



EUROMENE

European Network on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

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London School of Hygiene & Tropical Medicine

October - 2016



Overview

- Background
 - Contextual and scientific challenges
- EUROMENE proposal
 - Aims/objectives and methodological approach
- Network timeline & establishment
- First year activities



Contextual challenges

ME/CFS Research in Europe

- Previous absence of collaborative approach
- Research and health services concentrated on few centres of competence
- Fragmented research and health services resources



Scientific challenges

- Unknown aetiology
- Clinical variability
- Lack of diagnostic biomarkers
- Limited treatment options
- High associated socio-economic burden



EUROMENE Proposal

Aims

To establish a sustainable network of researchers from diverse fields, to work in ME/CFS with multidisciplinary approach



EUROMENE Proposal

Task objectives

To collect population-based data on ME/CFS

To establish a synchronised European database

To access potential biomarkers, by harmonising infrastructure efforts

To unify an ME/CFS case definition for research prevention and treatment guidelines

To determine the social impact and assess economic consequences of ME/CFS

EUROMENE Proposal

Methodological strategy



WG1 Epidemiology



WG2 Biomarkers



WG3 Socio-economics



WG4 Clinical research / diagnostic criteria



WG5 Conferences, seminars, training schools

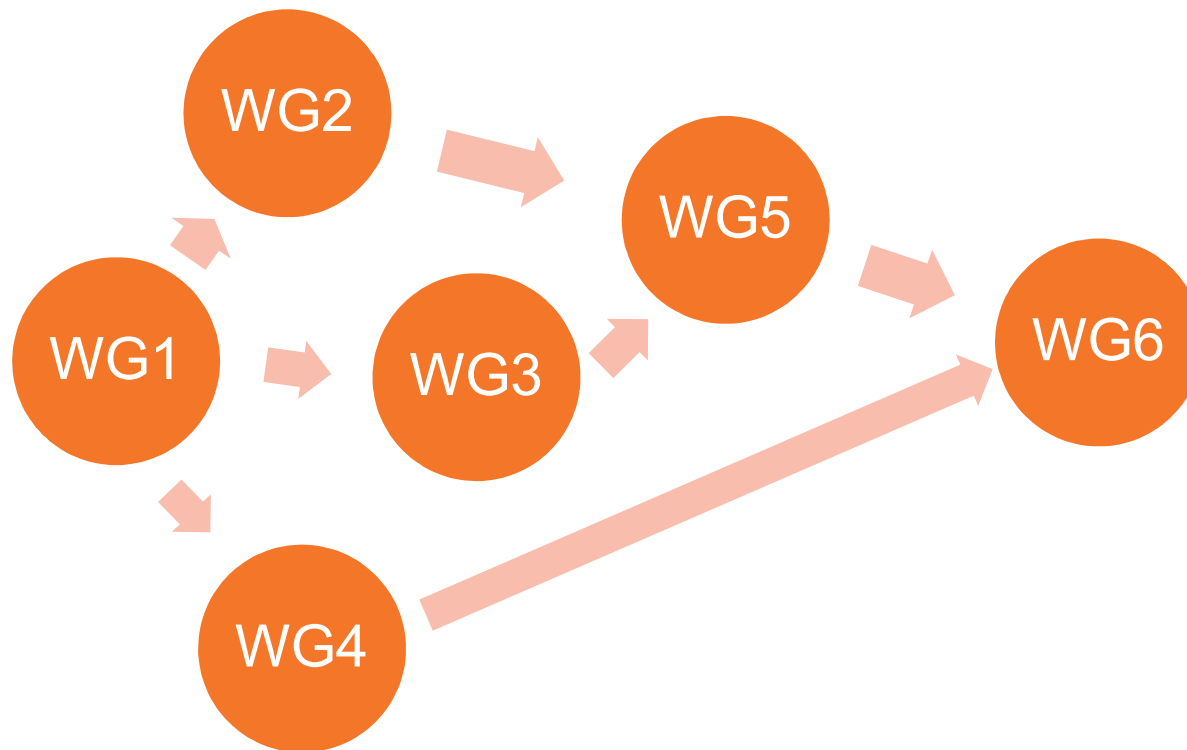


WG6 Dissemination & patient involvement

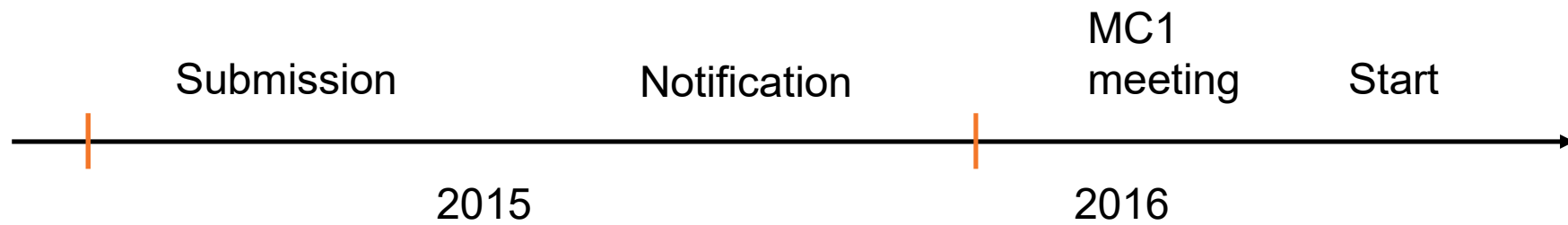


EUROMENE Proposal

Methodological strategy



EUROMENE - timeline



EUROMENE Timeline

Dec 2014 – COST Association open call for proposals

Mar 2015 – EUROMENE proposal submission

Nov 2015 – Consensus Evaluation Report
Scientific Committee

Apr 2016 – Management Committee meeting
Memorandum of Understanding
Implementation of the COST Action
EUROMENE - CA 15111

http://www.cost.eu/COST_Actions/ca/CA15111?management



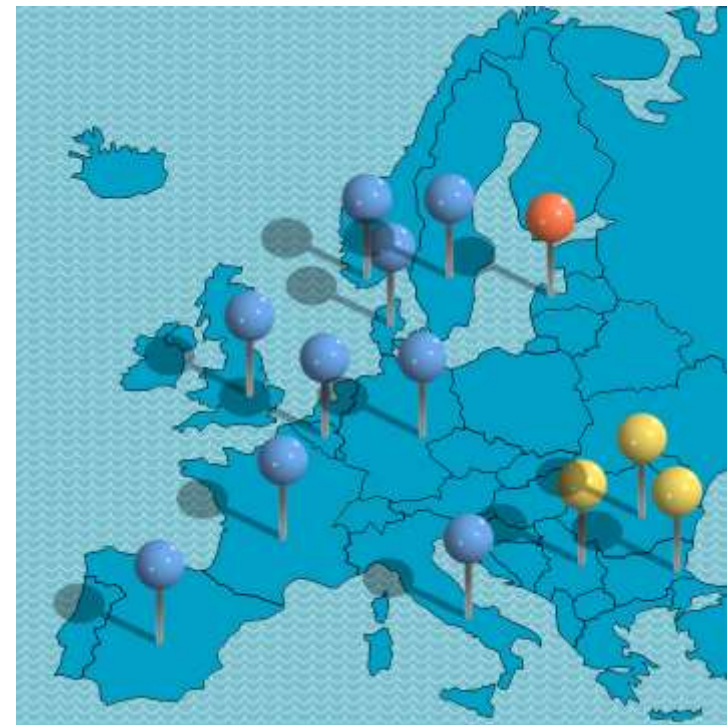
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- MC nominations by a national representative, in case of competing groups

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■ COST Member Countries

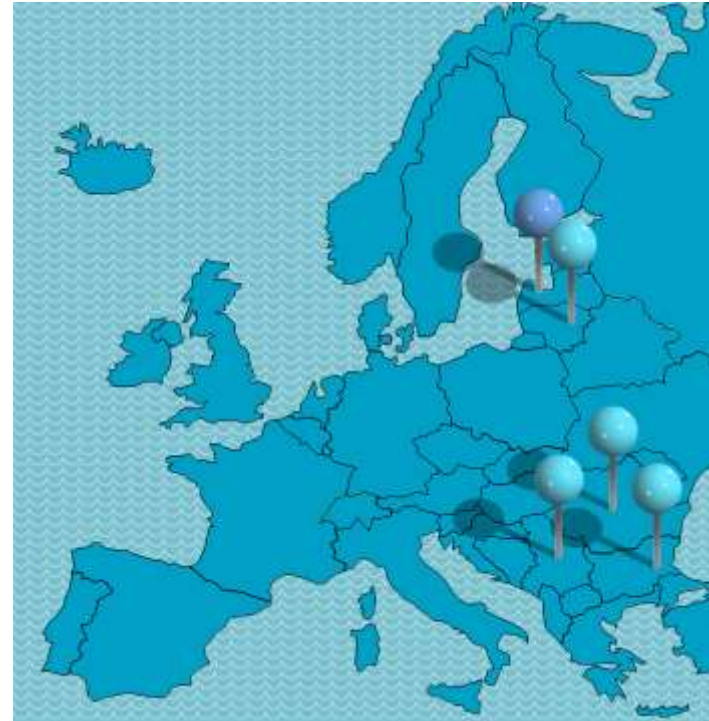
Austria, **Belgium**, Bosnia and Herzegovina, **Bulgaria**, Croatia, Cyprus, Czech Republic, **Denmark**, Estonia, Finland, **France**, **Germany**, Greece, Hungary, Iceland, Ireland, **Italy**, **Latvia**, **Lithuania**, Luxembourg, Malta, Montenegro, The Netherlands, **Norway**, Poland, Portugal, **Romania**, **Serbia**, Slovakia, Slovenia, **Spain**, **Sweden**, Switzerland, Turkey, **United Kingdom** and the former Yugoslav Republic of Macedonia



COST Action 15111 EUROMENE

- COST Inclusiveness Target Countries (ITCs)

*Bosnia-Herzegovina, **Bulgaria**, Cyprus, Czech Republic, Estonia, Croatia, Hungary, **Lithuania**, **Latvia**, Luxembourg, Malta, Montenegro, Poland, Portugal, **Romania**, Slovenia, Slovakia, the former Yugoslav Republic of Macedonia, **Republic of Serbia** and Turkey*



COST Action 15111 EUROMENE

- COST Near Neighbour Countries (NNC)

Albania, Algeria, Armenia, Azerbaijan, **Belarus**, Egypt, Georgia, Jordan, Lebanon, Libya, Moldova, Morocco, the Palestinian Authority, Russia, Syria, Tunisia and Ukraine.





Management CA 15111 EUROMENE

MC Chair: Prof Modra Murovska (Latvia)

MC Vice-chair: Dr Eliana Lacerda (UK)

WG1 Epidemiology

- Dr Jesus Castro (Spain)

WG2 Biomarkers

- Prof Carmen Scheibenbogen (Germany)

WG3 Socio-economics

- Prof Derek Pheby (UK)

WG4 Clinical research/diagnostic criteria

- Dr Elin B Strand (Norway)

WG5 Conferences, seminars, training schools

- Prof Evelina Shikova-Lekova (Bulgaria)

WG6 Dissemination & patient involvement

- Dr Lorenzo (Lorusso Italy)



EUROPEAN COOPERATION IN SCIENCE AND TECHNOLOGY



COST is supported by the
EU Framework Programme
Horizon 2020



ME/CFS – a global challenge



European Network on
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

{EUROMENE}



EUROMENE Proposal

First steps

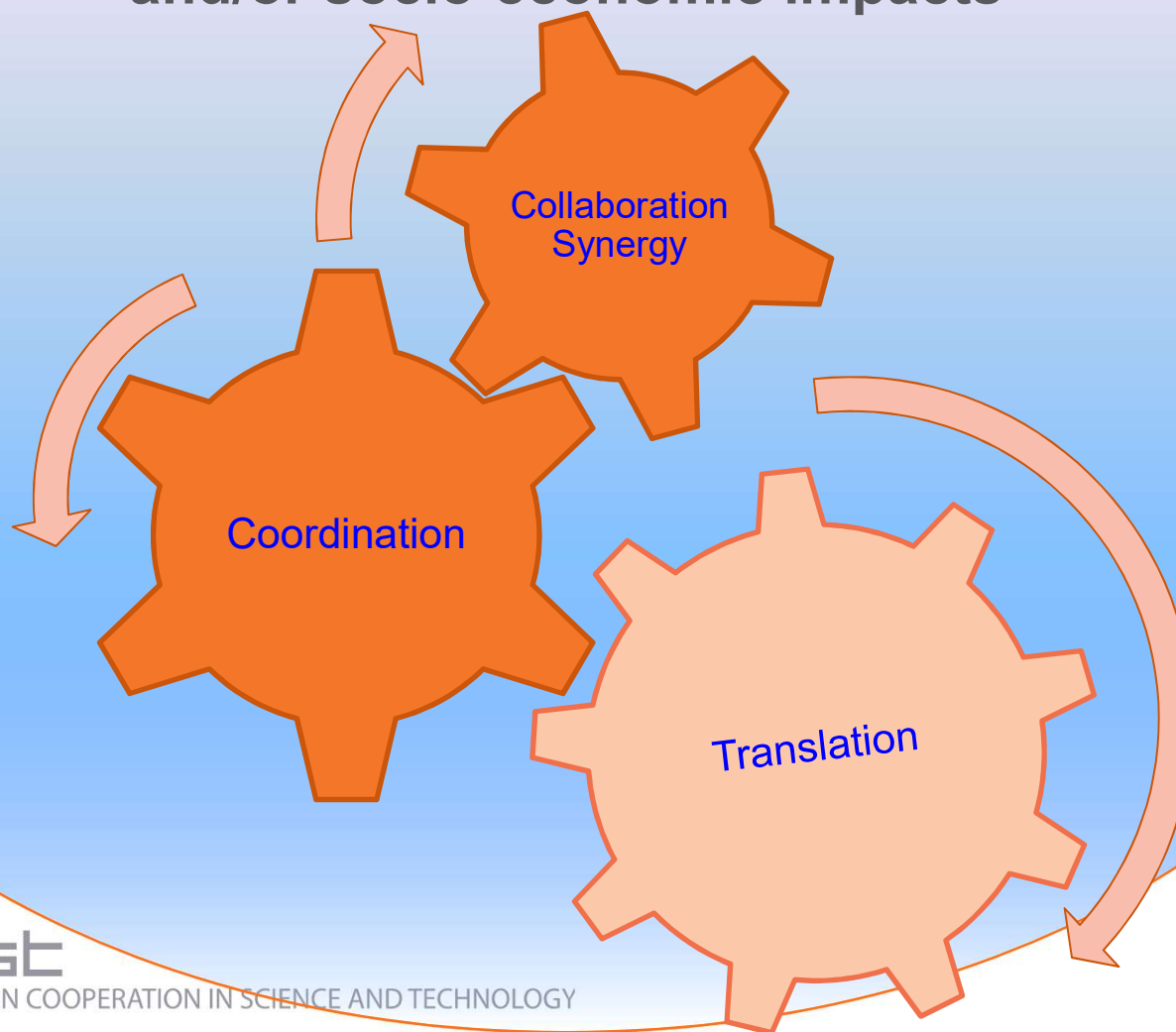
Mapping of existing resources

Seeking agreement for standardising protocols

Establishing biobank platform and bioinformatics data repository

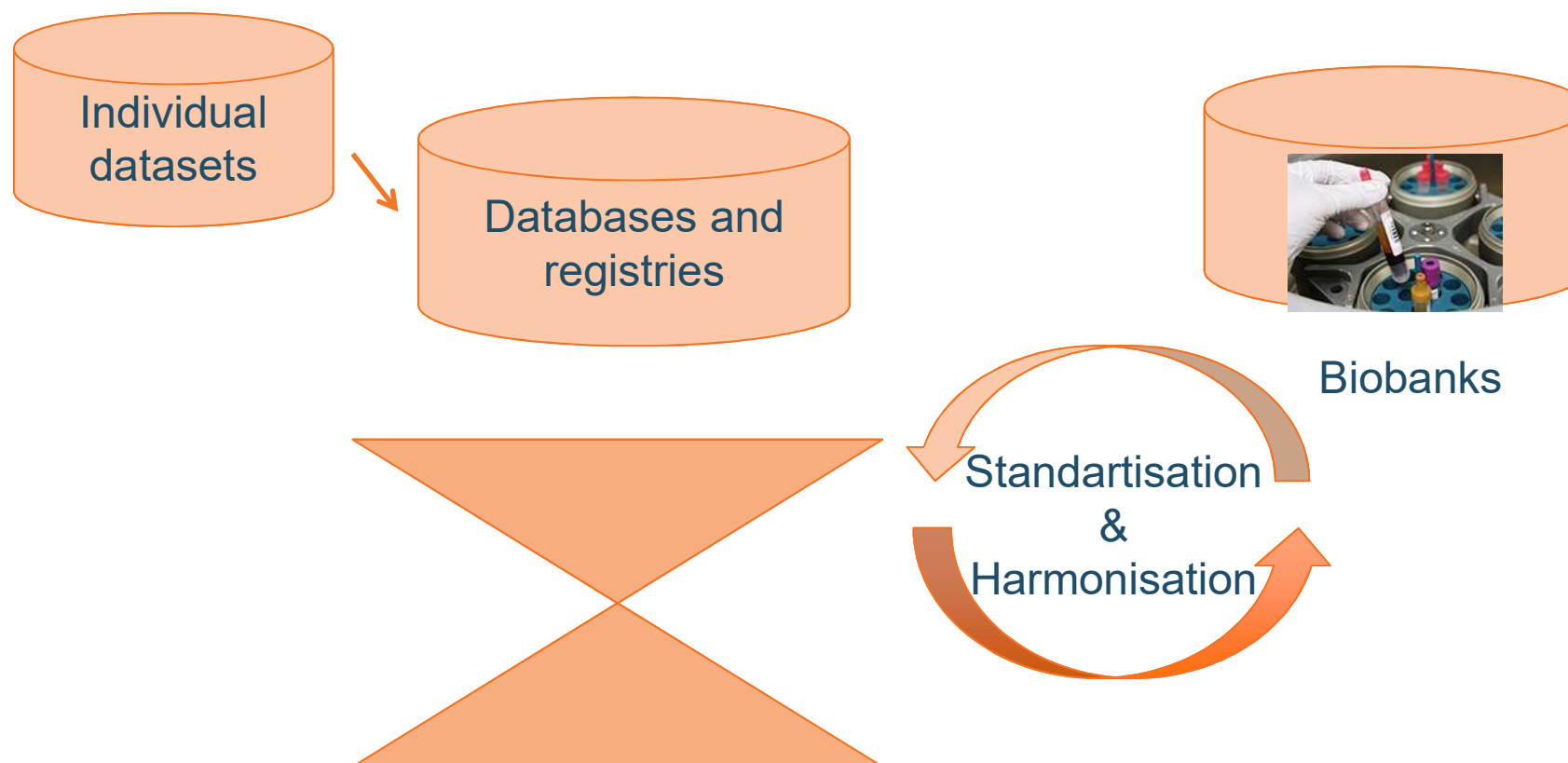
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Foreseen scientific, technological
and/or socio-economic impacts



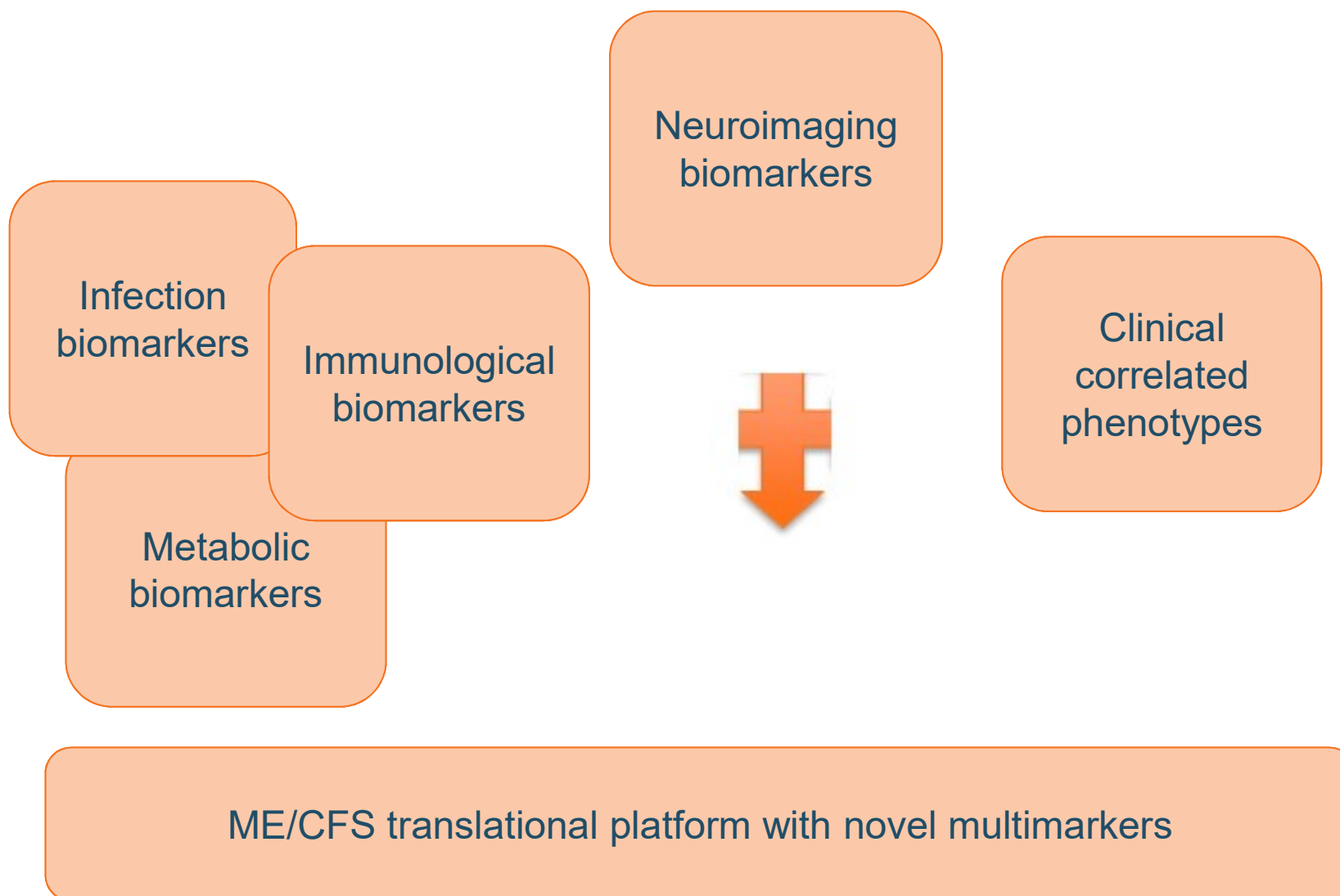


WG1 - Epidemiology





WG2 - Biomarkers





WG3 – Socio-economics

Opportunity-cost based disease costs

Medical cost

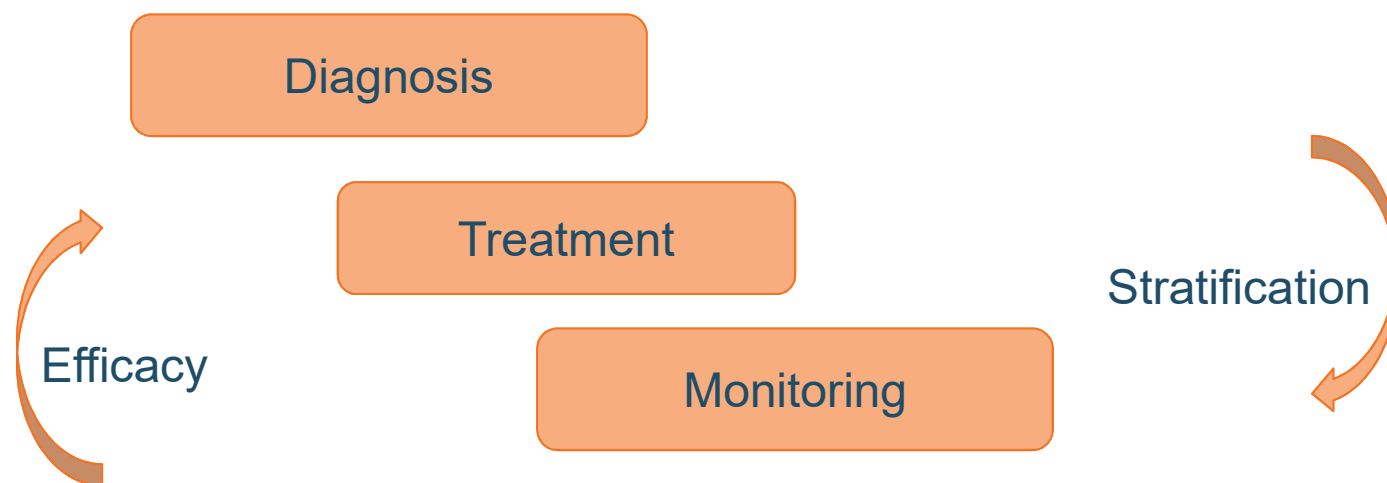
Care cost

Imputed cost

Predictive tool for socio-economic forecasts
Guideline cost-effectiveness forecasts



WG3 - Clinical research & diagnostic criteria



Harmonised guidelines



WG4 - Conferences, seminars, training schools, STSMs

Early carrier investigators

- Preference in Short Term scientific missions
- Two Training schools
- Coaching in network
- Additional training sessions
- Strong integration into outreach activities

- Annual seminars/workshops
- Major conference at the end



First year Meetings

- Riga 29-30 September 2016
 - MC meeting, CG meeting, WG meeting
- Berlin 27 January 2017
 - One-day Working group meeting about synchronization progress
- Barcelona 16-17 March, 2017
 - Second CG meeting, WG meeting, First Workshop

Thank you!

COST Participants

Country	MC Member
Belgium	▶ Prof Mira MEEUS
Belgium	▶ Dr Els TOBBACK
Bulgaria	▶ Prof Evelina SHIKOVA-LEKOVA
Denmark	▶ Dr Henrik NIELSEN
France	▶ Prof Jérôme AUTHIER
France	▶ Prof Jean-Dominique DE KORWIN
Germany	▶ Prof Carmen SCHEIBENBOGEN
Germany	▶ Prof Thomas HARRER
Italy	▶ Dr Lorenzo LORUSSO
Italy	▶ Prof Enrica CAPELLI
Latvia	▶ Dr Uldis BERKIS
Norway	▶ Prof Anne Marit MENGSHOEL
Norway	▶ Dr Elin B STRAND
Romania	▶ Dr Magdalena BUDISTEANU
Romania	▶ Dr Carmen Adella SIRBU
Serbia	▶ Dr Slobodan SEKULIC
Spain	▶ Dr Jesus CASTRO-MARRERO
Spain	▶ Dr Julià BLANCO
Sweden	▶ Prof Jonas BLOMBERG
United Kingdom	▶ Dr Eliana LACERDA
United Kingdom	▶ Prof Derek PHEBY

Country	MC Substitute
Germany	▶ Dr Madlen LÖBEL
Latvia	▶ Prof Angelika KRUMINA
Latvia	▶ Ms Santa RASA
Latvia	▶ Ms Zaiga NORA-KRUKLE
Norway	▶ Mr Babak ASADI-AZARBAIJANI
Norway	▶ Dr Ingrid Bergliot HELLAND
Spain	▶ Dr Jose ALEGRE-MARTIN
Spain	▶ Prof Jordi MIRÓ
United Kingdom	▶ Prof Jonathan EDWARDS
United Kingdom	▶ Dr Luis NACUL

COST Near Neighbour Countries

Institution Name	MC Observer
Republican Research & Practical Center for Epidemiology & Microbiology (RRPCEM)	▶ Dr Svetlana Orlova

Science officer of the Action:
[Dr Inga DADESHIDZE](#)

Administrative officer of the Action:
[Ms Jeannette NCHUNG ORU](#)



Thank you!

