objectives in its strategic plan (2011-2015) which was developed within the framework of its 2010 Operating Grant:

1. Making dementia a European priority through representing the interests of people with dementia, partnering with European institutions and jointly developing policy;

2. Supporting policy with facts by improving the information exchange between AE, its members and other stakeholders, by setting up a European Dementia Observatory and by comparing national systems and identifying best practices;

3. Basing our actions on ethical principles by understanding ethical principles and approaches, promoting a rights-based approach to dementia and finding common ground and building consensus on ethical issues;

4. Building a stronger organisation by supporting and involving national associations, involving people with dementia and their carers, establishing AE conferences as unique networking opportunities, developing strategic partnerships, providing a sound governance structure and diversifying the organisation’s funding.

On the basis of these strategic objectives, Alzheimer Europe develops annual work plans outlining the priority areas and projects of the organisation.

**Strategic objectives and specific activities**

AE has four key strategic objectives:

1. Making dementia a European priority,
2. Supporting policy with facts,
3. Basing our actions on ethical principles and
4. Building a stronger organisation.

As part of the 1st objective, AE developed close ties with the different European institutions and created the European Alzheimer’s Alliance comprised of Members of the European Parliament. The organisation also actively participated in the preparation of the French Presidency Conference on Alzheimer’s disease, the Swedish Presidency Conference on dignified ageing and the Spanish Presidency Conference on mental health of elderly people. AE also contributed to policy discussions on a European level, such as information to patients, cross-border health care or the Commission Transparency Initiative. In 2012, AE will develop a memorandum of understanding with ALCOVE, the Joint Action on dementia. Finally, AE took an active part in the consultation process for the development of the Strategic Research Agenda of the Joint Programming on Neurodegeneration and the stakeholder involvement process of the European Innovation Partnership for Active and Health Ageing.

As part of the second objective, AE carried out inventories of national legislation on legal issues affecting people with dementia and their carers. The national reports on healthcare decision
making, guardianship systems and restrictions of freedom were published in the 2009, 2010 and 2011 editions of the organisation's Dementia in Europe Yearbooks. In addition, AE actively communicated with its membership, European institutions and interested parties (~4,500 contacts on AE mailing list) on its activities, European and national policy developments, as well as science breakthroughs via its monthly e-mail newsletter.

As part of the third objective, AE set up the European Dementia Ethics Network with a steering committee comprised of national experts with a background in ethics. In this area, Alzheimer Europe analysed ethical issues in detail, provided an in-depth literature review and published recommendations on such issues as end-of-life care for people with dementia, the use of advance directives by people with dementia, the ethical implications of assistive technologies and of dementia research.

As part of its fourth objective, AE has ensured to involve people with dementia in its activities, meetings and projects and will be setting up a European Working Group of People with Dementia in 2012. AE has also organised successful annual conferences which attracted between 300 and 600 participants from different professional backgrounds and countries.

From 2006-2008, AE also coordinated a three year Commission financed project entitled «European Collaboration on Dementia - Eurocode» which resulted in reports on the socio-economic impact of dementia, psycho-social interventions, risk factors and prevention, the prevalence of dementia, the diagnosis and treatment of dementia and the provision of social support to people with dementia and their carers.

For its 2010, 2011 and 2012 activities, the organisation received operating grants which allowed the organisation to carry out a number of key activities described above, including the Dementia Ethics Network and the Dementia in Europe Yearbooks.

Expected outcomes

Alzheimer Europe has identified four key activities for its 2013 Work Plan which will build on the results of its 2010, 2011 and 2012 operating grants. These activities are geared towards a collaboration with and support of other European initiatives, such as the European Innovation Partnership on Active and Healthy Ageing, ALCOVE, the Joint Action on Dementia and the Joint Programming on Neurodegeneration. In particular, the organisation will carry out the following main activities:

1. National dementia strategies and policies
A significant number of EU countries have developed national strategies, or are in the process of doing so. However, the state of development and implementation varies greatly between countries. AE will carry out an inventory and comparison of national strategies, but will also pay close attention to the policies of those countries which have not yet developed formal strategies. Due to the great number of issues covered in dementia strategies, AE will divide this work over successive years. In 2012, it focused on the medical and scientific issues (research, early diagnosis, treatment, prevention, guidelines and medical education), whereas in 2013 it will focus on the social and care aspects (Care standards, independent living, dementia friendly communities, training of care staff and carer support). National reports will be developed with an overview of national strategies and policies and will be published in the 2013 edition of the Dementia in Europe Yearbook. Particular attention will be paid to developing synergies with the European Innovation Partnership on Active and Healthy Ageing and its two pillars on «care and cure» and on «active ageing and independent living».

2. Ethical discussion of societal attitudes towards dementia
Continuing the focus on ethical issues from previous operating grants (assistive technologies in 2010, dementia research in 2011 and restrictions of freedom in 2012), AE will dedicate its 2013 work on ethical issues to societal attitudes to dementia and an ethical discussion on the portrayal of dementia, the use of language and perceptions of the disease and how they contribute to social exclusion, stigma and discrimination. This will be done in collaboration with the experts identified through the European Dementia Ethics Network. In this area, AE will carry out an extensive literature review and develop recommendations in collaboration with ethical experts.
3. European Working Group of People with Dementia

Thanks to its 2010 operating grant and the consultation of its member organisations, user involvement was identified as a key priority for Alzheimer Europe and this led to the setting up of a European Working Group of People with Dementia in 2012. This working group will meet twice in 2013 and the Chair of the Working Group will participate in the meetings of the AE Board as a full Board member. The Group will be consulted and asked to ensure user representation and involvement in all AE activities. Members of the working group will nominated by the national member organisations of Alzheimer Europe. AE will support the attendance of one person with dementia from nominating organisations as well as that of a carer or other supporter.

4. Dissemination of European and national information on dementia

Alzheimer Europe will continue to gather and disseminate all information on dementia at both a European and national level and will collaborate closely with the European Innovation Partnership on Active and Health Ageing, the Joint Action and Joint Programming on Alzheimer’s disease. A focus of the dissemination work will also be on policy developments. Scientific information with regard to research on new treatments and new care approaches will also be highlighted in AE’s dissemination tools (extensive website and monthly newsletter).

5. Assessing the numbers of people with dementia

In 2013, AE will also update the figures on the prevalence of dementia and provide national reports on the numbers of people with dementia in all EU countries based on UN population statistics and the EuroCoDe prevalence rates. AE will also provide a report on the historical and forecast increase of these numbers (by providing estimates for the numbers of people with dementia over the past 5 and next 3 decades 1950–2050).

Keywords and portfolio

**Keywords**

Patients rights within Socio economic factors
Elderly within Target groups
Alzheimer within Dementia within Mental diseases and disorders within Non communicables diseases
Dementia within Mental diseases and disorders within Non communicables diseases

**Portfolio**

Interest groups within Health in Society

Reports & deliverables

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**Deliverables**

Dementia in Europe Yearbook
Report on the ethics of societal attitudes to dementia
Report on the European Working Group of People with Dementia
AE E-mail newsletter
AE Internet site
Technical and financial report
22nd Alzheimer Europe Conference: Changing perceptions, practice and policy (AEC)

Summary

General objectives

The Commission Communication on a European initiative on Alzheimer's disease ingled out four main areas for greater EU collaboration:
1. Acting early to diagnose dementia,
2. A shared European effort in research,
3. National solidarity and exchange of best care practices,
4. Respecting the rights of people with dementia.

In order to support the actions outlined in the Commission Communication on a European initiative on Alzheimer’s disease and other dementias, the 22nd AE Conference will focus on these four priorities and organise an exchange of information, experiences, projects and best practices in the following areas:

1. Medical and scientific update (early diagnosis, prevention, epidemiology)
2. Social and care aspects (psycho-social interventions, care services, stigma and discrimination, integration of Alzheimer’s disease in mental health promotion activities)
3. Legal and ethical issues (guardianship systems, consent, advance directives, patients’ rights)
4. Dementia strategies and policies (public health impact of dementia, national plans, financing of care, carer support measures, image of dementia).

In all areas, AE will identify key note speakers to provide state of the art presentations on the current knowledge and understanding, whilst inviting presenters to submit abstracts on ongoing and recently finalised research, projects and experiences.

In addition, AE will collaborate with EU funded initiatives to share the progress and results of research initiatives of programmes and projects like the Joint Programming Initiative on Neurodegenerative Disease, the Joint Action (ALCOVE-Alzheimer COoperation and Valuation in Europe), projects supported under the FP7 and AAL Programmes and by the Innovative Medicines Initiative (PharmaCog).

Expected achievements

In the past, Alzheimer Europe Conference have attracted between 300 and 600 participants and AE expects between 300 and 400 participants for its 22nd AE Conference in Vienna. Through its network of national Alzheimer associations, AE wants to disseminate information on its conference in all EU Member States. At its 20th conference in Luxembourg for example, 22 out of 27 Member States of the European Union were represented.

In order to encourage the participation of delegates from Eastern Europe, AE has introduced a reduced registration fee for participants from lower and middle-income countries as classified by the World Bank. For its 21st AE Conference in Warsaw for example, the early bird registration fees were for EUR 200 for participants from high income countries and EUR 100 for participants from low and middle income countries. In addition, AE will investigate the possibility of waiving
registration fees for representatives of some of its member organisations who might otherwise not be able to attend.

Although the conference language will be English, it is foreseen to have simultaneous translation into German for all sessions taking place in the main plenary room (including parallel session taking place in that room). During each parallel session time slot, an additional workshop or session will be organised in German. For its 22nd AE Conference in Vienna, AE will therefore ensure a concerted dissemination of the conference announcements via its German speaking member organisations in Austria, Germany, Luxembourg and Switzerland. Special attention will be paid in 2012 to reach out to mental health and public health experts.

Finally, AE will collaborate with other European networks (European Association of Geriatric Psychiatry, the European Federation of Neurological Societies, the Interdem Network, the European Alzheimer’s Disease Consortium, the European Union Geriatric Medicine Society and the International Association of Gerontology - European Union) to target participants of the conference.

Target audience

Due to the multi-disciplinary approach chosen for AE Conferences, the programme is targeted at different audiences. AE hopes to attract health care professionals, researchers, academics and people involved in Alzheimer associations, but also policy makers and people with dementia and their carers.

Additional attention will be paid to reaching out to public health experts and professionals active in the mental health field (mental health promotion).

At the 20th Alzheimer Europe Conference in Luxembourg for example, there were 318 participants which could be broken down as follows: 112 health and social care professionals, 78 Alzheimer association staff and volunteers, 49 academics and researchers, 29 industry representatives, 13 policy makers and civil servants, 12 persons with dementia and 25 participants who did not provide information on their professional background.

Thanks to its extensive network of national member organisations and its collaboration with other professional organisations (European Association of Geriatric Psychiatry, the European Federation of Neurological Societies, the Interdem Network, the European Alzheimer’s Disease Consortium, the European Union Geriatric Medicine Society and the International Association of Gerontology - European Union) hopes to disseminate information on the conference to the different professional networks and nationalities.

A unique feature of AE Conferences is the involvement of people with dementia as speakers and participants and AE has created a special bursary system to encourage their participation. As in previous years, AE will therefore waive the registration fees of 10 people with dementia and cover the travel and accommodation costs (including those of their carer if necessary). At past conferences, AE was also able to provide free places to carers and people with dementia from the host country through support obtained from foundations and will seek this type of support also for its 22nd AE conference.

Conference programme

On the evening of the first day of the conference (Thursday), Alzheimer Europe will organise the opening ceremony followed by a welcome reception for participants. The conference will be opened by the chairs of Alzheimer Europe and the Austrian Alzheimer association. In addition, AE will invite representatives of the European Commission and the Austrian government to formally welcome the participants and present their respective priority programmes in the field of dementia. AE will invite a person with dementia to deliver the keynote lecture.

During the two conference days, there will be a total of four plenary sessions (Friday and Saturday from 9.00-10.30 and from 16.00-17.30). These will be dedicated to the following four subjects:

1. Medical and scientific update (with presentations from the Joint Programming Initiative, the FP7 Programme and the Innovative Medicines Initiative),
2. Social and care aspects (with presentations from the Joint Action work on care approaches and the Ambient Assisted Living activities in the field of dementia),
3. Legal and ethical issues (with key presentations of Alzheimer Europe’s European Dementia Ethics Network and the Joint Action work on capacity assessment),
4. Dementia strategies and policies (with presentations on the implementation and progress of selected national Alzheimer plans and strategies).

Additionally, the conference will break out into parallel sessions (Friday and Saturday from 11.00-12.30 and from 14.00-15.30) which will again be sub-divided into the four main subject areas. The programme will be chosen from amongst the successful abstracts which will have been submitted under the call for abstracts which will be published in January 2012. A draft call for abstracts foresees the following key topics:

1. Medical and scientific update (early diagnosis, prevention, epidemiology)
2. Social and care aspects (psycho-social interventions, care services, stigma and discrimination)
3. Legal and ethical issues (guardianship systems, consent, advance directives, patients’ rights)
4. Dementia strategies and policies (national plans, financing of care, carer support measures, image of dementia).

Keywords and portfolio

**Keywords**
- Patients rights within Socio economic factors
- Elderly within Target groups
- Neurological diseases and disorders within Chronic diseases within Non communicables diseases
- Dementia within Mental diseases and disorders within Non communicables diseases
- Secondary care within Health system within Healthcare

**Portfolio**
- Ageing within Health in Society
- Mental health within Fostering good health

Reports & deliverables

**Final Report**
- Final Report

**Assessment Report**
- Internal Assessment

**Deliverables**
- First announcement and call for abstracts
- Conference website
- Second announcement and preliminary programme
- Conference programme and book of abstracts
- Conference presentations
- Conference video