



Strengthening Engagement in Public Health Research
STEPS

Report on National Workshop in Cyprus

19 March 2010

**Office of the European Parliament and the
Representation of the European Commission in Cyprus**

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1. SHORT GENERAL DESCRIPTION OF WORKSHOP

Introduction

The Workshop was organised by RUBSI on Friday 19 March 2010, at the Offices of the European Parliament and the Representation of the European Commission in Nicosia, who took the role of Co-organiser. The issue selected for discussion that was selected as of major importance in the field of public health and has not been seriously researched so far was “Alzheimer’s Disease, Elderly and the Family: The case of Cyprus”. Hence, the organisations invited varied from CSOs involved both in Ageing and in support for people with Alzheimer’s disease, the focal points for research in public health in Cyprus and governmental services involved in both research and the Alzheimer’s disease.

The workshop attempted to cover the objectives set at the meeting in Lodz and to follow the 4 themes that have to be covered according to the STEPS requirements. Although the attendance was relatively poor, the participants who attended had a very fruitful discussion, both on the issue of promoting public health research as well as on the public health issue selected for discussion. One of the major problems the workshop faced, both in terms of preparing the STEPS report, as well as for the presentation of the public health research conducted in Cyprus, was that there is no reporting in the SPHERES program for Cyprus, because the relevant SPHERES questionnaire was never completed. RUBSI is trying, within the framework of STEPS to collect as much available data as possible.

The title of the workshop

“Alzheimer’s Disease, Elderly People and the Family: The Case of Cyprus”

The aim of the workshop

1. To inform CSOs, researchers and government relevant bodies about STEPS
2. To promote the concept of public health research for the purpose of improving the quality of health and health services
3. To involve CSOs in public health research, so as to serve the objectives of the Science in Society Action
4. To define one topic of public health which is of national importance and point-out the need for this topic to be researched



The date and venue

Friday 19 March 2010, Office of the European Parliament and the Representation of the European Commission in Cyprus

Number of participants 14

The title of presentations and names and short introduction of speakers

1. "Objectives of the STEPS program and current situation regarding public health research in Cyprus", Christina Loizou, Senior Researcher, RUBSI
2. "The role of the CSOs in public health research", Dr Constantinos Phellas, Dean of School of Humanities, Social Sciences and Law, University of Nicosia, Executive Director, RUBSI
3. "Science in Society – EC 7th Framework Program", Matheos Spanos, Scientific Officer A', Research Infrastructure Unit, Cyprus Research Promotion Foundation
4. "EU Health Programme 2008-2013, Call 2010" Elena Makrygiorgi, Department of European Programs, Ministry of Health



2. REPORT ON FOUR THEMES

2.1. Public health research system in Cyprus.

1. Description of STEPS and the existing public health care research system

Presentation: “STEPS Program and Current Situation in Public Health Research in Cyprus” *Christina Loizou, Senior Researcher, RUBSI*

The presentation initially refers to the background of STEPS and its objectives and the means to achieve them. It gives the definition of Public Health and Research in Public Health as defined by STEPS, the commitment to the Treaty of Lisbon and a report of the current situation in Public Health Research in Cyprus.

The objectives of STEPS were highlighted as follows:

1. To involve the civil society organisations, the researchers and the ministries of health in mapping the research systems in public health
2. To organise national workshops in all new member states participating in STEPS
3. To develop a European perspective through a final conference

The objectives are set in order to help improve the health of citizens, to promote health and its protection and to improve the quality of health and of the health services for the citizens of Europe.

On a national level, as mentioned above, the SPHERES reporting on Cyprus was poor because the relevant information was never given by the Ministry of Health. The very general existing data was reported by Professor McCarthy after his visit in Cyprus in April 2009, which confirms the lack of data on public health research in Cyprus and a low publication level in this field. According to his report, the Department of Medical and Public Health Services has a mission statement which includes “Establishing of a medical and public health research component”, which is not fully developed, although statistical information coverage is gradually improving. It reports some information given by the Cyprus Research Promotion Foundation. This report refers to projects funded by the Research Promotion Foundation and by European Union Funds. It also gives a general



outline of public health in Cyprus in terms of Tertiary Education Courses, which confirms the absence of a University Medical School. It also confirms the poor statistical data from epidemiological studies.

Under this spectrum, any data is to be collected by RUBSI, since the SPHERES project did not manage to collect the necessary information. Therefore the information presented at the workshop referred to the data collected by RUBSI before the workshop (the data collection still continues). So the relevant workshop presentation included a presentation of STEPS, its objectives and its background, as well as the information received by that time regarding public health research in Cyprus. In particular the data collected was by that time supplied by the following:

- University of Nicosia:

Funding: National, European and Bi-communal (UNDP)

Topics of Research: Use of anabolic steroids in recreational sports; Smoking, Alcohol, Drugs; Epidemiology on Diabetes, Dislipidaemia, Hypertension, Metabolic Syndrome; Diabetic Nephropathy; Stroke; Atherosclerosis; Psychological Impact of Sports; Psoriasis; Obesity and Nutritional Habits; Eating disorders and stress; deafness; learning disabilities; health of asylum seekers

Publications: Journal Publications, Books, Online publications

- Cyprus University of Technology:

Funding: National (University)

Topics of Research: Sexual and reproductive Health of Migrants; Smoking; Elderly and Community Nursing

Publications: Journals

- Fredrick University Research Center

Funding: National, Bi-communal

Topics of Research: Health and Violence in the Family

Publications: Reports, Conference presentations, On-line publications



- Cyprus Monitoring Center for Drugs and Drug Addiction

Funding: National, European

Topics of Research: Use of Drugs and Drug Addiction

Publications: Yearly Reports, Journals

- RUBSI

Funding: National, European, Bi-Communal

Topics of Research: Psychosocial Aspects of Illness (Diabetes, HIV/AIDS, Cancer, Breast Cancer etc.); Organ transplants; Migrant Health; Ageing; Elderly and Physical Activity; Vaccinations; Health System Evaluations

Publications: Journal, Books, On-line publications, organisation of Conferences and Lectures.

Discussions

The participants discussed in detail the fact that research in Cyprus is fairly new, mainly due to the fact that academic institutions, who would be the major developers of research in Cyprus are all newly founded (from 1995 onwards), as compared with other member states where universities have been existing for more than 50 years. The other problem is that financing for research is relatively small on a national level. The major source of funding is through the Cyprus Research Promotion Foundation (RPF) and, of course, **with** Cyprus' accession to the EU things are much better, since Cyprus can also profit from research on a European level.

On a national level there is a problem with the legislation determining research which needs to be reformed. This affects also the Public Health Research Sector. The Member of the Parliamentary Committee, who was present, suggested that she should look into the matter. The other problem that is of great importance is that due to the recent financial crisis a lot of funds for research were cut back from the latest state budget. Both the representatives of Research Organisations, as well as the representative of the Cyprus Research Promotion Foundation(RPF) stressed this matter, because the cuts have mainly affected the CRPF and consequently the research undertaken mainly by private universities.



Also there was an issue raised regarding the permits required in order to conduct research in schools, due to restrictions by the Ministry of Education.

Another issue that was raised was the need to publish or announce publicly results of research, especially research which is financed by the tax payers' money, as the citizens should have the right to know these results.

The participants also stressed the need of developing a data basis / library on research in Cyprus that would serve both the purposes of providing statistics for national, European or international use, as well as for researchers who would like to use it as background reference in future projects. It was suggested by the MP that such a data basis could be financed by the structural funds.

The RPF representative also highlighted the need to develop research infrastructure for which Cyprus is, at the present, in an inferior position compared to other member states, particularly regarding clinical laboratories. For several research projects in this field, clinical laboratory tests have to be sent abroad.



2.2. The role of different civil society, especially the citizen organisations, in contributing to public health research.

The CSOs who participated in the workshop were:

- the Cyprus Alzheimer's Association
- the Cyprus Youth Council,
- the Cyprus Family Planning Association
- the Multidisciplinary Committee on Alzheimer's which act as a consulting body to the Ministry of Health and
- the Cyprus Sociological Association

Presentation: “The role of the CSOs in public health research”, *Dr Constantinos Phellas, Dean of School of Humanities, Social Sciences and Law, University of Nicosia, Executive Director, RUBSI*

Dr Constantinos Phellas did a presentation on the “Strengthening of the Participation in Research in the field of Public Health”. He stressed that research in health and the community welfare is the major field of public health in the 21st century. Public Health has an individual and collective dimension reflecting the individual and social needs as well as the choices of these individuals. The promotion, implementation and evaluation of public health and welfare programs are difficult and require the cooperation of state, private and non-government sector.

Dr Phellas highlighted the fact that the social networks established by non-governmental institutions constitute significant foundations for the planning of strategies in the area of public health and the reinforcement and support will result in a more effective health promotion. Patients' individual experiences and not just the experts' are considered important in gaining new knowledge and in the development of the field. The simple individuals who form the civil society organisations are in a position to acquire knowledge in health issues and provide material for the development of specialised models which complement medical science and health promotion.



By studying health beliefs, we are able to see through the wider framework of contemporary societies and not just the medical model. The general activity and contribution of the community in public health issues is important per se, but it becomes more effective when it offers the ground for involvement in collaborations or for the provision of counseling services to the community.

Nowadays, CSOs have spread in a variety of fields and have gained an important role in facing several social problems. Activities initiated by the community are of different forms. Such Communities are the Europa Donna Cyprus, the AIDS Friends Support Center, etc. These organisations offer care and counseling, as well as lobbying for politicians and the medical system. So it is important that such organisations to be independent so that they can successfully defend their members' rights.

The collaboration among these CSOs has indirect benefits both on physical and mental health and reinforces the social networking among the CSOs. Research in the field of Public Health can focus on the inequalities in health and develop programs within the community, through the involvement of CSOs. Through such programs a social health model can be adopted. Also it could be recognised that health and quality of life in the communities is influenced both by the policies and practices of the National Strategic Public Health Plan as well as by the nature of the communities themselves.

Discussion

The participants discussed the fact that the response of the CSOs in research in general is relatively poor, although of great importance. This is confirmed by the poor response in the case of STEPS, both in terms of completing and returning the questionnaire, as well as in terms of Workshop participation. For the latter, some remarks were made, for future consideration, mainly as regards the timing of the workshop, which was organised on weekdays. This makes it difficult for CSO representatives to attend, bearing in mind that they are volunteers and it is difficult to leave their work on working hours. However, outside working hours timing would make it very difficult for civil servants to attend.



The good news that came from the Ministry of Health Representative is that whenever the CSOs are invited by the Ministry itself they do respond and they do participate in relevant events. So, the workshop suggested that in the future, any events planned of this character, might be organised with the collaboration of the Ministry of Health.

STEPS is a very good opportunity to bring together the research organisations, the CSOs, and government departments in order to focus on the importance of the cooperation in research in the field of Public Health. The workshop is valuable in itself for showing the input of the civil society in research with the involvement of the CSOs and for providing the researchers with new ideas of what has to be researched. On the other hand the experience of the public themselves, especially those who live with a disease and those who care for sick people can be very valuable in order to record the situation in public health in the country, as well as the needs, the problems and the policies that have to be developed. It can also be very useful for the health professionals to get to know the patients' point of view in terms of facing the disease and treating it, thus helping them to understand the patients and be able to provide a better quality health service.

Involvement in research also gives the opportunity to the CSOs to widen their perspectives and give another dimension to their role. They could become more active, in community life and be able to defend the rights of the patient populations they represent.

The role of the Cyprus Alzheimer's Association and of the Multidisciplinary Committee on Alzheimer's Disease

Mrs Diakou, the President of the Cyprus Alzheimer's Association gave a general description of the organisation and its activities. She explained that the Association has local branches in many towns of Cyprus and that they are the ones who had the initiative of creating 2 day centers for people with Alzheimer's disease, one in the capital and one urban. The centers offer daily care to their members as well as various forms of therapy, like educational lessons, art and music therapy, ergo-physiotherapy etc. She announced the Association's intention for developing the rural center into a hotel for people with Alzheimer's disease, where families could leave the patient for a small period in order to be able to get a break from the care. The main goals of the Association are:



- To raise public awareness on Alzheimer's disease
- To lobby for the patients' rights (legal, welfare and medical)
- To safeguard the social support of the people with Alzheimer's, and support their families financially and morally
- To reinforce any medical or social effort for the prevention and treatment of Alzheimer's disease.

The Association takes part in European, peripheral and International Conferences and has recently participated in the World Conference that was organised in Thessalonica, Greece. She also announced two world prizes for Cyprus in a Photo-Competition with the theme of Alzheimer's. Apart from the support it offers to patients, both the Association and the Multidisciplinary Committee are involved in campaigns, mainly in the Media, but also in education. Their campaign in some schools managed to raise awareness at many levels and children were actively involved in disseminating material about Alzheimer's. In one school specifically the children organised theater and painting with the theme of Alzheimer's. Both the Association and the Multidisciplinary Committee are involved in lobbying to the Ministry of Health, to the Parliament and to other Forums. They also participated in small-scale epidemiological research (2005), on a bi-communal basis, which was funded by the UNDP and which estimated an 8,000-10,000 people suffering from Alzheimer's in both communities in Cyprus. Furthermore the Association participates in the conferences organised by the Alzheimer's Disease International.



2.3. Title of national public health topic. “Alzheimer’s Disease, the Elderly and the Family: The case of Cyprus”

Discussion

Background on Alzheimer’s Disease in Cyprus in terms of Research

The topic decided for discussion at the workshop was “Alzheimer’s Disease, the Elderly and the Family”. Alzheimer’s has only been researched to a very small scale in Cyprus, but recently it seems to affect a large percentage of the population. Only one very small epidemiological study was conducted on a bi-communal basis in 2005, which estimated that around 8,000-10,000 people suffer from Alzheimer’s in Cyprus.

No epidemiological study has been done in the general population following the standard procedures in order to define prevalence, and only a small-scale research has studied the carers, from the nursing point of view. The president of the Alzheimer’s Association and the representatives of the Multidisciplinary Committee on Alzheimer’s commissioned by the Ministry of Health presented all the actions done so far in Cyprus, as well as their activities on an international spectrum. Both representatives spoke about the actions needed to be taken in the direction of assessing the needs of the families that care for people who live with the disease, as well as the promotion of measures of improving the quality of life of these families.

The research conducted by the Nursing Department of the Cyprus University of Technology

The representative of the Nursing Department of the Cyprus University of Technology, Dr Evridiki Papastavrou, who was the researcher involved in the study on the carers of people with Alzheimer’s disease, which was conducted in 2005, showed that the families of the people with Alzheimer’s suffer burdens both financial and psychological, such as depression, especially those who have health problems themselves. They also face problems due to the lack of education as regards coping methods. The research was conducted in 171 couples and the findings were published in the PubMed of the Journal of Advanced Nursing. The findings of the study confirm the literature mainly as regards levels of stress, depression and burden, which are derived from ignorance on how to treat and care for their patient. It is also understandable that as time passes, the demands of the patient’s



care increase, while the level of support decreases. Due to the course of the disease, the carer gradually realizes that he/she is caring for a stranger, as the patient basically loses his/her personality. It is also noted that people try not to disclose the Alzheimer's condition, in an attempt to prevent being stigmatized. It is estimated that stigma in Cyprus due to Alzheimer's is around the same levels as abroad. Quite often the families experience abandonment by their social environment. In the cases of wives – carers, they even experience demands from their own children, who do not realize the effort required for the care of the person with Alzheimer's Disease. Thus carers experience increased levels of depression, since on many occasions they are ill themselves. This has a negative impact on the level of care, which is, due to the circumstances decreased.

The study showed that the women-carers are the ones who carry the heaviest burden, because they are usually the ones who take up this role. It is very rare that when a woman suffers with Alzheimer's disease, the man will take the role of the carer. Usually one of the daughters has to do the caring. This is very important, because while in the case of a male carer, he does have support from the family, in the case of female carers, they are usually alone. It was also noted that quite often women have to give up their jobs in order to offer the proper care, something that men do not usually do. It was also noted that even in the cases where the person is hospitalized, or cared in an institution, the family still experiences depression at high levels, mostly because they feel guilty for not caring of the person themselves.

Another issue that was discussed was the role of the migrant domestic helpers, which is a very strong institution in Cyprus in terms of elderly people care. It was noted that only a small minority of the elderly (according to the official statistics of the Social Welfare Services, it is only around 4% of the elderly population) reside in elderly peoples' nursery homes and this only happens when the family cannot, especially because of the person's very poor condition, take care of their elderly.

The Multidisciplinary Committee

The Multidisciplinary Committee whose role is advisory to the Ministry of Health includes, apart from the Cyprus Alzheimer's Association, Medical Doctors, Psychiatrists,



Neurologists, physiotherapists, ergotherapists, and the Cyprus Psychologists' Association. The Committee is interdisciplinary. The Committee supports the Cyprus Alzheimer's Association. One of the main tasks undertaken is to advise the Ministry of Health on the very serious field of Prevention. For this reason, a specialist university professor from Greece has been called to educate general practitioners and psychiatrists who work in primary health care. She is also helping to design the National Strategic Plan on Alzheimer's disease, which also includes prevention in younger ages.

Actions that need to be taken

- Need to raise further public awareness on the issue of the Alzheimer's disease in order to diminish social stigma. The 21st of September, which is the World Alzheimer's Day is used by the Association in order to raise public awareness. This is done through the Media and in special kiosks set up for this purpose in the central town squares, where leaflets, handouts and other material is handed out to the public. The campaign should also spread more in schools; a suggestion was made by Dr Kouta, who also participates in the Educational Reform Committee that such subjects should be introduced in schools during the free hour that the children will have on Fridays before they are picked up by their parents, for raising awareness and lessening the social stigma related to diseases.
- Need to educate the families and especially the carers in order to be able to cope with the extremely demanding task and the difficulties of caring for a person with Alzheimer's disease.
- Need to raise awareness on the issue of early diagnosis
- Need to reform the legislation in order to give the person the right to write his/her will before their situation worsens.
- Need to improve and develop the day centers into respite centers, where the families can leave their patient under care for sometime, in order to be able to rest. The centers will provide special care for persons with Alzheimer's disease.
- Need to create a special clinic where the public can apply for help in relation to Alzheimer's. The clinic should also be able to provide early diagnosis. It should also be able to cope with all the stages of the disease with specialized professionals from all related disciplines. It could also undertake the role of educator both for the patients as well as their carers.



○ **Need for research**

- Need for an epidemiological research in order to define the prevalence of the disease. This would help the Ministry in its efforts for a National Strategic Scheme. It will also fill in the gaps that exists in terms of comparing percentages in Cyprus with the situation in other countries
- Need for a survey in the general population in order to investigate knowledge, attitudes and beliefs with regard to the disease. This would help enormously in defining the nature of awareness campaigns. RUBSI has taken the responsibility to proceed with this survey in the near future
- The above survey can also serve as a pilot research for another detailed research on the carers and families of people with Alzheimer's disease. This would result in drawing out recommendations for educating the families and for providing psychosocial support. It was decided that a proposal on such study will be submitted in the next Research Promotion Foundation call for funding. The proposal will be submitted in collaboration with the research organizations who participated in the workshop



2.4. European dimensions.

The European Dimension of the promotion of Public Research was covered in the workshop in two ways:

1. Presentation of funding opportunities in Public Health Research at European level
2. The workshop was supported by the Offices of the European Parliament and the Representation of the European Commission in Cyprus and it was hosted at their premises in Nicosia. Furthermore, it was widely advertised on their website which is part of a wider EU's network. This means that the announcement of the workshop was accessible to all EU members who were logging on the EU's official website.

Presentations

A) *Science in Society: Spread of Knowledge and Society Involvement* - European Commission 7th Framework Programme.

The presentation was done by Dr Matheos Spanos, Scientific Officer A', Research Infrastructure Unit, Cyprus Research Promotion Foundation.

Dr Spanos spoke about the Research Promotion Foundation's role as a focal point in Cyprus for Research. He emphasized the responsibility of RPF in announcing, funding and surveying the National programs and in coordinating the participation of Cyprus in European and International Research Programs and in International Organisations. He proceeded to present the 7th Framework Program, which is of 7 years duration (2007-2013) and has a 50 billion Euros budget. The strategic objectives of the program are to reinforce the scientific, the technological basis and the competitiveness of the European industry and to promote research which supports the policies of the European Union. Dr Spanos presented very shortly the programs COOPERATION, IDEAS, PEOPLE and NUCLEAR RESEARCH and more extensively on the program CAPACITIES. This program reinforces the research capacities required by Europe in order to become a dominant economy of knowledge intensity, and covers the following actions:

- Research infrastructures
- Research for Media
- Areas of Knowledge
- Research resources



- Special actions of international cooperation
- Inclusion of science in the social tissue – Science in Society

The Science in Society action focuses on

- *A stronger management of the relation between Science and Society* which includes research on the ethics of Science and Technology, promotion of the inter-relation between science and culture and promotes the debate on morals in Science.
- *The reinforcement of the potential and widening of the horizons with relation to Gender Issues and Science education*, which means the reinforcement of women's participation in scientific research, the promotion of science education in schools, science museums, scientific centers etc., and the reinforcement of the relation between science education and career.
- *The promotion of Bilateral Means of Communication, which facilitate the engagement of citizens in science*, which includes the encouragement of the promotion of the European dimension of scientific events addressing the public and scientific competitions – prizes.

Dr Spanos gave the deadlines for submitting proposals for the year 2011 and gave a short description of the programs running in Cyprus at the moment under this action. He closed his presentation by quoting the Commissionaire Gheoghegan-Quinn who said “Science must belong to Society”

B) EU Health Programme 2008-2013, Calls 2010

The presentation was given by Ms Elena Makrigiorgi, Administrative Officer, EU Coordination Unit, Ministry of Health, Cyprus. Mrs Makrigiorgi spoke about the European programmes on health for which the Ministry of Health is the focal point in Cyprus.

- 2nd Programme of Community Action in the field of health 2008-2013. The programme intends to complement, support and add value to the policies of MS and contribute to increased solidarity and prosperity in the EU. Its Objectives are: (1) to improve citizens' Health Security, (2) to promote health (3) to generate and disseminate health information and knowledge. Total budget of 321.5 million euros. Potential Participants: from EU Member States, EEA Countries, Accession and Candidate Countries, Croatia, European Neighbourhood Countries and Western Balkan Countries - Research Institutes and Universities, Public Administrations, Non-Governmental Organisations
- Call for Proposals 2010. Budget of 47,100.000 euros for 2010. The priorities are:



1) To Improve citizens' health security: *1.1. Protect citizens against health threats:* prevention and control of communicable diseases, preparedness for health emergencies, response capacity against CBRN attacks: *1.2. Improve citizens' safety:* prevention in the field of patient safety, safety of blood, tissues, cells and organs,

2) To Promote Health: *2.1. Foster healthier ways of life and reduction of health inequalities:* promoting health in all policies, public health capacity building, reduction of health inequalities, *2.2. Promote healthier ways of life and reduce major diseases and injuries by tackling health determinants:* children and young people, health and work, nutrition and physical activity, sexual health and HIV-AIDS, Mental Health, addiction prevention (alcohol, illicit drugs), prevention of major and chronic diseases and rare diseases (cancer, cardiovascular health, Alzheimer disease and other dementias, Autism spectrum disorders, Neurodegenerative diseases, rare diseases) healthy environments, Injury Prevention

3. To Generate and disseminate health info and knowledge: *3.1. Exchange knowledge and best practise,* *3.2. Collect, analyze and disseminate health information: European health information system, dissemination and application of health information,* *3.3. Analysis and reporting*

- Projects are co-financed and main preference will be given to projects contributing to a) improving health of EU citizens, measured where possible by appropriate indicators, b) Reducing health inequalities in and between EU Member States and Regions and c) Building capacity for development and implementation of effective public health policies particularly in areas of high need. Issues of Strategic Importance are to a) Involve new actors for health in sustained, co-operative and ethically sound actions, at regional or local level and across participating Countries, b) Demonstrate the evidence base and ability to provide measurable results where possible. Mrs Makrigiorgi ended her presentation by listing the projects in which the Ministry is involved.

3. The European dimension of the Alzheimer's Disease and the prospects of promoting the issue at a European level

Discussion:

Prevalence of Alzheimer's disease is increasing alongside with the Ageing of the European Population. It is a relatively new public health issue in terms of research. Under



this spectrum, many conferences and publications help in the exchange of scientific knowledge, but still the topic needs to be raised as a European issue..

On European level the Cyprus Alzheimer's Association was / is involved or participated in the following:

- In 2008 the President of France Mr Sarkozy hosted a European Conference where he set goals in prioritizing the issue of treatment of Alzheimer's disease. The conference was addressed by the EU Commissioner Mrs Androulla Vasiliou. Since then, the all the European Presidencies have been organising conferences on the issue.
- Under this spectrum, Cyprus has decided to include Alzheimer's disease as a major topic suggested for Discussion on the Agenda under the Cyprus Presidency of the European Union in 2012
- In 2012 the European Conference on Alzheimer's will be hosted in Cyprus under the Auspices of Alzheimer's Europe.



3. RESUMEE OF GENERAL DISCUSSIONS

The Workshop participants initially discussed about the general issue of research in Cyprus and the difficulties faced because of the financial crisis and the reduced funds in the field of research. It was noted that a data basis should be introduced, where all Cyprus research projects and publications should be listed, as well as a library. This should include public health research.

Regarding public health research it was noted that there is a lack of epidemiological data, an area that is gradually being developed. It was pin-pointed that the infrastructure for health and medical research in Cyprus is relatively limited and on many occasions researchers have to collaborate with laboratories abroad.

The importance of the CSOs' involvement in Public Health research was highlighted, as it offers a different spectrum than the health professional's approach to disease and treatment. Patients' experiences, cultural beliefs and personal approach to treatment, could benefit both the patients as well as the health professionals.

Regarding the national health topic, which concentrated on Alzheimer's disease, it was noted that so far it has not been thoroughly researched, although, considering the ageing of the population and the extended life expectancy, it is a public health issue that will have to be faced seriously, both by health professionals, as well as by public health policy makers. The research bodies participating at the workshop decided to proceed with research proposals in partnership, with the collaboration of the CSOs involved.

The European dimension prospect was discussed within the framework of the existing public health research funding programs. Finally the national health topic's European prospect was discussed, and it was decided that Cyprus would take an initiative through the 2012 EU presidency, both by bringing forward Alzheimer's disease on the Agenda, as well by organising a conference.



4. CONCLUSIONS, RECOMENDATONS

4.1 Conclusions

1. It is difficult to safeguard the participation of NGOs in such Workshops without the involvement of the Ministry of Health. Weekdays make it difficult on volunteers to get time off work in order to participate.
2. Research in Cyprus is suffering a crisis which is part of the wider financial crisis experienced in the country and in Europe.
3. STEPS was a very good opportunity to bring together the research organisations, the CSOs, and government departments in order to focus on the importance of the cooperation in research in the field of Public Health. The workshop showed the value of the input of the civil society in research in this field, since it was able provide the researchers with new ideas of what has to be researched.
4. The workshop gave the participants the opportunity to get acquainted with the funding opportunities offered at European level in the field of public health, especially regarding the involvement of CSOs in research and especially in public health research
5. Public Health Research can also be very useful for the health professionals to get to know the patients' point of view in terms of facing the disease and treating it, thus helping them to understand the patients and be able to provide a better quality health service.
6. Regarding the National Topic, Alzheimer's disease is a major issue that needs to be prioritized by European member states, mainly because of the ageing of the population in Europe and the increase in incidences.
7. In Cyprus there was only two small-scale research surveys conducting, one bi-communal and one for carers. Both projects show the necessity for further research in the field.
8. The Cyprus Alzheimer's Association together with the Multidisciplinary Committee on Alzheimer's carry most of the burden regarding support to patients and their families as well as raising public awareness campaigns.
9. Cyprus will include the issue of Alzheimer's disease high in the Agenda of the EU presidency ion 2012



10. A European conference will be held on Alzheimer's in Cyprus in 2012 under the auspices of Alzheimer's Europe
11. The Workshop participants agreed to cooperate in future research projects on Alzheimer's with the support of the Ministry of Health and the Cyprus Research Promotion Foundation.

4.2 Recommendations

1. There is need to create a data basis and a research library which would serve both in terms of collecting all available information on research conducted at national level and at european and international level. This would benefit both the public as well as the academia, as the data basis can be used for background purposes, as well as for referencing. Such a data basis will include work done in Public Health
2. Future workshops in Public Health should be organised with the cooperation and involvement of the Ministry of Health, since the CSOs seem more responsive to events organised by the Ministry of Health
3. There is need to conduct further research in Cyprus as there is a gap in the provision of statistical data for many public health and health issues compared to other member states
4. Regarding Alzheimer's, there is need to conduct research both in terms of epidemiology as well as in terms of qualitative studies on carers and the family. Research findings can form the basis for the designing of policies under the National Strategic Plan on Alzheimer's. Epidemiological research will show the figures, while qualitative study will show the problems and difficulties the families and carers face, with regard to the care of the patient with Alzheimer's, as well as the needs for education, and campaigns for raising awareness. The latter will serve in the direction of lifting the social stigma and in urging people for early diagnosis for prevention purposes.
5. There is a need to reform the legislation regarding the rights of people with Alzheimer's disease, both in terms of drawing their will, as well as for safeguarding their rights as patients.



6. Need to found new institutions regarding Alzheimer's disease in Cyprus, which will offer inter-disciplinary scientific support to patients with Alzheimer's disease as well as information and early diagnosis tests for prevention purposes.
7. Alzheimer's disease should be addressed as an issue on European level, as the European population is ageing and consequently figures are increasing.



5. ATTACHMENTS

5.1. Agenda of the workshop.



STEPS (Strengthening Engagement in Public Health Research)
Science in Society, Capacities, 7^o Πρόγραμμα Πλαίσιο ΕΕ

Friday 19 March 2010
Office of the European Parliament and the
Representation of the European Commission in Cyprus

Organiser: RUBSI – Research Center in Behaviour and Social Issues

Program:

9.30 Welcome Address

Dr Constantinos N Phellas, Dean of the School of Humanities, Social Sciences and Law,
University of Nicosia, Executive Director of RUBSI

9.40 Presentation: Objectives of the STEPS Program and the Current Situation Regarding Public Health Research in Cyprus

Christina Loizou, Senior Researcher, RUBSI

10.00 The role of the Civil Society Organisations in Public Health Research

Dr Constantinos N Phellas

10.15 Break - Coffee

European Research Programs

10.40 Science in Society – EC 7th Framework Program

Matheos Spanos, Scientific Officer A', Research Infrastructure Unit,
Cyprus Research Promotion Foundation

10.55 European Executive Agency for Health and Consumers

Mrs Elena Makrygiorgi, Department of European Projects, Ministry of Health on European Programs

11.10 Discussion: “Alzheimer Disease, Elderly People and the Family: The case of Cyprus”

12.00 Workshop Evaluation

12.15 End of Workshop

5.2 List of participants (name, surname, organisation).

Name	Organisation - Capacity	Email
Dr Constantinos N. Phellas, Sociologist	1. Dean of the School of Humanities, Social Sciences and Law, University of Nicosia 2. Executive Director, RUBSI 3. President of the Cyprus Sociological Association	phellas.c@unic.ac.cy
Christina Loizou, Sociologist	1. Senior Researcher, RUBSI 2. Vice- President, Cyprus Sociological Association	loizou.c@unic.ac.cy
Christiana Dipli, Psychologist	Researcher, RUBSI	dipli.c@unic.ac.cy
Elina Demetriadou, Psychologist	Researcher, RUBSI	elinademetriadou87@gmail.com
Dr Stella Demitriou-Mishaouli, Paediatrician	Member of Parliament, Representative of the Parliamentary Committee on Health	smisiaouli@parliament.cy
Mrs Elena Makrygiorgi	Department of European Projects, Ministry of Health	emakrygiorgi@moh.gov.cy
Mrs Paraskevi Mama Health Professional	First Officer of Visiting Health Professionals, Ministry of Health	pmama@moh.gov.cy
Dr Yiannis Kalakoutas, Psychiatrist	1. Director of the Mental Health Services, Ministry of Health 2. Chairman, Multi-disciplinary Committee on Alzheimer's Disease	director.mhs@cytanet.com.cy
Mr Matheos Spanos	Officer A, Department of Research Infrastructure, Cyprus Research Promotion Foundation	mspanos@research.org.cy
Mrs Noni Diakou	President, Cyprus Alzheimer's Association	nonidiakou@yahoo.com
Mrs Yiota Nicolaou	Secretary, Cyprus Alzheimer's Association	alzncyprus@cytanet.com.cy
Dr Christiana Kouta, Qualified Nurse, Specialist in Health Promotion	1. Lecturer, Department of Nursing, School of Health Sciences, Cyprus University of Technology 2. Member of Board, Cyprus Family Planning Association	christiana.kouta@cut.ac.cy
Dr Evridiki Papastavrou, Qualified Nurse	Lecturer, Department of Nursing, School of Health Sciences, Cyprus University of Technology	e.papastavrou@cut.ac.cy
Mr Panicos Argyrides	President, Cyprus Youth Council	president@cyc.org.cy



5.3 List of Steering Committee.

- *Dr Constantinos Phellas*, Executive Director, RUBSI, **Workshop Manager**
- *Dr Costas Constantinou*, Director , RUBSI, **Finances**
- *Mrs Christina Loizou*, Senior Researcher, RUBSI, **Coordinator**
- *Mrs Noni Diakou*, President, Cyprus Alzheimer's Association, **Contact Liaison**
- *Mrs Alexandra Attalides*, Press Attaché, Office of the European Parliament and the European Representation in Cyprus, **Organising of Venue**

5.4 Summary of the evaluation.

Evaluation questionnaire asked for the participant's view on the following:

- Comprehension of the presentations
- Flow of the agenda
- Venue facilities
- Use of Technology
- Composition of participation group
- The degree to which they felt that the workshop has served the purpose of exchanging views among Researchers, CSOs, Government organistaions, and Professionals
- The degree to which the National Topic was adequately covered
- The degree to which they felt that Alzheimer's would become a focus issue after the discussion during the workshop
- The duration of the workshop
- The general organisation of the workshop
- The degree to which the workshop has managed to urge them to get involved in public health research

In all of the above, all the participants answered that they were very satisfied. The only negative comment that came out from the questionnaires was about the parking facility, something which is very important in Cyprus, due to the inadequacy of the public transport system.