European Commission

Health Information under the 2008-2013 Health Programme

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Presentation outline

➢ The "traditional" presentation: projects delivering HI related outputs

➢ Key issues as a way forward: in light of the new programme

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The pipeline of projects: old and new

The list of relevant projects since 2005-2006

- PHAMEU 2006130
- EURHOBOP 2008312
- EUREQUO 2007102
- EURO- URHIS 200511912
- iSARE 2007112
- EUBIROD 2007115
- EURONEOSTAT II 20081311
- EUROMOMO
- EURO-PERISTAT Action
- Use of Sub-national indicators to Improve Public Health in Europe (UNIPHE)
- European Musculoskeletal Conditions Surveillance and Information Network
- Public Health Innovation and research in Europe (PHIRE)
- Inventory of good practices in Europe for Promoting gender equity in health (ENGENDER)
- INEQCITIES 20081213
- DAYSAFE 2009 11 09
- PROSAFE 2007 331
- DAY SURGERY DATA PROJECT 2008 13 05
- EUREMS 2010 12 13
- EHLEIS 2010 23 01
- JAMIE 2010 22 06

New relevant projects

- 2011 12 01 RARECARENet (rare cancers)
- 2011 12 01 HONCAB (pilot network on cross border care)
- 2011 12 07 EUHANET (Rare Disease specific network)
- 2011 12 02 SHARE (Rare Disease specific network)
- 2011 21 01 PASQ (patient safety)
- 2011 23 02 PARENT (patient registries)
- 2011 23 01 EUnetHTA JA2 (HTA)
- 2011 22 01 EJA (Rare diseases registries)
- 2011 21 02 ACCORD (Organ donation)

2011 12 01 RARECAREnet

➤ Building a network to provide comprehensive information on rare cancers to the community at large (oncologists, general practitioners, researchers, health authorities, patients)

➤ The specific objectives are to support improvements in the following areas:

  ➤ Timeliness and accuracy of diagnosis

  ➤ Access to high quality treatment for patients with rare cancers

  ➤ Identification of centres of expertise for rare cancers in Europe

  ➤ Standardization of practices across Member States (MS)

2011 12 01 HONCAB

➤ Creation of pilot network of hospitals related to payment of care for cross border patients, providing a set of practical experiences of the opportunities and critical issues of cross border care delivery

➤ The network will review eight elective procedures in at least 10 7 MS as follows:

 ➤ Review of existing data on cross-border of patients already collected by network hospitals' information systems

 ➤ Analysis of grouping algorithms for the selected procedures

 ➤ Testing of the functionality of the data/information collection tools

2011 12 07 EUHANET &
2011 12 02 SHARE

"Traditional" Rare Disease specific information networks on:

➢ Paediatric Rheumatology in Europe

➢ Haemophilia and other inherited bleeding disorder

The two networks will cover:

➢ Data on diseases for which information/ data are rare and fragmented

➢ Quality of care/ diagnostic, guidelines and training towards healthcare professionals

➢ Involvement of patients

The 2011 Call Joint Actions

➢ Patient Safety and Quality of Care (PASQ)

➢ Cross-Border Patient Registries Initiative (PARENT)

➢ European network for HTA Joint Action 2 (EUnetHTA JA2)

➢ EUCERD Joint Action (EJA)

➢ Achieving Comprehensive Coordination in Organ Donation throughout the European Union (ACCORD)

Diverse deliverables, an important "health information" related part

➤ PARENT is supporting the aim of having comparable and coherent patient registries across the EU, through work on the development and governance of patient registries - enabling analyses of secondary data for public health and research purposes

➤ EJA will be supporting the JRC/ DG SANCO cooperation with technical expertise on the development of a common EU-platform or hub for Rare disease related data collection (patient registries)

Diverse deliverables, an important "health information" related part

➢ EUnetHTA JA2 is carrying out pilot HTAs based on common core model

➢ ACCORD is working on (1). Live donor registries and fostering international data sharing on live donation; (2) Increasing the availability of organs from deceased donors by strengthening the cooperation between intensive care units (ICUs) and donor transplant coordinators (DTCs);

➢ PASQ is developing an interactive platform/ exchange mechanism on Patient safety related practices/

Health information under the "Health for Growth" programme

Rationale for Health information in the 2008-2013 Health Programme

- A separate strand
- Underpinning the thematic priorities
- Resulting in horizontal/ vertical information related projects
- Success or failure?

Health information in the "Health for Growth" Programme 2014-2020

➢A priority action area under three out of the four specific objectives of the "Health for Growth" programme

➢A significantly reduced total budgetary allocation

The objectives

1) Promote health, prevent disease and foster supportive environments for healthy lifestyles

2) Protect citizens from serious cross-border health threats

3) Contribute to innovative, efficient and sustainable health systems

4) Facilitate access to better and safer healthcare for Union citizens

1) Examples of actions promoting health, preventing diseases and fostering supportive environments for healthy lifestyles

- Cost effective promotion and prevention measures for addressing **tobacco, alcohol, unhealthy dietary habits, physical inactivity**

- **HIV/AIDS, TB and hepatitis;** up-take of good practices for cost effective prevention, diagnosis, treatment and care

- **Chronic diseases** including **cancer**; good practices and prevention, early detection and management

- **Legislation on tobacco products** advertisement and marketing

- **Health information** and knowledge system; eg. Cancer Information system; economics of prevention

2) Examples of actions protecting citizens from serious cross-border health threats

- Improve **risk assessment** by providing additional capacities for **scientific expertise and map existing assessments**

- Support **capacity building**, cooperation with neighbouring countries, preparedness planning, non-binding approaches on vaccination, joint procurement

- **Legislation** in the fields of communicable diseases and other health threats (**Health Security Initiative**)

- **Health information** and knowledge system

3) Examples of actions contributing to innovative, efficient and sustainable health systems

- **Health Technology Assessment**

- **Up-take of health innovation and e-health solutions**

- **Health workforce** forecasting and planning (number, scope of practice, skills), mobility/migration of health professionals

- Mechanism for **pooled expertise and good practices** assisting Member States in their health systems reforms

- Health in an ageing society, including European Innovation Partnership on **Active and Healthy Ageing**

- **Legislation** in the field of **medical devices**, **medicinal products** and **cross-border healthcare**

- **Health information** and knowledge system including **Scientific Committees**

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4) Examples of actions facilitating access to better and safer healthcare for EU citizens

- **European Reference Networks** (on the basis of criteria to be set under Directive 2011/24/EU)

- **Rare diseases** (networks, databases and registries)

- **Patient safety and quality of healthcare** including the prevention and control of **healthcare-associated infections**

- **Antimicrobial resistance**

- **Legislation** in the field of **tissues and cells, blood, organs, medical devises, medicinal products, and patients' rights in cross-border healthcare**

- **Health information** and knowledge system

The challenge for health information: "evolve or disappear"

- Secure investments made so far (ECHI)
- Understand the four objectives
- Accompany the strategic re-focus of the "Health for Growth" Programme:
  - **health systems/care, disease prevention and management will cover more than 50% of the budget**
- Determine a broad and supportive HI strategy

The 2012 Call already reflects this new focus - Projects (1)

- ➤ Chronic disease management
  - ➤ EUROpean Treatment & Reduction of Acute Coronary Syndromes cost analysis (EUROTRACS)
  - ➤ Economics of Chronic Diseases (ECONDA)
  - ➤ Active Ageing with Type 2 Diabetes as Model for the Development and Implementation of Innovative Chronic Care Management in Europe (MANAGE-CARE)
- ➤ Cancer
  - ➤ Benchmarking comprehensive cancer care that provides interdisciplinary treatment for patients, and yield examples of best practice in comprehensive cancer care (BENCH-CAN)

The 2012 Call already reflects this new focus – Projects (2)

➢ Rare disease specific information networks (link with future ERNs)

  ➢ European network and registry for homocystinurias and methylation defects (E-HOD)

  ➢ Inherited NeuRoMetabolic Diseases INFORMATION NETWORK (InNerMeD-I-Network)

  ➢ European Surgical Registry for Rare Endocrine Tumours (EUROCRINE)

  ➢ New e-Health services for the European Reference network on rare Anaemias (e-ENERCA)

The 2012 Call – Joint Action areas relevant to HI

➢ European Health Workforce Planning and Forecasting (EUHWforce)

➢ Facilitating exchange of organs donated in EU member states (FOEDUS)

➢ The impact on maritime transport of health threats due to biological, chemical & radiological agents, including communicable diseases (SHIPSAN ACT)

Health information in the future: a tentative conclusion

More than ever ...

- Data and facts are not like pebbles on a beach, waiting to be picked up and collected
- They can only be perceived and measured through an underlying theoretical and conceptual framework, which defines relevant facts, and distinguishes them from background noise
- *Even though there is no new health strategy, the effects of the crisis and the new HfG programme provide such a framework*

Thank you for your attention