Report on the event
“Dementia in Europe: a challenge for our common future”
Italian Presidency of the Council of European union
Rome – November 14th 2014

Pietro Checcucci

Working Group on Ageing - Seventh meeting
Geneva, November 20th - 21st 2014
PROGRAMME OF THE EVENT (I)

The EU perspective on dementia: an overview of challenges, activities and achievements
John F. Ryan, Acting Director Public Health, Directorate-General Health and Consumers, European Commission

Session 1: Activities on dementia at EU-level

Presentation of the core results and major indications from the JA ALCOVE
Pierre Krolak-Salmon, French coordination of the JA
Nicola Vanacore, Italian coordinator of the WP Epidemiology

The EU Joint Programme–Neurodegenerative Disease research (JPND)
Adriana Maggi, JPND vice-chair

Innovative practices identified by the European Innovation Partnership Active and Healthy Ageing (EIP AHA)
Jorge Pinto Antunes, DG Innovation for Health and Consumers

Development of new medicines for the treatment of Alzheimer Disease
Valentina Mantua, expert for Central Nervous System medicines, AIFA - Italian Medicines Agency

Session 2: Activities on dementia at international level

WHO perspective
Tarun Dua - Matthijs Muijen, Mental Health and Neuro-Degenerative Disorders WHO

Follow-up of the 2013 G8 Commitments
Dennis Gillings, World Dementia Envoy

The role of patients and carers’ Associations at International level
Charles Scerri, Alzheimer Europe
Session 3: National level initiatives on dementia
The new Italian National strategy
Teresa Di Fiandra, DG Prevention, Ministry of health

Session 4: Strengthening activities
Empowerment: The role of patients and carers’ Associations in the Italian context and examples of good practices
Luisa Bartorelli, Alzheimer Uniti; Gabriella Salvini Porro, Federazione Alzheimer; Patrizia Spadin, AIMA

Session 5: The way forward
Partnership: a new Joint Action on dementia
Geoff Huggins, Director of Health and Social Care Integration, UK Scottish Government

Session 6: Conclusions and closure
Conclusions by Italian and EU coordinators: final document/declaration based on perspectives for future work (the EU Joint Action, the involvement of the: Latvia and Luxembourg)
Italy: Vito De Filippo, Undersecretary of State to the Ministry of Heath
European Commission: Jürgen Scheftlein, DG Sanco, DG Research
Next EU Presidencies: Latvia, Luxembourg
SOME KEY FACTS AND FIGURES REPORTED

- 6 millions of cases in Europe
- 9 millions reported in India and China. This huge amount can be related to a gap in timely diagnosis and less resources available for service provision
- In 2050 projection expect 11 millions cases in Europe, while the increase at global level would be around 71%
- The disease costs 1% of global GDP
- At global level more funds for research on neuro-degenerative diseases would be required, also considering that current spending corresponds to 1/10 of the investments on cancer research
- Considering that 30% of dementia cases can be connected to risk factors (the same related to cardiovascular diseases), it appears essential to work on prevention and risk reduction
THE EU PERSPECTIVE ON DEMENTIA: AN OVERVIEW OF CHALLENGES, ACTIVITIES AND ACHIEVEMENTS (I)

December 2008 - Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's. These diseases constitute a priority for action in the context of the ageing of the EU's population.

July 2009 - The Commission presented its Communication on a ‘European initiative on Alzheimer’s disease and other dementias. The Communication defined four strategic objectives for EU action and Member State cooperation:

1) Acting early to diagnose dementia and promote well-being with age;
2) A shared European effort to better understand dementia conditions: Improving epidemiological knowledge and coordination of research;
3) Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering dementia;
4) Respecting the rights of people with dementia.

19th January 2011 - the European Parliament adopted the Resolution on a European initiative on Alzheimer's disease and other dementias supporting the Commission Communication

2009 / 2013 - A number of initiatives and key activities were implemented in the frame work of the EU strategy, including the Joint Action Alzheimer Cooperative Valuation in Europe (ALCOVE), the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) and EU-level activities in the fields of research (including the Joint Programming Initiative on Neurodegenerative Diseases - JPND)
After key achievements in the period, the Commission has launched action to:

- Maintain its coordination role in the development of the EU policy on dementia and to support Member States in their activities at national level
- Take forward action at EU level by launching a second Joint Action on dementia under the Work Plan 2014 of the Health Programme, build on the results of the Joint Action ALCOVE, focussing on post-diagnostic support, improvement of care pathways, the use of medicinal products and specifically psychotropic substances, care for family carers, workforce skills, and the quality of residential care
- Provide further opportunities to support research under Horizon 2020
- Stimulate the development and use of e-Health solutions in the field of dementia
- Continue playing a global role and collaborate with international stakeholders,
- particularly in the context of the initiative ‘Global action against dementia’ launched by the G8 Declaration, adopted on December 11th 2013.
WHO PERSPECTIVE (I)

Focus on the Report *Dementia: a Public Health Priority (2012)*

The *Mental Health Gap Action Programme (mhGAP)*, launched by WHO in 2008 (which included dementia as a priority condition), the High-level Meeting of the United Nations General Assembly on prevention and control of non-communicable diseases, in 2011, which adopted a Political Declaration which recognized that “mental and neurological disorders, including Alzheimer’s disease, are an important cause of morbidity and contribute to the global non-communicable disease burden”

Projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old, and countries in demographic transition will experience the greatest growth.

The global costs of the disease are estimated at US$ 604 billion per year at present and are expected to increase.

The report was expected to be a resource that would facilitate governments, policy-makers, and other stakeholders to address the impact of dementia as an increasing threat to global health.
WHO PERSPECTIVE (II)

Key findings messages were in particular:

✓ People live for many years after the onset of symptoms of dementia
✓ Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems
✓ People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them

Key objectives are:

✓ Promoting a dementia friendly society globally
✓ Making dementia a national public health and social care priority worldwide
✓ Improving public and professional attitudes to, and understanding of, dementia;
✓ investing in health and social systems to improve care and services for people with dementia and their caregivers
✓ Increasing the priority given to dementia in the public health research agenda
To analyse how systems and caring policies need to adapt, how to accelerate innovation in dementia care, how to prioritise dementia research investments, and the role that “big data” can play in improving dementia research and care, WHO and OECD are currently leading a series of actions aimed at supporting national efforts to adapt health systems.

To support countries in their national efforts to recognize dementia as a public health priority and to take action, WHO will host the first Ministerial Conference on Global Action Against Dementia from 3 to 4 March 2015 in Geneva, Switzerland.

The Conference will be supported by OECD and the UK Department of Health.
THE NEW ITALIAN NATIONAL STRATEGY (I)

**Italian National Plan on Dementia** – Strategy for the promotion and improvement of quality and pertinence of interventions and assistance on dementia

**The Italian context:**

- Projections estimate that cases of dementia could triplicate during next 30 years, due to ageing population
- Current offer of services is based on 500 “memory clinics”, which started their activity after 2000, within the national Project CRONOS, especially addressed to Alzheimer evaluation and treatment

After 14 years of intervention, it seems particularly urgent to:

- Update services, enhancing excellence experiences and addressing a better integration between health and social services
- Develop public health policies and measures to fight social stigma and aimed at empowering patients and their caregivers, starting from a correct and updated knowledge of the disease
Objective 1 – health and social interventions and measures
- Awareness and knowledge raising of the population, patients and their relatives and professionals about prevention, timely diagnosis, treatment and assistance
- Foster research to improve care and the quality of life of patients and caregivers
- Organize epidemiologic surveys

Objective 2 – Integrated network of services
- Reorganization of current memory clinics integrating diagnosis and services and taking care of ethical aspects
- Attention to quality of services
- Preparation of a public service charter

Objective 3 – Strategies and intervention for care pertinence
- Improvement of services delivery and monitoring
- Improvement of the quality of care delivered both at home and within nursing homes
- Foster pertinence in the use of drugs, technologies and psycho-social interventions

Objective 4 – Awareness raising and stigma reduction for improving the quality of life
- Deliver correct information to patients and their relatives to allow timely diagnosis
- Improve the quality of life of patients and their full social integration
- Empowering persons and communities involving families and associations in services planning
Other major issues:

- Development of indicators and quality standards for services monitoring
- Elaboration of guidelines for diagnosis communication, the informed consent of the patient and the use of available legal solutions
- Ethical aspects such as advance directive
- Elaboration of guidelines for patient in working age
- Further research and analysis on the early onset of dementia
Thank you for your attention!