



# Added value and impact of proposing a COST Action

COST Action CA15111 EUROMENE



# ME/CFS – a global challenge

## ME/CFS

- Unknown aethiology
- No disease biomarker identified yet
- Highly debilitating
- Relatively common
- High economic cost
- Variable clinical criteria



European Network on  
Myalgic Encephalomyelitis / Chronic Fatigue Syndrome

**(EUROMENE)**

## Theories

- Post-viral
- Neuroimmune/  
autoimmune/  
post-  
vaccinational
- Oxidative stress/  
metabolic  
disturbance
- Low dose  
radiation (bura  
bura disease)



# ME/CFS – societal burden

Burden arising from brain disease in Europe ~ 200 billion / pa



Burden from ME/CFS ~ 40 billion / pa

Prevalence – est. 0.11-0.56%

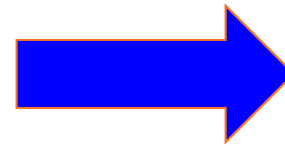
Healthcare cost pressure encourages public / private funding for ME/CFS research

Major programs in US, Japan, in Europe in some countries



# Challenge / networking instrument

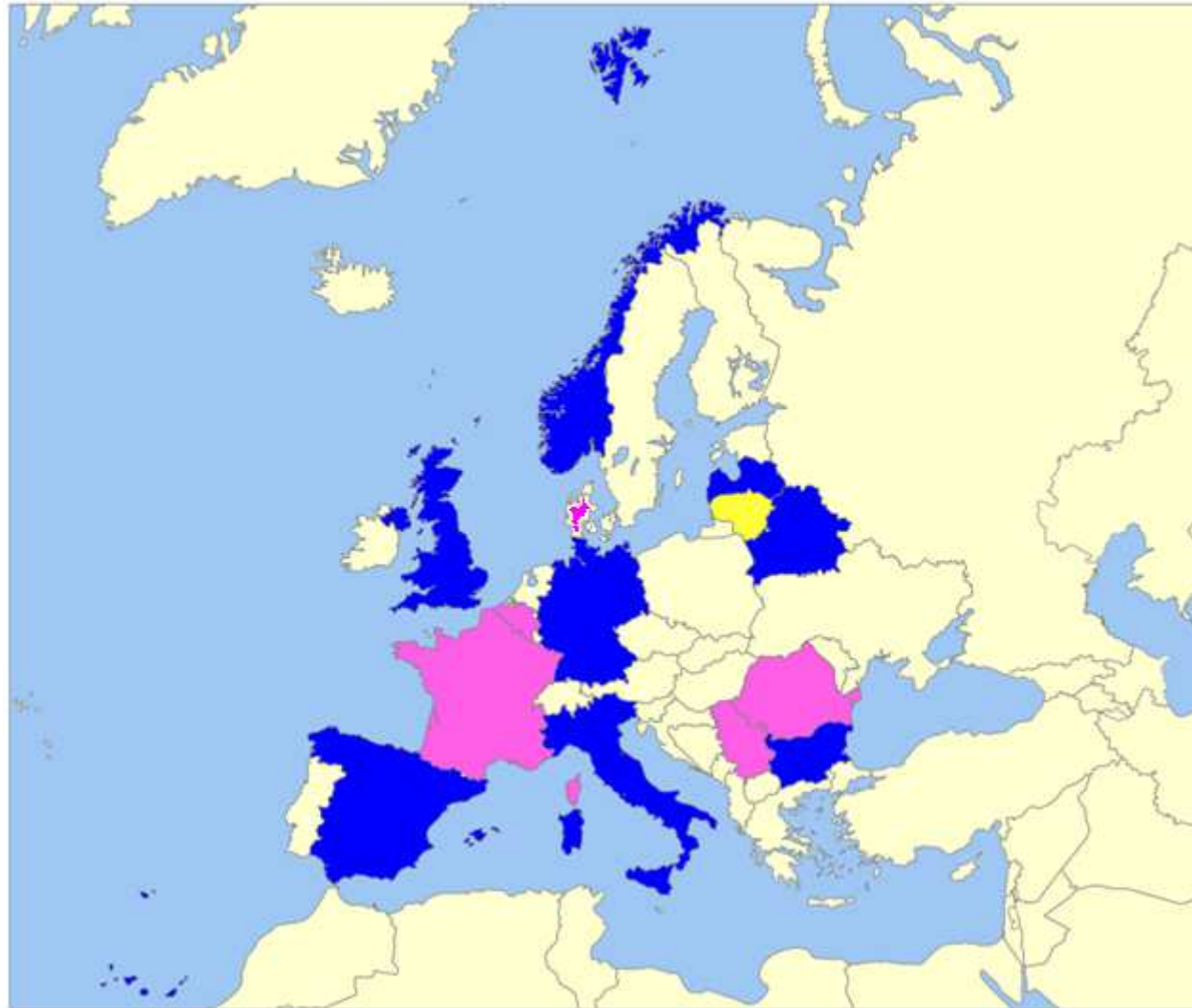
- Funding fragmented, insufficient, temporary
- Centres have divergent research emphasis (virology, immunology, biochemistry, clinical)
- Biobanks and molecular resources insufficiently standardised
- Variability of clinical criteria and their application routines
- New methods appear requiring joint research effort (PET, fMRI)
- Clinical research lacks networking platform among practitioners




# COST action



# EUROMENE – proposal geography



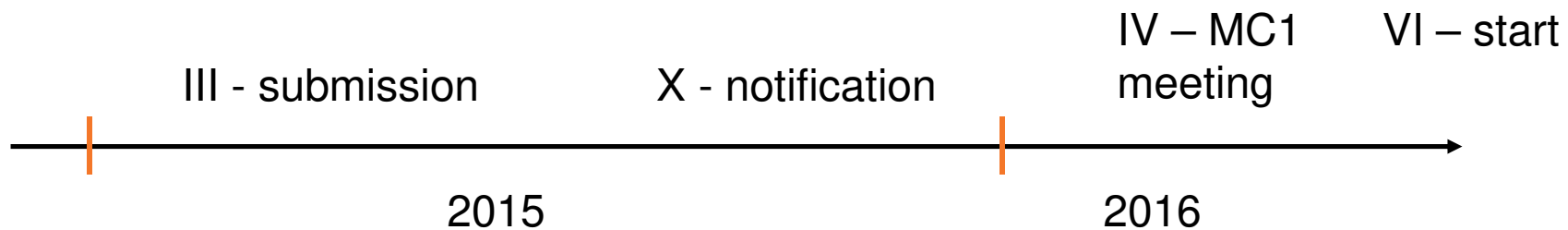


## Geographical considerations - experience

- In case of multiple groups, MC nominations are a national issue
- COST Inclusiveness Target Countries - *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* – a special focus target group, especially scientifically addressing specific situation (post-viral fatigue paradigm)



# EUROMENE - timeline



- Submission to COST once before – in 2014
- EUROMENE network has also applied to CSAs in FP7, thematic discrepancies



# COST Action 15111 EUROMENE

## Objective

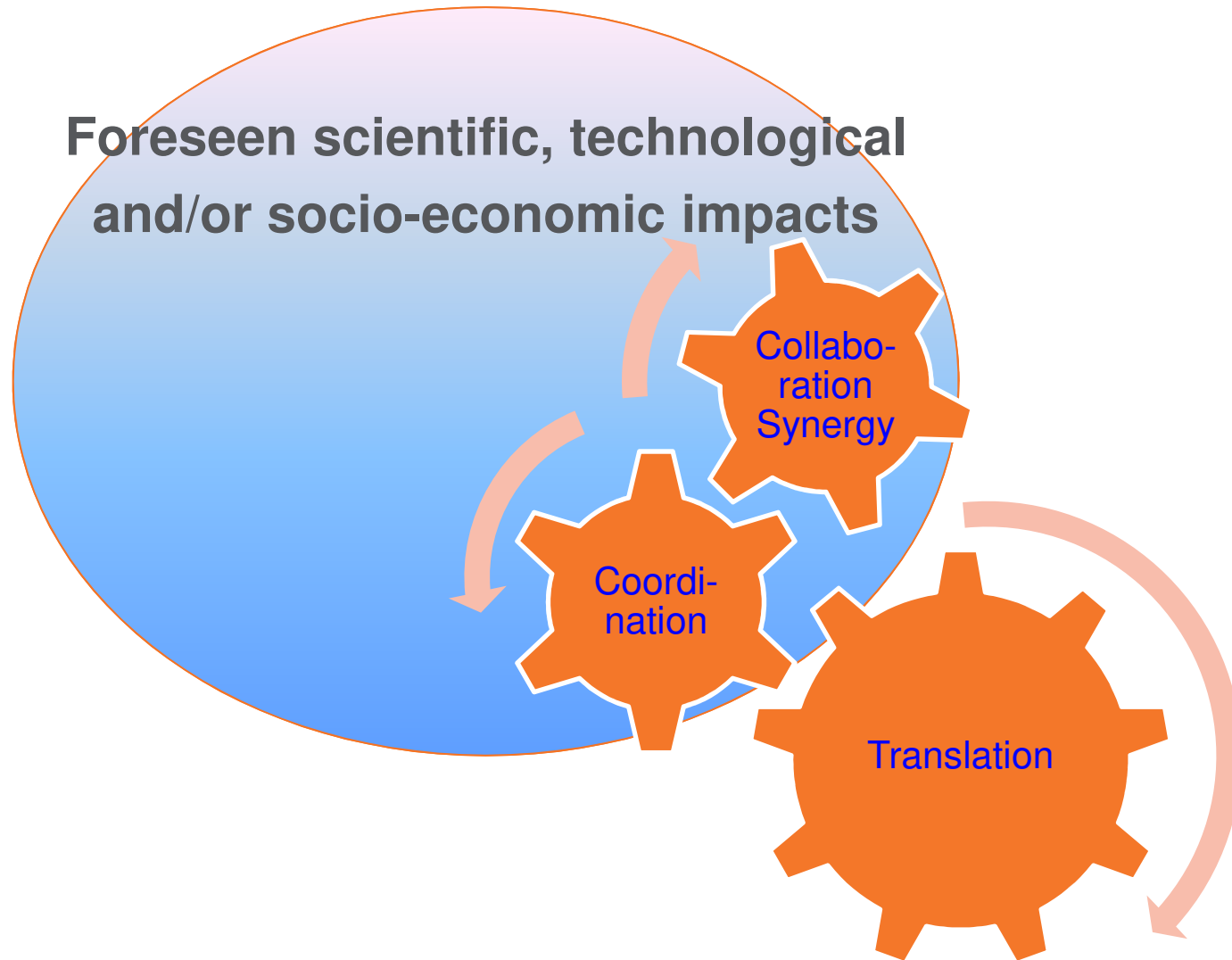
The main objective of the Action is the establishment of a sustainable integrated network of researchers in Europe working in the field of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), this way tackling the research challenges arising from unknown aetiology, clinical variability, lack of diagnostic biomarkers and limited treatment options, high associated socio-economic burden

Action Chair: Prof Modra Murovska

Vice-chair: Dr Eliana Lacerda



# COST Action 15111 EUROMENE



# Working groups CA 15111 EUROMENE

## Working group on epidemiology

- Dr Jesus Castro
- Dr Slobodan Sekulic

## Working group on biomarkers

- Prof Carmen Scheibenbogen
- Prof Enrica Capelli

## Working group on socio-economics

- Prof Derek Pheby
- Dr Julia Blanco

## Working group on clinical research enablers and diagnostic criteria

- Dr Elin B Strand
- Prof Jerome Authier

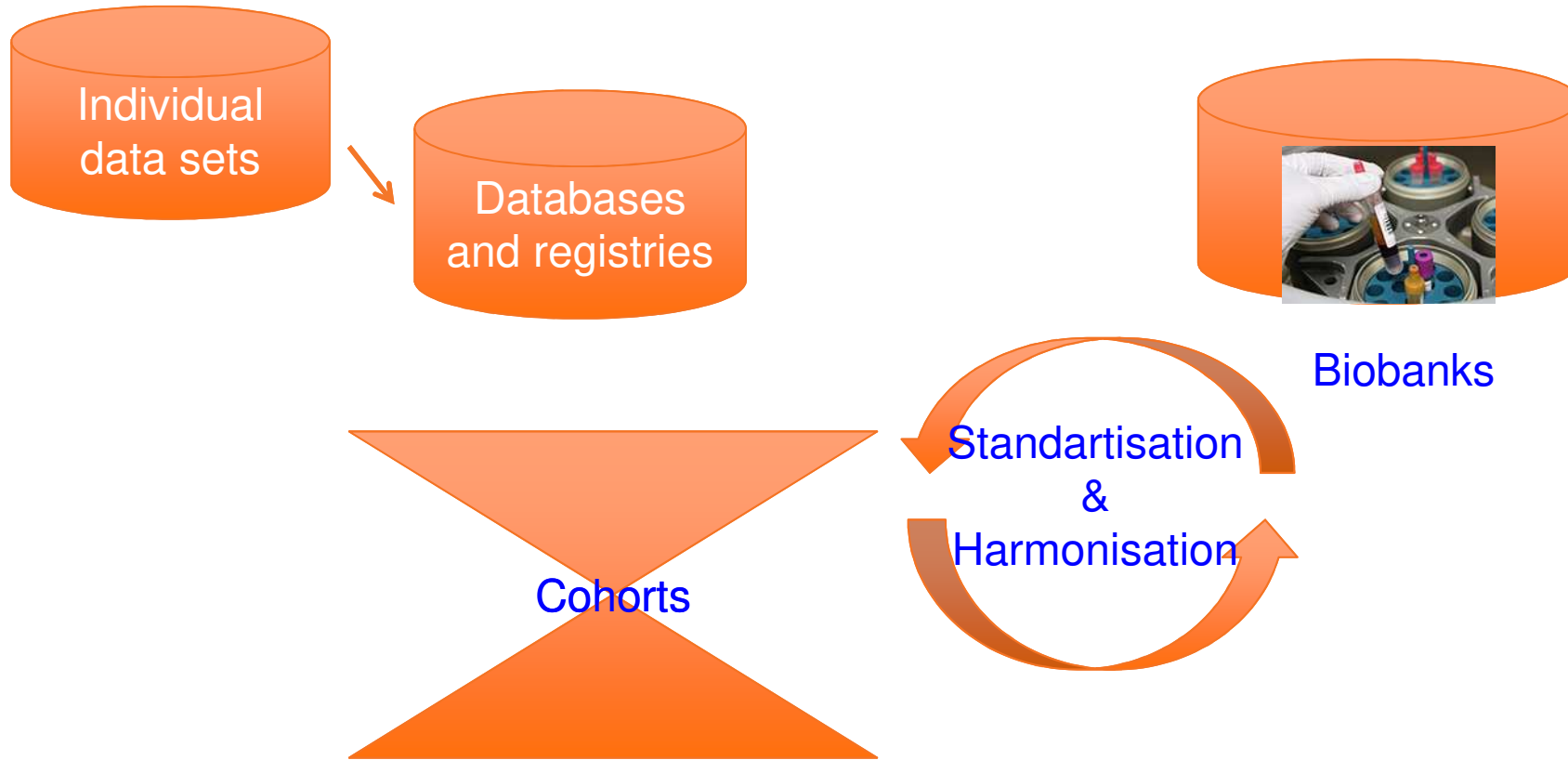
## Working group on conferences, seminars, training schools

- Prof Evelina Shikova-Lekova

## Working group on dissemination and exploitation, patient involvement, digitalisation

- Dr Lorenzo Lorusso
- Prof Anne Marit Mengshoel

# WG on Epidemiology



Open ME/CFS research resources platform



# WG on biomarkers

Immunological  
biomarkers

Infection  
biomarkers

Neurological  
Imaging and  
functional  
markers

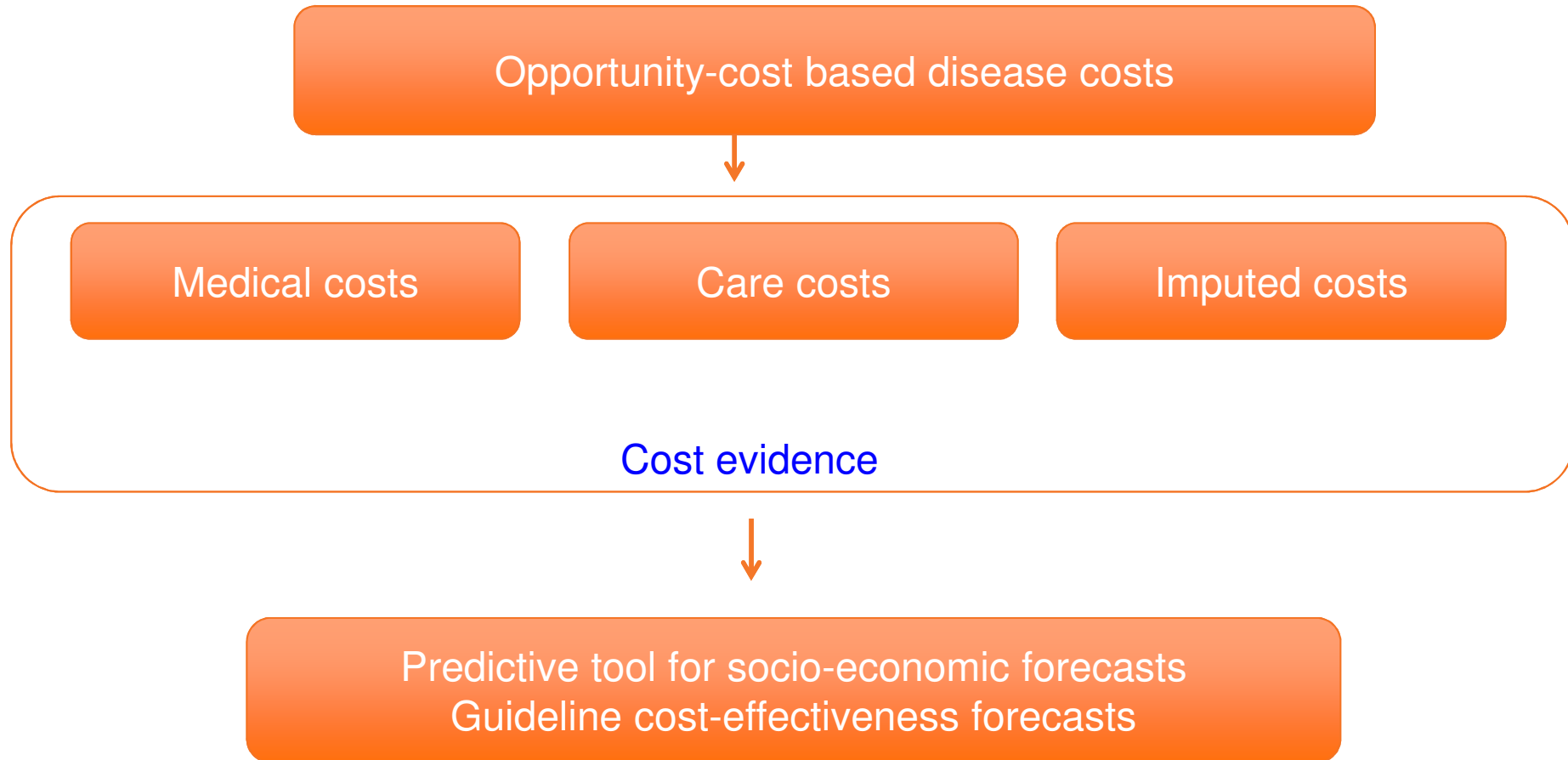
Metabolic  
biomarkers


Genetic and  
epigenetic  
biomarkers



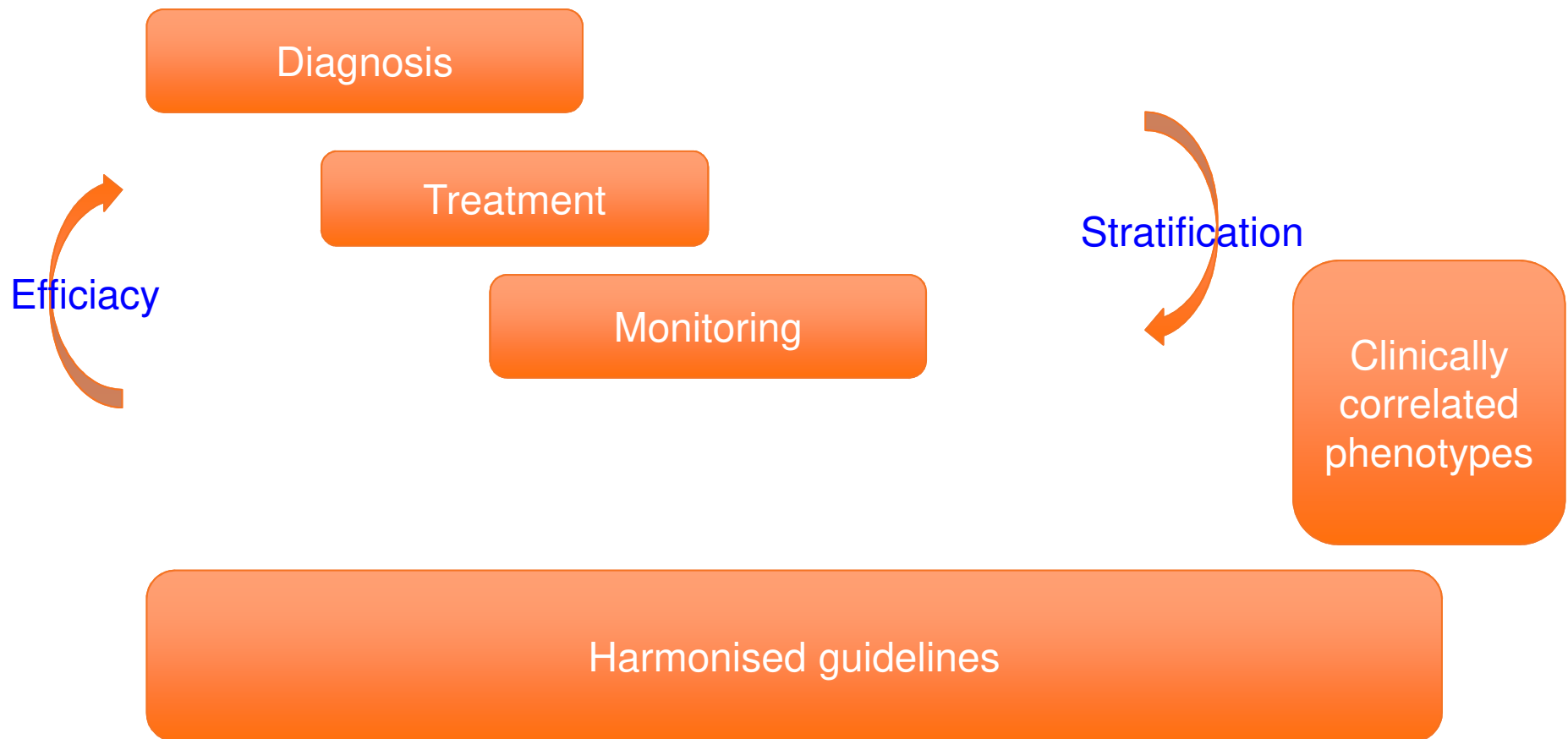
ME/CFS biomarker database and translational platform

# WG on Socioeconomics





# WG on clinical research enablers and diagnostic criteria





# WG on 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

STSM coordinator: Dr. Els Tobbac, vice-coordinator Dr. Carmen Adella Sirbu



## Next meetings

- Riga 29-30 September, 2016: MC meeting, Core group meeting, Working group meeting
- Berlin 27 January, 2017: one-day Working group meeting about synchronization progress
- Barcelona 16-17 March, 2017: Second Core groups meeting, Working group meeting, First Workshop