

European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (*EUROMENE*)

COST action CA15111

Deliverable 3

Report on existing ME/CFS biobanks, deployment and access, data availability and restrictions

Bio-resources features	Countries with existing biobanks opened for collaboration					
	Germany	Italy	Spain	Norway	France	UK
Number of donors with ME/CFS	500	100	1640	120	150	286
Number of donors in control groups	100	40	400 (FMS) 300 (chronic pain) 300 (AR) 300 (MDD) 125 (HC)	160 (healthy)	none	135 (healthy) 46 (multiple sclerosis) 46 (chronic fatigue non-ME/CFS)
Sample type	Blood	Blood, Plasma, FTA@DNA	Blood, urine, saliva	Blood, urine, saliva	Blood derivatives, CSF, urine	Blood derivatives

Data attached	Clinical data	Participating category (diagnosis)	>800 clinical, laboratory test results, variables	~700 clinical, laboratory test results and other variables	Diagnostic category	780 clinical laboratory test results and other variables at 2 time-points
Representativeness (care level)	Secondary care	Community	Community, primary and tertiary outpatient care	Secondary care	Secondary care	Community, primary, secondary care
Representativeness Geography	Berlin Brandenburg	Lombardy/ North Italy	Barcelona, Granada and Valencia, Spain	Oslo	France	Greater London, East of England
Location	Berlin, Charité	Pavia University Laboratory	VHIR/Salamanca Hospital Valencia IBSP-CV Biobank Granada University	Oslo University Hospital	Henry Mondor University Hospital, Cretéil	Royal Free Hospital Biobank, London
Expertise of participating institution	Immunology	Molecular biology, genetics, immunology	Genetics, immunology, mitochondrial metabolism, transcriptomic and proteomic biomarkers, epidemiology/clinical research, database	Genetics, autoimmunity/immunology	Genetics, immunology, clinical imaging	Immunology, genetics, epidemiology, clinical research
Sources of founding	Various	Patients Associations	Local organizations of affected patients, private donations, Spanish Biobank Networking (ISC-III, Madrid, Spain)	Oslo University Hospital	University, Patients Association, private donations	NIH, various NGOs, private donations
Charities and other institutions supporting the bio-resource	Lost voices, MERUK	AMCFS	ESTEVE Foundation	No	PICRI program	MEA, MERUK, ME Trust

Bio-resources features	Countries with existing local diagnosis based biobanks	
	Belarus	Latvia
Number of donors with ME/CFS	23	237
Number of donors in control groups	25 epilepsy 11 meningoencephalitis 9 multiple sclerosis 10 healthy	104 healthy donors 56 fibromyalgia 57 epilepsy 43 meningitis/meningoencephalitis
Sample types	Blood, plasma DNA	Blood, plasma
Data attached	Clinical data, laboratory test results	Clinical and laboratory data
Representativeness (care level)	Hospital care outpatient	Primary care
Representativeness Geography	Minsk, Minsk region	Latvia
Location	Republican Research and Practical Centre for Epidemiology and Microbiology, Minsk	Rīga Stradiņš University A.Kirchenstein Institute of Microbiology and Virology
Expertise of participating institutions	Virology, immunology, epidemiology	Virology, microbiology, immunology, clinical research
Sources of funding	Ministry of Health, Academy of Sciences Belarus	Latvian Council of Science, Rīga Stradiņš University, 7th FP Project “BALTINFECT”
Charities and other institutions supporting the bio-resource	No	No

ME/CFS – myalgic encephalomyelitis/chronic fatigue syndrome;

RA - rheumatoid arthritis;

MDD – Major depressive disorder;

HC- healthy controls;

VHIR –Vall d’Hebron Institute of Research;

ISCIII – Instituto de Salud Carlos III,

NIH – National Institute of Health,

NGOs – non-governmental organizations;

MERUK – ME Research UK;

AMCFS – Associazione Malati di CFS,

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MEA – ME Association;
PICRI – Partenariat Institutions Citoyens pour la Recherche et 'Innovation.



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