

The Research Potentials of MetabERN: a survey to investigate and prioritize actions

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Workpackage 6

Research



Surveys on research capacities and interests

We performed 3 surveys in each of the 69 MetabERN centres :

*one proposed to the leadership of the **university***

*one proposed to the management of the clinical **department***

*one proposed to the researchers in the **laboratories***

All together 126 questions were asked about :

level of research activity

thematic priorities

estimated quality and impact of research

motivation and barriers to do research

available facilities and infrastructures

Most centres answered the surveys

Completion rate of answered questionnaires was higher than 65%

Analysis of research activity in participating centers could be performed from 122 responses

country	center	answering center
BE	6	6
BU	1	0
CR	1	1
CZ	1	1
DK	1	1
HU	1	1
FR	9	9
DE	10	10
IT	11	11
LI	1	0
NL	5	5
NO	2	2
PL	2	2
PO	4	4
SO	1	1
SP	5	5
SW	2	2
UK	6	6
total	69	67
ratio		97%
Number of responses		148

Strengths of research in participating centers

High motivation and commitment

Good facilities and working conditions

Significant research activity, including for the HCPs who are in charge of care

Research is competitive at the level of international standards

Positive impact on teaching

Positive impact on links with industry

More competitive fields are:

- genetic and pathophysiology
- epidemiology, registries and cohorts
- population screening and establishment of guidelines

Weaknesses

The main barrier to do research is the lack of time due to high clinical workload, insufficient funding comes second

Weakest fields are:

- preclinical research
- research in technology
- e-health research

Potential threat

The weakest field is social sciences, with little research activity dedicated to RD awareness, patient's quality of life, or support to caregivers.

This situation has possible negative impact on interaction with patient's representatives and their active participation in care and research.