

Le Azioni Congiunte nella programmazione Europea: strumento chiave per prioritizzare i bisogni, creare capacity building e massimizzare implementazioni e impatti nei sistemi salute regionali

Workshop tecnico 3 – Registri JA JACARDI

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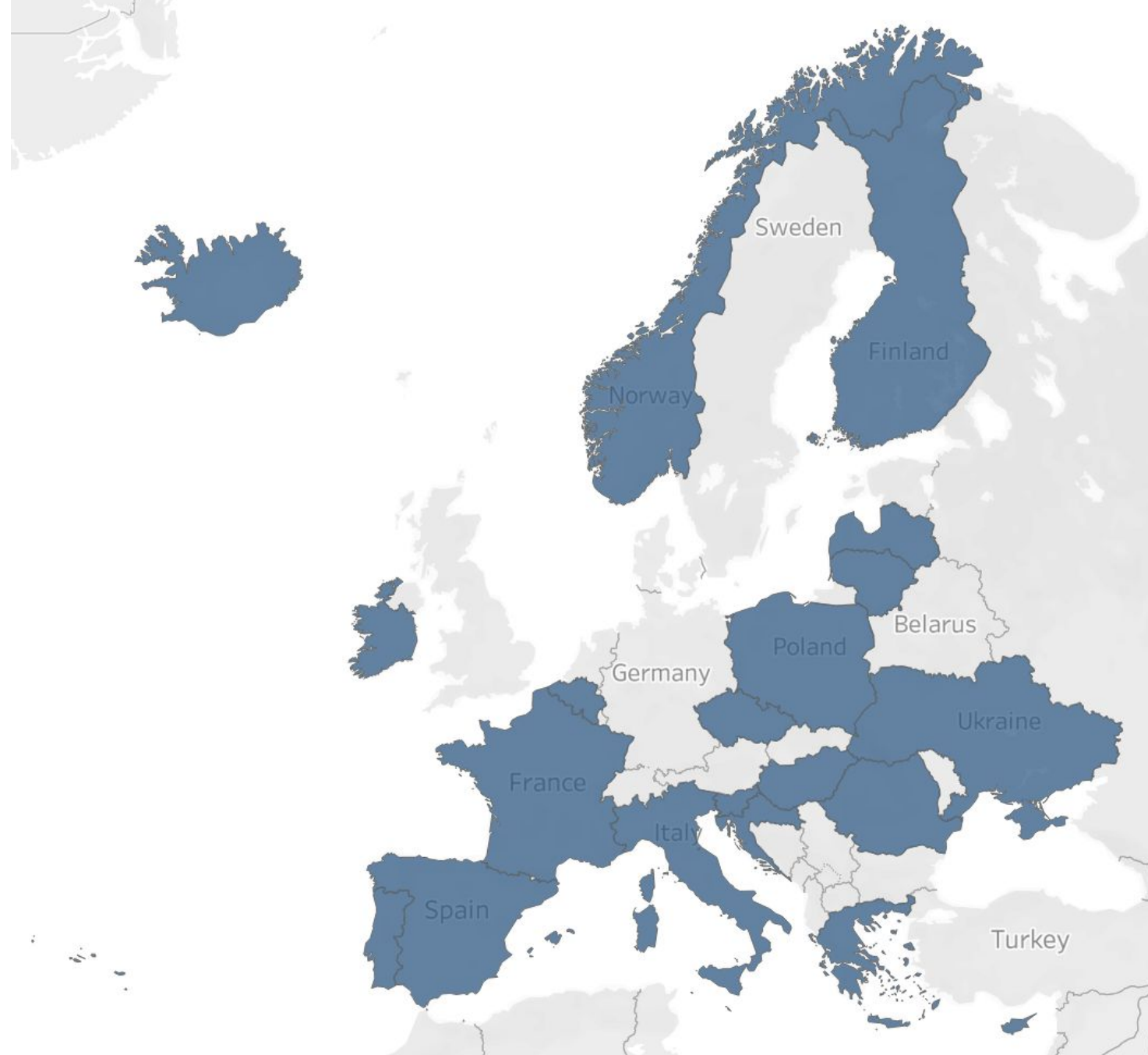
DP-g-22-06.03 Direct grants to Member States' authorities: prevention of NCDs – cardiovascular diseases and diabetes

OBJECTIVES, SCOPE AND ACTIVITIES

The aim of the joint action(s) is to reduce the burden of NCDs and related risk factors, both at personal and societal level, targeting or addressing the specifics of cardiovascular diseases and diabetes and their health determinants, as necessary.

| | |
|-----------------------|-----------|
| Total MS | 21 |
| Total Partners | 77 |
| CAs | 21 |
| AEs | 52 |
| APs | 4 |

Total budget: € 66,249,465.69
€ 53 Million (co-founded by EU)



WPs

WP1--COORDINATION

WP5--METHODOLOGICAL FRAMEWORK

WP6-HEALTH LITERACY

WP7-DATA/REGISTRIES

WP8-SCREENING

WP9-CARE PATHWAYS

WP10-SELF-MANAGEMENT

WP11-LABOUR SETTING

WP4--SUSTAINABILITY

WP3--EVALUATION

| Pilots' topics | WP6 Health literacy and awareness | WP7 Data availability and quality | WP8 Screening high-risk populations and individuals | WP9 Integrated care pathways | WP10 Patients' self-management | WP11 Labour participation |
|---|---|--|---|---|--|--|
| Macro area coverage | Health literacy: Community health literacy; health literacy development; health literacy of an individual; health literacy responsiveness; organisational health literacy. Health promotion and awareness | Data availability; data quality and coverage of pre-existing registers and data sources; data harmonisation, accessibility and sharing; value of data; epidemiology, quality of care, health equity and benchmarking | Population screening (population based survey; clinical assessment); Personal/individual level screening and risk assessment (Clinical setting; Non Clinical setting) | Care delivery; decision support; information systems and technology; social/community resources | Making lifestyle changes; self-monitoring and self-care (including medication management and/or adherence); communicating with healthcare professionals (including shared decision making); coping with CVD/DM in daily life | Awareness on inclusiveness and work ability; Inclusion, maintenance, return to work and participation of people with NCDs in the workplace; Prevention of NCDs, correct management and integration in the labour settings; Employment opportunities for young adults diagnosed with CVDs or DM |
| Target groups | General population and people who have or are at risk of CVD/DM. Target groups: children&adolescents, pregnant women, healthcare professionals, caregivers, migrants, vulnerable people | General population and people/patients who have or are at risk of CVD/DM. Special focus will be given to identifying country or region-level gender and ethnic inequalities or differences | General population and people/patients who are at risk of CVD/DM. Specific focus on target groups: adolescents, elderly, women with a history of gestational diabetes, migrants | Patients who have CVD/DM. Specific focus on target groups: young adults, migrants, socio-economically vulnerable people, healthcare professionals | Patients who have CVD/DM. Specific focus on target groups: elderly, healthcare professionals, policy makers | Working-age patients who have NCDs, employers and employees in working age |
| Expected population reached | 20-1 Million | Millions | 200-1.7 Million | 75-150,000 | 50-10,000 | 50-4,700 |
| Estimated Countries implementing | 13 (HR, CZ, FI, FR, IS, IT, LT, MT, PL, PT, RO, ES, UA) | 8 (BE, FI, FR, IS, IT, LV, RO, ES) | 11 (BE, FI, FR, HU, IE, IT, LV, RO, SI, ES, UA) | 11 (BE, FI, FR, HU, IS, IT, LV, PL, RO, SI, ES) | 6 (BE, FI, IE, IT, MT, ES) | 5 (FI, IT, LT, PL, ES) |
| Estimated number of pilots' | 24+1 included in WP11 | 39+4 from APs | 18 | 29 | 13 | 15 |

Abbreviations: CVD/DM=Cardiovascular diseases/diabetes mellitus; NCDs=Non-communicable diseases; APs=Associated Partners

>142 pilots

18 EU countries covered

WP7- Data availability, quality, accessibility and sharing

Dpcm del 3 marzo 2017 “Identificazione dei sistemi di sorveglianza e dei registri di mortalità, di tumori e di altre patologie, in attuazione del Decreto legge n. 179 del 2012”

Elenco A2) Registri di patologia di rilevanza nazionale e regionale

| | Denominazione | Ente di livello nazionale presso il quale è istituito | Ente di livello regionale presso il quale è istituito |
|-------|---|---|---|
| A2.1 | Registro insufficienza renale cronica e trattamento sostitutivo (dialisi) | Centro Nazionale Trapianti | Centro di riferimento regionale |
| A2.2 | Registro tumori | Ministero della salute | Centro di riferimento regionale |
| A2.3 | Registro vaccinati | Ministero della salute | Centro di riferimento regionale |
| A2.4 | Registro delle protesi impiantabili | Istituto Superiore di Sanità | Centro di riferimento regionale |
| A2.5 | Registro insufficienza cardiaca terminale e assistenza ventricolare | Centro Nazionale Trapianti | Centro di riferimento regionale |
| A2.6 | Registro insufficienza epatica terminale e trapianto di fegato | Centro Nazionale Trapianti | Centro di riferimento regionale |
| A2.7 | Registro trapianti sperimentali di organi, tessuti e cellule | Centro Nazionale Trapianti | Centro di riferimento regionale |
| A2.8 | Registro degli eventi coronarici e cerebrovascolari | Ministero della salute | Centro di riferimento regionale |
| A2.9 | Registro diabete | Ministero della salute | Centro di riferimento regionale |
| A2.10 | Registro endometriosi | Ministero della salute | Centro di riferimento regionale |
| A2.11 | Registro trapianti di cellule staminali emopoietiche | Centro Nazionale Trapianti | Centro di riferimento regionale |
| A2.12 | Registro delle lesioni midollari di origine traumatica e non traumatica | Ministero della salute | Centro di riferimento regionale |
| A2.13 | Registro Nazionale Coagulopatie Congenite | Istituto Superiore di Sanità | Centro di riferimento regionale |
| A2.14 | Registro Nazionale Ipotiroidei Congeniti | Istituto Superiore di Sanità | Centro di riferimento regionale |
| A2.15 | Registro Nazionale della talassemia e delle altre emoglobinopatie | Centro nazionale sangue | Centro di riferimento regionale |

WP7- Data availability, quality, accessibility and sharing

9

MS participating in WP7

15

Italian AEs participating

43

Pilots to be implemented

12

Italian partners will implement pilots

7,8M

Total WP Direct costs

1144

Total WP efforts in PM

WP7- Data availability, quality, accessibility and sharing

Objectives:

- Review the current data sources and registers on CVD and DM in EU countries
- Identify needs and gaps on data sources and registers in EU countries
- Design and implement pilots, which aim to improve both epidemiological monitoring and monitoring the quality of care for CVD and DM
- Develop harmonisation and standardisation guidelines for data and data collection
- Establish a network for CVD and DM registers in Europe, to support implementation and sharing of good practices in EU countries
- Define and exemplify the value(s) of data and the potential uses of data and registers
- Assess the feasibility, effectiveness, and sustainability of the pilots and develop a roadmap

WP7- Data availability, quality, accessibility and sharing

Task 1 - Mapping of current data and data source availability to assess the situation of CVD and DM in EU countries, and identifying the local needs and gaps

Task 2 - Pilot preparation - Development of the Pilot Implementation Plans to improve data availability and quality

Task 3 - Pilot preparation - Standardisation and harmonisation of data and data collection, integration and sharing

Task 4 - Description and evaluation of data value, collection and integration

Task 5 – Pilot implementation

Task 6 – Assessment and roadmap

WP7 - Data availability, quality, accessibility and sharing

| Pilot | Country (Partner) | Diseases (CVD/DM) | Target group | Age group | General Aim | Estimated population reached | Setting | Thematic area |
|-------|---|-------------------|--|-----------|---|------------------------------|---|--|
| 25-37 | Iceland (CA DOHI); Italy (Ae Marche; Ae ALISA; Ae Burlo; Ae AOUP; Ae Reggio Calabria; and Associated partners Basilicata Region; Campania Region; Lazio Region and Umbria Region.); Latvia (CA SPKC); Romania (CA INSP, Ae IUBCVT) | CVD and DM | General population and patients | NA | To implement a national/local register in countries without existing CVD/DM registries to monitor epidemiological and clinical situations. The development of new local or national registries could initially be based on current data available and capacity of data linkage among different data sources. Gathering of new data, if possible, could be considered as a second step in the development of new registries. | Millions | Data source; Registries; Digital database/platform; template report | Data availability |
| 38-50 | Belgium (CA Sciensano) Finland (CA THL and AE UEF); Iceland (CA DOHI); Italy (Ae ASLTO3; Ae Burlo; Ae Lombardy); Latvia (CA SPKC); Romania (CA INSP, Ae INDNBM) France (CA SpF; Ae CHU Toulouse) Spain (Ae HULAFE) | CVD and DM | General population and patients | NA | To improve the quality and coverage of pre-existing registries and data sources on CVD/DM, aiming at improving representativeness, reliability, data gaps (e.g., socioeconomic determinants, country or region of origin/ethnicity, PROM/PREM measures), integration with electronic health care records, linkage between data sources (health and administrative data), as well as improving of data collection (manual/automatic). | Millions | Data source; Registries; Digital database/platform; template report | Data quality and coverage of pre-existing registers and data sources |
| 51-60 | Finland (CA THL and AE UEF); Italy (Ae Burlo); Latvia (CA SPKC); France (CA SpF) Spain (Ae INCLIVA; Ae FIB-H120; Ae CNIC; Ae FUNDESALUD; Ae ISABIAL) | CVD and DM | General population and patients | NA | To develop a database designed to host the content, structure, and results of the critical information needed to know the epidemiological and clinical situation of CVDs, the quality of their management and the results/impacts (e.g., PROMS/PREMS), to be used at a national level but actionable for international comparison and benchmarking. To develop a tool to simulate the impact in CVDs prevalence and cost across Europe of public health policies aimed at reducing the prevalence of modifiable CV risk factors (smoking, obesity, diabetes, etc) | Millions | Data source; Registries; Digital database/platform; template report | Data harmonisation, accessibility and sharing |
| 61-67 | Finland (CA THL and AE UEF); Spain (Ae FIB-H120; Ae FUNDESALUD, Ae CNIC) Latvia (CA SPKC); France (CA SpF) | CVD and DM | General population and patients, with a special focus on women | NA | To develop a web-based interactive tool to identify country or region-level gender inequalities in socio-economic factors and in CVDs indicators, and to assess the relationship between both gender gaps. This will alert regarding gender inequities still present in countries/regions useful also for awareness campaigns; identify areas needing improvement; monitor changes over time in gender inequities, and be used as a platform for the scientific assessment of the potential health consequences of socio-economic gender disparities | Millions | Data source; Registries; Digital database/platform; template report | Value of data; epidemiology, quality of care, health equity and benchmarking |



JA JACARDI – Registro Diabete

Roma, 14 luglio 2023

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Thank you

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