

Supplementary material

Table S1: List of the MetabERN centres and participation to the survey

Country	MetabERN centres	Number of answers			
		Clin.	Univ.	Lab.	Total
BE	CHU Liège	1	3	2	6
	Cliniques universitaires St Luc-Univ. catholique Louvain	0	1	0	1
	Ghent University hospital	0	0	0	0
	Metabolic Center ULB-VUB	2	2	2	6
	University Hospital of Antwerp UZA	1	1	1	3
	UZ Leuven	2	0	1	3
BU	University hospital "Alexandrovska" in Sofia	0	0	0	0
CR	University Hospital Center Zagreb	0	0	1	1
CZ	General University Hospital in Prague-GUH	1	1	1	3
DK	Copenhagen University Hospital, Rigshospitalet	1	0	0	1
FR	Hôpitaux Universitaires Paris Ile de France Ouest	0	0	0	0
	Hôpitaux Universitaires Paris Nord Beaujon	1	2	0	3
	Hôpitaux Universitaires Lyon	0	0	0	0
	Hôpitaux Universitaires Paris Nord Antoine-Béclère	1	1	0	2
	Hôpitaux Universitaires Paris Nord Louis-Mourier	1	1	1	3
	Hôpitaux Universitaires Paris Necker-Enfants Malades	0	1	0	1
	Hôpitaux Universitaires Paris Robert-Debré	0	0	1	1
	Hôpitaux Universitaires Lille	1	1	1	3
Hôpitaux Universitaires Marseille	0	0	0	0	
DE	Helios Dr. Horst Schmidt Kliniken	0	0	1	1
	Charité-Universitätsmedizin Berlin	1	1	0	2
	Hannover Medical School	0	0	0	0
	Medical Center University of Freiburg	1	2	2	5
	Muenster University Hospital	0	0	1	1

	Otto-von-Guericke-University Magdeburg	0	0	0	0
	Universitätskinderklinik Giessen	1	2	1	4
	Universitätsklinikum Heidelberg	1	1	1	3
	University Medical Center Hamburg-Eppendorf	1	1	1	3
	University Medical Center Mainz	2	1	1	4
HU	Hungary-University of Debrecen	1	1	1	3
IT	Azienda Sanitaria Universitaria Integrata di Udine	2	1	1	4
	Meyer Children's Hospital Firenze	0	0	0	0
	ASST Monza San Gerardo Hospital	1	2	0	3
	Azienda Ospedaliera Universitaria "Federico II", Napoli	1	1	2	4
	Azienda Ospedaliera Universitaria Integrata di Verona	0	0	0	0
	Ospedale Pediatrico Bambino Gesù, Roma	0	0	0	0
	Giannina Gaslini Institute, Genova	1	0	1	2
	San Paolo Hospital, ASST Santi Paolo e Carlo, Milano	1	1	1	3
	University Hospital of Padova	1	1	0	2
	Azienda Ospedaliero-Universitaria Pisana	0	1	0	1
Azienda Ospedaliera Universitaria Senese	2	2	2	6	
LI	Vilnius University Hospital Santariskiu klinikos	0	0	0	0
NL	Erasmus MC, University Medical Center, Rotterdam	2	1	0	3
	Maastricht University Medical Center	0	0	1	1
	University Medical Center of Groningen	2	1	0	3
	University Medical Center Utrecht (UMCU)	1	1	1	3
	Academic Medical Center Amsterdam	1	0	1	2
NO	Oslo University Hospital	1	2	1	4
	Helse Bergen HF, Haukeland University Hospital	0	0	0	0
PL	Krakov University Hospital	1	1	4	6
PO	Centro Hospitalar Lisboa Norte, EPE	1	1	1	3
	Centro Hospitalar do Porto, EPE (CHP)	1	1	0	2
	Centro Hospitalar do Sao Joao, E.P.E.	1	1	2	4

	Centro Hospitalar e Universitário de Coimbra, E.P.E.	2	1	1	4
	Hospital Senhora da Oliveira – Guimarães	0	0	0	0
SO	University Medical Centre Ljubljana	1	1	1	3
SP	University Clinical Hospital of Santiago de Compostela.	1	0	0	1
	Hospital Sant Joan de Déu, Barcelona	1	2	0	3
	Hospital Universitario Cruces, Vizcaya	1	1	1	3
	Hospital Universitario Vall d'Hebron, Barcelona	1	0	0	1
	Hospital Universitario "12 de Octubre" Madrid	1	2	1	4
SW	Karolinska University Hospital, Solna	2	1	0	3
	Sahlgrenska University Hospital University of Gothenburg	0	1	1	2
UK	Cambridge University Hospitals	0	0	0	0
	Birmingham Children's Hospital	1	2	1	4
	University Hospitals Bristol, Bristol Children's Hospital	0	0	0	0
	Central Manchester University Hospitals	0	0	0	0
	Great Ormond Street Hospital London	0	0	0	0
	University Hospital of Birmingham	1	0	0	1
		52	52	44	148



European
Reference
Networks

Survey MetabERN for Departments

* 1. Can you please type in your contact details

Name

Email Address

Phone Number

* 2. Please select the name of your hospital /institute from the drop down menu

3. Please select what is applicable to your situation

- male
- female

4. Name of the higher education institution (in original language)

5. Faculty/ department/ institute (in English)

6. Name of the faculty/ department/ institute (in original language)

7. Type of institution

- Public university
- Private university

- Public college
- Private college
- Research institute

*8. What is the legal status of your institution

- Public
- Private
- mixed

*9. What is your position

- Professor
- Associate Professor
- Lecturer
- Senior Research Fellow
- Postdoc/Research Fellow
- Research Assistant
- Teaching Assistant
- Dean, head of department or other senior administration position
- Other (please specify)

*10. Please select the areas and fields in which your institution is undertaking research activities, please select all the ones of interest:

- Animal research
- Basic research
- Preclinical research
- Clinical research

*11. Please indicate which are, the main research activities performed inside your Institution

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Health Systems Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human and Social Science Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiology/Natural History of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research in Genetics and Pathophysiology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pre-Clinical Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research Platforms/Infrastructures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development and availability of tools needed to accelerate research on rare diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*12. Academic Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans; health care resources)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*13. Industrial Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans; health care resources)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 14. Human and social science research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Society and RD (e.g., social perception, accessibility to care,...)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RD, Research and Innovation (e.g., public/private cooperation, role of patients org,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care practices (self- management, health education policy,...)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients awareness (e.g., understanding genetic data, importance of animal models,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for caregivers	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public Health and RD (e.g., health care policies, prospective public policies,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methods for social support to improve quality of life	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services accessibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orphan Drugs availability	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methods to assess QoL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 15. Epidemiology & Natural History of diseases

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Databases/data management systems for epidemiology studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cohorts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biomarkers to assess diagnosis, prognosis and severity of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnosis/prognosis methods (e.g., other than biomarkers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identification of new entities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Networks for ultra rare diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*16. Research in genetics and physiopathology

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Gene identification and Molecular Mechanisms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New database method developments to be applied to omics research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput genomics/sequencing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New bioinformatic methods and developments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., atomic microscopy...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Omics technology (e.g., proteo, metabolo..)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of new animal models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New Imaging/Microscopy methods	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of new therapeutic tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*17. Pre-clinical therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Proof-of-concept	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug libraries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Search for active chemical compounds	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic target identification/validation (e.g., stem cells, systems biology)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell therapy research (e.g., viral vectors...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Innovative biotechnological research (e.g., monoclonal antibodies, cell and gene therapy, enzyme therapy...)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug toxicology/pharmacology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*18. Therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Drug development	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phase I/II Clinical Trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bioproduction centres	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiological/clinical/ therapeutical investigations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical devices	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assesment of surgery procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transplants	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharma/academic partnerships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*19. Platforms / Infrastructures development

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Bioinformatics	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacogenomic diagnostic assays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Population Registries	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetically-modified animal model repositories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
GMP platforms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genomic and proteomic platforms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-term cohort of patients studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*20. Human resources

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Rotational positions for clinicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rotational positions for researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific training in RD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in bioinformatics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*21. Development and availability of tools needed to accelerate research on rare disease.

*23. What is the main impact of the research activities undertaken at your faculty/ department / institute?

	high impact	impact to some extent	low to none impact	do not know	Not applicable
Contribute to international research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contribute to national research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support of local/ regional innovation of development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informing teaching, to be sure that teaching is based on up-to- date research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*24. What is the approximate number of staff in research and teaching at your faculty/department/ institute?

total number

Full Professors



Full Professors total number menu

Nurses with responsibilities for research only



Nurses with responsibilities for research only total number menu

total number

Physicians with responsibilities for research only



Physicians with responsibilities for research only total number menu

PhDs with responsibilities for research only



PhDs with responsibilities for research only total number menu

Nurses with responsibilities for teaching only



Nurses with responsibilities for teaching only total number menu

Physicians with responsibilities for teaching only



Physicians with responsibilities for teaching only total number menu

PhD with responsibilities for teaching only



PhD with responsibilities for teaching only total number menu

Nurses with responsibilities for teaching and researching



Nurses with responsibilities for teaching and researching total number menu

Physicians with responsibilities for teaching and researching



Physicians with responsibilities for teaching and researching total number menu

PhD with responsibilities for teaching and researching



PhD with responsibilities for teaching and researching total number menu

25. What is the approximate total working days of your staff for teaching and/or research ? (If you don't have Prof 2,3 etc and PhD 4,5, etc, you just fill in 0 in all columns, if you are able to fill in how many hours they teach and do research you can fill in 0 at the last column. If you are not able to specify between teaching and researching you fill in 0 in column 1 and 2 and you estimate the total working days in column 3)

	Days of teaching only	Days of research only	Always different but works for
Professor 1	<input type="text"/> Professor 1 Days of teaching only menu	<input type="text"/> Professor 1 Days of research only menu	<input type="text"/> Professor 1 Always different but works for menu
Professor 2	<input type="text"/> Professor 2 Days of teaching only menu	<input type="text"/> Professor 2 Days of research only menu	<input type="text"/> Professor 2 Always different but works for menu

Days of teaching only

Days of research only

Always different but works for

Professor 3	<input type="text"/> Professor 3 Days of teaching only menu	<input type="text"/> Professor 3 Days of research only menu	<input type="text"/> Professor 3 Always different but works for menu
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Professor 4	<input type="text"/> Professor 4 Days of teaching only menu	<input type="text"/> Professor 4 Days of research only menu	<input type="text"/> Professor 4 Always different but works for menu
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Professor 5	<input type="text"/> Professor 5 Days of teaching only menu	<input type="text"/> Professor 5 Days of research only menu	<input type="text"/> Professor 5 Always different but works for menu
-------------	----------------------------------------------------------------	----------------------------------------------------------------	-------------------------------------------------------------------------

PhD 1	<input type="text"/> PhD 1 Days of teaching only menu	<input type="text"/> PhD 1 Days of research only menu	<input type="text"/> PhD 1 Always different but works for menu
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PhD 2	<input type="text"/> PhD 2 Days of teaching only menu	<input type="text"/> PhD 2 Days of research only menu	<input type="text"/> PhD 2 Always different but works for menu
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PhD 3	<input type="text"/> PhD 3 Days of teaching only	<input type="text"/> PhD 3 Days of research only menu	<input type="text"/> PhD 3 Always different but works for menu
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	Days of teaching only menu	Days of research only	Always different but works for
Phd 4	Phd 4 Days of teaching only menu	Phd 4 Days of research only menu	Phd 4 Always different but works for menu
PhD 5	PhD 5 Days of teaching only menu	PhD 5 Days of research only menu	PhD 5 Always different but works for menu
PhD 6	PhD 6 Days of teaching only menu	PhD 6 Days of research only menu	PhD 6 Always different but works for menu
Physician 1	Physician 1 Days of teaching only menu	Physician 1 Days of research only menu	Physician 1 Always different but works for menu
Physician 2	Physician 2 Days of teaching only menu	Physician 2 Days of research only menu	Physician 2 Always different but works for menu
Physician 3	Physician 3 Days of teaching only menu	Physician 3 Days of research only menu	Physician 3 Always different but works for menu
Physician 4	Physician 4 Days of teaching only menu	Physician 4 Days of research only menu	Physician 4 Always different but works for menu
Physician 5	Physician 5 Days of teaching only menu	Physician 5 Days of research only menu	Physician 5 Always different but works for menu

	Days of teaching only menu	Days of research only	Always different but works for
Physician 6	Physician 6 Days of teaching only menu	Physician 6 Days of research only menu	Physician 6 Always different but works for menu
Physician 7	Physician 7 Days of teaching only menu	Physician 7 Days of research only menu	Physician 7 Always different but works for menu
Nurse 1	Nurse 1 Days of teaching only menu	Nurse 1 Days of research only menu	Nurse 1 Always different but works for menu
Nurse 2	Nurse 2 Days of teaching only menu	Nurse 2 Days of research only menu	Nurse 2 Always different but works for menu
Nurse 3	Nurse 3 Days of teaching only menu	Nurse 3 Days of research only menu	Nurse 3 Always different but works for menu
Nurse 4	Nurse 4 Days of teaching only menu	Nurse 4 Days of research only menu	Nurse 4 Always different but works for menu
Nurse 5	Nurse 5 Days of teaching only menu	Nurse 5 Days of research only menu	Nurse 5 Always different but works for menu
Nurse 6	Nurse 6 Days of teaching only	Nurse 6 Days of research only menu	Nurse 6 Always different but works for menu

	Days of teaching only menu	Days of research only	Always different but works for
Nurse 7	<input type="text" value="Nurse 7 Days of teaching only menu"/>	<input type="text" value="Nurse 7 Days of research only menu"/>	<input type="text" value="Nurse 7 Always different but works for menu"/>
Nurse 8	<input type="text" value="Nurse 8 Days of teaching only menu"/>	<input type="text" value="Nurse 8 Days of research only menu"/>	<input type="text" value="Nurse 8 Always different but works for menu"/>
Do you have more staff? Can you please specify. <input type="text"/>			

***26. Do colleagues at your faculty/ department/ institute have access to the following facilities and infrastructures and rate their quality:**

	International standard	Good national standard	Insufficient	Do not know	Not applicable
Research support services / unit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching labs (if different from the research Labs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Large research equipment that requires technicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific databases (e.g. ISI Web of Knowledge)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Common practice	Possible but rarely used/done	Not practiced	Not possible, due to regulations/laws	Do not know	Not applicable
Contract research for international companies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaborative research with domestic companies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contract research for domestic companies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Working in industry (contract or part-time)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spin-off creation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patent activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*28. How would you rate the quality of the following at your faculty/ department/ institute?

	International standard, or close to it	Good national standard	Insufficient	Do not know	Not applicable
Research Excellence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attractive institutional environment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Industry contacts and collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International networking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

International standard, or close to it
 Good national standard
 Insufficient
 Do not know
 Not applicable

Quality Assurance

*29. Do you award doctorates

Yes

No

*30. How frequently are the following?

	Common practice	Possibly but rarely used	Not practiced	Not possible due to regulations/laws
Doctoral thesis can be written in English	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD courses are taught in English	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transferable skills training is provided	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interdisciplinary research is encouraged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International mobility for doctoral candidates (to attend conferences, access libraries and labs abroad)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International exchange of doctoral candidates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International joint doctoral Programmes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Programmes in collaboration with industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Common practice	Possibly but rarely used	Not practiced	Not possible due to regulations/laws
Support units for doctoral studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research study rooms for candidates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Provision of accommodation for doctoral candidates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

*31. Have you participated in any clinical trials before?

- Yes
- No

*32. What was your role in the latest clinical trial that you have participated in?

- Not participated in clinical trial
- Principal investigator
- Co-investigator
- Sub-investigator

*33. What do you think are the benefits of conducting clinical trials?

	Strongly agree	Agree	Agree to some extent	Disagree
Doctors may help patients with new treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can contribute to medical progress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can obtain a wider and deeper understanding of the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can obtain research grants or other rewards	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can enhance their reputation in society or in the hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can obtain credits to be a board certified doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can write papers about the clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The clinical trial will have benefits for patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conducting clinical trial is just a waste of time and energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*34. What are the major problems in conducting clinical trials?

	A serious problem	A problem	A small problem	No problem
Lack of time for clinicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shortage of clinical research coordinators/ research nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties with data management and/or	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	A serious problem	A problem	A small problem	No problem
statistical analysis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insufficiency of infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of systemic support from the hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties in communication (e.g	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ethical committee,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enrollment of trial participants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obtaining of informed consent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of communication with trial sponsor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Funding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Signing of the contract between the company and the hospital administration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other difficulties to be listed

*35. Have you ever participated in a multinational clinical trial?

- Yes
 No

*36. What are in your opinion the major obstacles in participation in a multinational clinical trial?[CB1]

[CB1]The following two questions will be linked to the answer to question 7 (yes or no) and we could separately analyse the answers form the yes and no group

	A serious problem	A problem	A small problem	No problem
Investigator qualifications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Infrastructure of clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difference of the medical system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Regulation process and legal system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Language barriers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost-effectiveness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other difficulties to be listed	<input type="text"/>			

*37. What do you think is important for overcoming the obstacles for the development of clinical trials?

	Very important	Important	Partially important	Not important
Reform of the system and regulatory rules	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Financial support to improve the quality of clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training specialized people in clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very important	Important	Partially important	Not important
Establishment of clinical trial centers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Good training programs for clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public relations to citizens	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*38. Are you interested in conducting clinical trials?

- Yes
- No

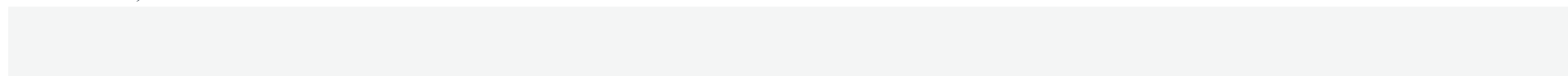
*39. Who decides on how this budget is allocated to the faculties/ departments?

- Institutional leadership (Dean, president, director)
- A central body of the institution (academic senate or similar)
- Ministry/ national agency

*40. How would you generally describe facilities and infrastructure at your institution

	International standard or close to it	Good national standard	Insufficient	Do not know	Not applicable
Research support services / unit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	International standard or close to it	Good national standard	Insufficient	Do not know	Not applicable
Research laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching labs (if different from research Labs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Large research equipment that requires technicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific databases (e.g. ISI Web of Knowledge)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledge Transfer Office	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Science Park	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research ethics committee	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Libraries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research publication repositories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Computer equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IT Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accommodation for visiting scholars	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Buildings/premises in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Power supply/ electricity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication infrastructure (phone, internet etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



*41. Does your institution have, or engages in, any of the following

	Yes very strong	Yes occasionally / some	No	Do not know	Not applicable
Spin-offs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research collaboration with industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International research collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research collaboration with public/ state offices and agencies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*42. Has your institution been involved in applications for research projects (regardless whether successful or not)?

	Frequently as an applicant	Frequently as a partner	Occasionally as an applicant	Occasionally as partner	No involvement of application
National, involving colleagues from another institution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Horizon 2020 / FP7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other European project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other International project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*43. When have you been last research active as a health professional?

(Research activity is defined here as being involved in the design or implementation of a research project either as a researcher or a supervisor)

- Within the last 2 years
- More than 2 years ago
- Never been research active as a health professional

*44. Have you published any of the following over the last 3 years 2014-2017?

	Yes mostly with single authorship	Yes mostly co-authored	Only supervising	No
ISI journal articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*45. If co-authored, who do you write with more often?

	Colleagues from my institution	Colleagues from other institutions	European Colleagues	Intercontinental Colleagues	No co-authoring
ISI journal articles	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*46. What factors had motivated you to be research active?

	Did not motivate me	Yes some motivation	very strong motivation	N/A
Personal motivation', 'Completing an academic degree'	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional development	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Career advancement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Did not motivate me	Yes some motivation	very strong motivation	N/A
Part of the professional role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For publication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain more expertise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*47. If not active in research define the potential barriers to research engagement:

If active in research: Is there anything you can point out that prevents or discourages you from engaging in research.

- Not enough time available to engage in research
- Clinical workload pressures
- Lack of support/encouragement
- Lack of funding
- Lack of available resources for research
- Difficulties gaining ethical approval
- Research not valued in organisation
- Weaknesses in research skills
- Personal circumstances (e.g., family commitments limiting time for research)
- Lack of research opportunities
- Lack of supervision/mentorship
- Difficulties collecting or gaining access to data
- There is no reason why people should be limited or not engaged in research

***48. What are the main problems that researchers face at your institution**

	Strongly agree	Agree to some extent	Disagree to some extent	Strongly disagree	Do not know	N/A
There is no or insufficient research funding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are no or insufficient research facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some research facilities can only be accessed by some researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no or insufficient administrative capacity to prepare research proposals, manage research projects etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have no international research contacts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers are not internationally mobile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is not possible to hire international researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have to teach, and cannot put enough focus on their research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have other jobs on the side and cannot put enough focus on their research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***49. What do you think are the reasons why people in your Institution are not, or limited engaged in research?**

	strongly agree	agree to some extent	neither agree nor disagree	disagree	strongly disagree	Do not know
There are no or insufficient research facilities	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research is too much concentrated in a few institutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher education institutions are focusing too much on teaching, and neglect research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research is not sufficiently applied, and ignores the needs of the industry and society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is too much focus on applied research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interdisciplinary research is not sufficiently encouraged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The best researchers are leaving the country, which is a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
The best researchers are leaving the country, but they still continue to Contribute to national research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young researchers are leaving the country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young talented people look for careers outside of the research and higher Education sectors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*51. Of the changes listed in the table below, indicate how effective you believe they would be for increasing the level of research activity in your Institution

	Would have no effect	Would be somewhat effective	Would be greatly effective
Increased protected working time for research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher levels of ongoing research training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recruiters in the health service giving more value to research experience when selecting candidates for clinical positions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A more simplified and efficient ethics application process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Greater levels of mentorship and support when conducting research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities to advance one's research qualifications (e.g. post-doctoral fellowships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More funded research posts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities for collaboration with other clinical or academic researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*52. About research Infrastructure, what is applicable for you?

	Don't know it	Know it	Collaborate with it
BBMRI Biobanking and Biomolecular Resources Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C-ERIC Central-European Research Infrastructures Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLARIN Common Language Resources and Technology Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EATRIS European Advanced Translational Research Infrastructure in Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECRIN European Clinical Research Infrastructure Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
ELIXIR The European Life-Science Infrastructure for Biological Information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERA European Research Area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERIC European Research Infrastructure Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESFRI European Strategy Forum on Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EU-OPENSREEN European Infrastructure of Open Screening Platforms for Chemical Biology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Euro-BioImaging European Research Infrastructure for Imaging Technologies in Biological and Biomedical Sciences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
INFRAFRONTIER European Research Infrastructure for the generation, phenotyping, archiving and distribution of mouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISBE Infrastructure for Systems Biology Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MIRRI Microbial Resource Research Infrastructure disease models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NRRI Research Infrastructure Roadmap	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PRACE Partnership for Advanced Computing in Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RI Research infrastructure(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*53. About biobanks, what is applicable for you?

	Don't know it	Know it	Collaborate with it
Basque Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanco.pt (Portuguese National Consortium of Biobanks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank of the Estonian genome center	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BioNER: Biobank of the Institute of Rare Diseases Research/Institute of Health Carlos III	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-net – brain tissue bank Aachen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net – brain tissue bank Munster (pediatric neuropathology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net Germany : National network of brain banks in Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell line and DNA Biobank from patients affected by genetic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CIBERER Biobank (Biobank of rare diseases)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA biobank of the Department of Molecular Genetics and Diagnostics, National Institute of Environmental Health (NIEH) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EuroBioBank European Network of DNA, cell and tissue banks for Rare Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human DNA and cell biobank of Genethon – genetic diseases, mainly neuromuscular diseases – part of the EuroBioBank network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human tissue biobank of Neuromuscular diseases (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuromuscular Tissue Bank (NMTB) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telethon Network of Genetic Biobanks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*54. About registry and database, what is applicable for you?

	Don't know it	Know it	Collaborate with it
(NCARDRS) National Congenital Anomaly and Rare Disease Registration Service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian Country Node of the Human Variome Project (HVP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian registry for inborn errors of metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian Neuromuscular Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian patient database for Wilson disease – contributes to the EuroWilson registry (terminated)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Canadian Neuromuscular Disease Registry – part of the TREAT-NMD network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DDRMD – Dutch Diagnosis Registration Metabolic Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch Neuromuscular Database CRAMP: Computer Registry of All Myopathies and Polyneuropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Fabry disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type C	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECARUCA: cytogenetic and clinical database on rare chromosomal disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-HOD European Network and Registry for Homocystinurias and Methylation Defects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EIMD: European registry and network for intoxication type metabolic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English alpha-1 antitrypsin deficiency registry – contributes to the Alpha One International Registry (AIR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
English hyperoxaluria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English phenylketonuria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EPNET: European porphyria Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-RARE Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESNEK – Rare paediatric neurological disease registry Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUNEFRON: registry of the European network for the study of orphan nephropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUROCAT European Surveillance on congenital anomalies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUROGLYCANET – International patient registry and cohort for congenital disorders of glycosylation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European cystinosis cohort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European Porphyria Registry (EPR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fabry Disease Registry –DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FOS : Fabry Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of glycogen storage disease type 2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of patients affected by Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French registry of neuromuscular diseases from reference centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Galactosemia Patient Registry – part of the Galactosemia Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
German mucopolysaccharidosis patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HOS : Hunter Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
iNTD Network – International Working Group on Neurotransmitter Related Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Collaborative Gaucher Group (ICGG) Gaucher Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Morquio A registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Niemann-Pick Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LOVD: GAA gene (Glucosidase, alpha, acid) variant database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mendelian cytogenetics network online database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MITOCON: National registry mitochondrial disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mucopolysaccharidosis type 1 (MPS I) Registry –	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuro-Heart-Registry: Registry for patients with heart involment in neurovascular diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMDcy: Cypriot Neuromuscular Diseases – contributes to TREAT-NMD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMD-ES: Spanish Registry of Neuromuscular Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Norwegian Porphyria Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pompe Disease Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Portuguese Fabry patient registry – contributing to the international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RAMEDIS : Rare Metabolic Diseases Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RAMEDIS : Rare Metabolic Diseases mutation Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Patients with Niemann-Pick Type C Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
and other rare diabetes syndromes – contributing to EURO-WABB			
Registry_Biobank Name	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The International Collaborative Gaucher Group (ICGG) Gaucher registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Mps I registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Pompe registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TREAT-NMD: Accelerating Treatments for Neuromuscular Diseases (registries)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK10K RARE NEUROMUSCULAR – Genetic neuromuscular diseases variant database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
X-ALD: X-linked adrenoleukodystrophy database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*55. About scientific organisation, what is applicable for you?

	Don't know it	Know it	Collaborate with it
AECOM – Asociación Española para el Estudio de los Errores Congénitos del Metabolismo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
APS – Arbeitsgemeinschaft für Pädiatrische Stoffwechselstörungen (Working group for paediatric metabolic disturbances, Germany)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B4B – Brains for Brain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BIMDG – British Inherited Metabolic Disease Group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLIMB – Children Living with Inherited Metabolic Diseases, UK	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
EBC – European Brain Council	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERNDIM Quality assurance in laboratory testing for IEM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESGCT – European Society of Gene and Cell Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EURORDIS – European Organisation for Rare Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fondazione Telethon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IBBS – International Brain Barriers Society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IRDIRC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISNS – International Society for Neonatal Screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SEEIM – Sociedad Española de Errores Innatos del Metabolismo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SFEIM – Société Française pour l'Étude des Erreurs Innées du Métabolisme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SIMD – Society for Inherited Metabolic Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SISMME – Societa' Italiana per lo Studio delle Malattie Metaboliche Ereditarie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SPDM – Sociedade Portuguesa de Doenças Metabólicas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SSIEM – The Society for Study of Inborn Errors of Metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*56. How many ongoing research do you participate in at your department at the moment.

57. How many of these are clinical trials?

58. How many of the clinical trials are in phase I?

59. How many of the clinical trials are in phase II?

60. How many of the clinical trials are in phase III?

61. How many of the clinical trials are in phase IV?



European
Reference
Networks

Survey MetabERN for Universities

* 1. Can you please type in your contact details

Name

Email Address

Phone Number

* 2. Please select the name of your hospital /institute from the drop down menu

3. Please select what is applicable to your situation

male

female

4. Type of institution

- Public university
- Private university
- Public college
- Private college
- Research institute

* 5. What is the legal status of your institution

- Public
- Private
- mixed

* 6. What is your position

- Professor
- Associate Professor
- Lecturer
- Senior Research Fellow
- Postdoc/Research Fellow
- Research Assistant
- Teaching Assistant
- Dean, head of department or other senior administration position
- Other (please specify)

*7. Please select the areas and fields in which your institution is undertaking research activities, please select all the ones of interest:

- Animal research
- Basic research
- Preclinical research
- Clinical research

Questions to inquire the level of activity in the research thematic area.

*8. Please indicate which are, the main research activities performed inside your Institution

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Health Systems Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human and Social Science Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiology/Natural History of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research in Genetics and Pathophysiology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pre-Clinical Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research Platforms/Infrastructures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Development and availability of tools needed to accelerate research on rare diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*9. Academic Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans; health care resources)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*10. Industrial Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
health care resources)					
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>

* 11. Human and social science research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Society and RD (e.g., social perception, accessibility to care,...)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
RD, Research and Innovation (e.g., public/private cooperation, role of patients org,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care practices (self- management, health education policy,...)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Patients awareness (e.g., understanding genetic data, importance of animal models,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for caregivers	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Public Health and RD (e.g., health care policies, prospective public policies,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Methods for social support to improve quality of life	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services accessibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orphan Drugs availability	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methods to assess QoL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 12. Epidemiology & Natural History of diseases

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Registries	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Databases/data management systems for epidemiology studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cohorts	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biomarkers to assess diagnosis, prognosis and severity of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnosis/prognosis methods (e.g., other than biomarkers)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Identification of new entities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Networks for ultra rare diseases	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 13. Research in genetics and physiopathology

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Gene identification and Molecular Mechanisms	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New database method developments to be applied to omics research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking research	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput genomics/sequencing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New bioinformatic methods and developments	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., atomic microscopy...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Omics technology (e.g., proteo, metabolo..)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of new animal models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New Imaging/Microscopy methods	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of new therapeutic tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 14. Pre-clinical therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Proof-of-concept	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug libraries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Search for active chemical compounds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic target identification/validation (e.g., stem cells, systems biology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell therapy research (e.g., viral vectors...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Innovative biotechnological research (e.g., monoclonal antibodies, cell and gene therapy, enzyme therapy...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug toxicology/pharmacology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 15. Therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Drug development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phase I/II Clinical Trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bioproduction centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiological/clinical/ therapeutical investigations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assesment of surgery procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transplants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Pharma/academic partnerships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 16. Platforms / Infrastructures development

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Bioinformatics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacogenomic diagnostic assays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Population Registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetically-modified animal model repositories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
GMP platforms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genomic and proteomic platforms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-term cohort of patients studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 17. Human resources

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Rotational positions for clinicians	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rotational positions for researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific training in RD	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in bioinformatics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*18. Development and availability of tools needed to accelerate research on rare disease.

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Network development	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creation of transnational research consortiums	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational calls for projects funding	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opening of national research programmes to international collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational research infrastructures	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of an inventory/directory of databases of experts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational collection of funded RD research projects	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*19. What influences and governs research at your institution?

	Strongly agree	Agree to some extent	Disagree to some extent	Strongly disagree	No information available	Not applicable
Ministry/ national research agency has a strong say	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Central university level mostly decides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Faculties/ departments/ institutes decide very much on what they do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Individual professors/ Researchers do very much what they want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In my own position, I can influence research agendas at my faculty/department/ institute	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*20. Please rate the importance of funding sources for research

	Very important	Of some importance	Not important	Do not know	Not applicable
Institutional funding by government	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research grants (EU)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other international research grants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contracts from industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Endowment income, donations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research Board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Very important	Of some importance	Not important	Do not know	Not applicable
Charity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Private company	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific Society/Patients Organization	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local Institutional Funding by Single Universities,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local and/or Regional authorities,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Funding by Health Authorities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Funding by no-profit, Private Agencies (e.g. Telethon),	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***21. Who decides on how this budget is allocated to the faculties/ departments?**

- Institutional leadership (Dean, president, director)
- A central body of the institution (academic senate or similar)
- Ministry/ national agency

***22. How would you generally describe facilities and infrastructure at your institution**

International standard or close to it Good national standard Insufficient Do not know Not applicable

	International standard or close to it	Good national standard	Insufficient	Do not know	Not applicable
Research support services / unit	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Research laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching labs (if different from research Labs)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Large research equipment that requires technicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific databases (e.g. ISI Web of Knowledge)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Knowledge Transfer Office	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Science Park	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Research ethics committee	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Libraries	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Research publication repositories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Computer equipment	<input checked="" type="radio"/> C	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
IT Services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accommodation for visiting scholars	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Buildings/premises in general	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Power supply/ electricity	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Communication infrastructure (phone, internet etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*23. Does your institution have, or engages in, any of the following

	Yes very strong	Yes occasionally / some	No	Do not know	Not applicable
Spin-offs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research collaboration with industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International research collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research collaboration with public/ state offices and agencies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*24. Has your institution been involved in applications for research projects (regardless whether successful or not)?

	Frequently as an applicant	Frequently as a partner	Occasionally as an applicant	Occasionally as partner	No involvement of application
National, involving colleagues from another institution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Horizon 2020 / FP7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other European project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other International project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*25. When have you been last research active as a health professional?

(Research activity is defined here as being involved in the design or implementation of a research project either as a researcher or a supervisor)

- Within the last 2 years
- More than 2 years ago
- Never been research active as a health professional

*26. Have you published any of the following over the last 3 years 2014-2017?

	Yes mostly with single authorship	Yes mostly co-authored	Only supervising	No
ISI journal articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*27. If co-authored, who do you write with more often?

	Colleagues from my institution	Colleagues from other institutions	European Colleagues	Intercontinental Colleagues	No co-authoring
ISI journal articles	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*28. What factors had motivated you to be research active?

	Did not motivate me	Yes some motivation	very strong motivation	N/A
Personal motivation', 'Completing an academic degree'	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Did not motivate me	Yes some motivation	very strong motivation	N/A
Professional development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Career advancement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Part of the professional role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For publication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain more expertise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*29. If not active in research define the potential barriers to research engagement:

If active in research: Is there anything you can point out that prevents or discourages you from engaging in research.

- Not enough time available to engage in research
- Clinical workload pressures
- Lack of support/encouragement
- Lack of funding
- Lack of available resources for research
- Difficulties gaining ethical approval
- Research not valued in organisation
- Weaknesses in research skills
- Personal circumstances (e.g., family commitments limiting time for research)
- Lack of research opportunities
- Lack of supervision/mentorship

- Difficulties collecting or gaining access to data
- There is no reason why people should be limited or not engaged in research

***30. What are the main problems that researchers face at your institution**

	Strongly agree	Agree to some extent	Disagree to some extent	Strongly disagree	Do not know	N/A
There is no or insufficient research funding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are no or insufficient research facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Some research facilities can only be accessed by some researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no or insufficient administrative capacity to prepare research proposals, manage research projects etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have no international research contacts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers are not internationally mobile	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is not possible to hire international researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have to teach, and cannot put enough focus on their research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Most researchers have other jobs on the side and cannot put enough focus on their research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***31. What do you think are the reasons why people in your Institution are not, or limited engaged in research?**

	strongly agree	agree to some extent	neither agree nor disagree	disagree	strongly disagree	Do not know
There are no or insufficient research facilities	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research is too much concentrated in a few institutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher education institutions are focusing too much on teaching, and neglect research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research is not sufficiently applied, and ignores the needs of the industry and society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is too much focus on applied research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interdisciplinary research is not sufficiently encouraged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The best researchers are leaving the country, which is a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
The best researchers are leaving the country, but they still continue to Contribute to national research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young researchers are leaving the country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young talented people look for careers outside of the research and higher Education sectors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*33. Of the changes listed in the table below, indicate how effective you believe they would be for increasing the level of research activity in your Institution

Would have no effect

Would be somewhat effective

Would be greatly effective

	Would have no effect	Would be somewhat effective	Would be greatly effective
Increased protected working time for research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher levels of ongoing research training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recruiters in the health service giving more value to research experience when selecting candidates for clinical positions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A more simplified and efficient ethics application process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Greater levels of mentorship and support when conducting research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities to advance one's research qualifications (e.g. post-doctoral fellowships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More funded research posts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities for collaboration with other clinical or academic researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*34. What is applicable for you in the following list about research infrastructure

	Don't know it	Know it	Collaborate with it
BBMRI Biobanking and Biomolecular Resources Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C-ERIC Central-European Research Infrastructures Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLARIN Common Language Resources and Technology Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EATRIS European Advanced Translational Research Infrastructure in Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
ECRIN European Clinical Research Infrastructure Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ELIXIR The European Life-Science Infrastructure for Biological Information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERA European Research Area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERIC European Research Infrastructure Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESFRI European Strategy Forum on Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EU-OPENSREEN European Infrastructure of Open Screening Platforms for Chemical Biology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Euro-BioImaging European Research Infrastructure for Imaging Technologies in Biological and Biomedical Sciences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
INFRAFRONTIER European Research Infrastructure for the generation, phenotyping, archiving and distribution of mouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISBE Infrastructure for Systems Biology Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MIRRI Microbial Resource Research Infrastructure disease models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NRRI Research Infrastructure Roadmap	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PRACE Partnership for Advanced Computing in Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RI Research infrastructure(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*35. What is applicable for you in the following list about biobanks

	Don't know it	Know it	Collaborate with it
Basque Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
Biobanco.pt (Portuguese National Consortium of Biobanks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank of the Estonian genome center	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BioNER: Biobank of the Institute of Rare Diseases Research/Institute of Health Carlos III	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-net – brain tissue bank Aachen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net – brain tissue bank Munster (pediatric neuropathology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net Germany : National network of brain banks in Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell line and DNA Biobank from patients affected by genetic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CIBERER Biobank (Biobank of rare diseases)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA biobank of the Department of Molecular Genetics and Diagnostics, National Institute of Environmental Health (NIEH) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EuroBioBank European Network of DNA, cell and tissue banks for Rare Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human DNA and cell biobank of Genethon – genetic diseases, mainly neuromuscular diseases – part of the EuroBioBank network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human tissue biobank of Neuromuscular diseases (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuromuscular Tissue Bank (NMTB) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telethon Network of Genetic Biobanks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*36. What is applicable for you in the following list about registry and database

	Don't know it	Know it	Collaborate with it
(NCARDRS) National Congenital Anomaly and Rare Disease Registration Service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian Country Node of the Human Variome Project (HVP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian registry for inborn errors of metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian Neuromuscular Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian patient database for Wilson disease – contributes to the EuroWilson registry (terminated)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Canadian Neuromuscular Disease Registry – part of the TREAT-NMD network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DDRMD – Dutch Diagnosis Registration Metabolic Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch Neuromuscular Database CRAMP: Computer Registry of All Myopathies and Polyneuropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Fabry disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type C	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECARUCA: cytogenetic and clinical database on rare chromosomal disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-HOD European Network and Registry for Homocystinurias and Methylation Defects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EIMD: European registry and network for intoxication type metabolic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
English alpha-1 antitrypsin deficiency registry – contributes to the Alpha One International Registry (AIR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English hyperoxaluria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English phenylketonuria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EPNET: European porphyria Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-RARE Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESNEK – Rare paediatric neurological disease registry Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUNEFRON: registry of the European network for the study of orphan nephropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUROCAT European Surveillance on congenital anomalies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUROGLYCANET – International patient registry and cohort for congenital disorders of glycosylation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European cystinosis cohort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European Porphyria Registry (EPR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fabry Disease Registry –DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FOS : Fabry Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of glycogen storage disease type 2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of patients affected by Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French registry of neuromuscular diseases from reference centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Galactosemia Patient Registry – part of the Galactosemia Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
German mucopolysaccharidosis patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HOS : Hunter Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
iNTD Network – International Working Group on Neurotransmitter Related Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Collaborative Gaucher Group (ICGG) Gaucher Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Morquio A registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Niemann-Pick Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LOVD: GAA gene (Glucosidase, alpha, acid) variant database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mendelian cytogenetics network online database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MITOCON: National registry mitochondrial disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mucopolysaccharidosis type 1 (MPS I) Registry –	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuro-Heart-Registry: Registry for patients with heart involment in neurovascular diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMDcy: Cypriot Neuromuscular Diseases – contributes to TREAT-NMD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMD-ES: Spanish Registry of Neuromuscular Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Norwegian Porphyria Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pompe Disease Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Portuguese Fabry patient registry – contributing to the international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
RAMEDIS : Rare Metabolic Diseases Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RAMEDIS : Rare Metabolic Diseases mutation Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Patients with Niemann-Pick Type C Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes – contributing to EURO-WABB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry_Biobank Name	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The International Collaborative Gaucher Group (ICGG) Gaucher registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Mps I registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Pompe registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TREAT-NMD: Accelerating Treatments for Neuromuscular Diseases (registries)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK10K RARE NEUROMUSCULAR – Genetic neuromuscular diseases variant database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
X-ALD: X-linked adrenoleukodystrophy database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*37. What is applicable for you in the following list about scientific organisation

	Don't know it	Know it	Collaborate with it
AECOM – Asociación Española para el Estudio de los Errores Congénitos del Metabolismo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
APS – Arbeitsgemeinschaft für Pädiatrische Stoffwechselstörungen (Working group for paediatric metabolic disturbances, Germany)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B4B – Brains for Brain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BIMDG – British Inherited Metabolic Disease Group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLIMB – Children Living with Inherited Metabolic Diseases, UK	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EBC – European Brain Council	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERNDIM Quality assurance in laboratory testing for IEM	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESGCT – European Society of Gene and Cell Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EURORDIS – European Organisation for Rare Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fondazione Telethon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IBBS – International Brain Barriers Society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IRDIRC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISNS – International Society for Neonatal Screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SEEIM – Sociedad Española de Errores Innatos del Metabolismo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SFEIM – Société Française pour l'Étude des Erreurs Innées du Métabolisme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SIMD – Society for Inherited Metabolic Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SISMME – Societa' Italiana per lo Studio delle Malattie Metaboliche Ereditarie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SPDM – Sociedade Portuguesa de Doenças Metabólicas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SSIEM – The Society for Study of Inborn Errors of Metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



European
Reference
Networks

Survey MetabERN for Laboratories

PAGE TITLE

* 1. Can you please type in your contact details

Name

Email Address

Phone Number

* 2. Please select the name of your hospital /institute from the drop down menu



3. Please select what is applicable to your situation

- male
- female

4. Academic degrees (if you have several, just the once that are most important for your researcher career)

	Year of award	Country of award
Undergraduate degree (or equivalent)	<input type="text"/> Undergraduate degree (or equivalent) Year of award menu	<input type="text"/> Undergraduate degree (or equivalent) Country of award menu
Master degree (or equivalent)	<input type="text"/> Master degree (or equivalent) Year of award menu	<input type="text"/> Master degree (or equivalent) Country of award menu
Doctorate	<input type="text"/> Doctorate Year of award menu	<input type="text"/> Doctorate Country of award menu
Specialization Degree	<input type="text"/> Specialization Degree Year of award menu	<input type="text"/> Specialization Degree Country of award menu

5. Type of institution

- Public university
- Private university
- Public college
- Private college
- Research institute

*6. What is your position

- Professor
- Associate Professor
- Lecturer
- Senior Research Fellow
- Postdoc/Research Fellow
- Research Assistant
- Teaching Assistant
- Dean, head of department or other senior administration position
- Other (please specify)

7. What type of research do you perform?

- Animal research
- Basic research
- Preclinical research

Clinical research

*8. Please indicate which are, the main research activities performed inside your Institution

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Health Systems Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human and Social Science Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiology/Natural History of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research in Genetics and Pathophysiology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pre-Clinical Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic Research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research Platforms/Infrastructures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development and availability of tools needed to accelerate research on rare diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*9. Academic Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans; health care resources)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 10. Industrial Health Systems Research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Research policy (e.g., guidelines development; national plans; health care resources)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost analysis (e.g., guidelines implementation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New technologies (e.g., New diagnostic tests, population screening programmes, Innovative therapeutics)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health-Technology assessment of Orphan Drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e-Health activities	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 11. Human and social science research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Society and RD (e.g., social perception, accessibility to care,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RD, Research and Innovation (e.g., public/private cooperation, role of patients org,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care practices (self- management, health education policy,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients awareness (e.g., understanding genetic data, importance of animal models,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support for caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public Health and RD (e.g., health care policies, prospective public policies,...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methods for social support to improve quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services accessibility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orphan Drugs availability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Methods to assess QoL	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 12. Epidemiology & Natural History of diseases

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Registries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Databases/data management systems for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
epidemiology studies					
Cohorts	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Biomarkers to assess diagnosis, prognosis and severity of diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diagnosis/prognosis methods (e.g., other than biomarkers)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Identification of new entities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Networks for ultra rare diseases	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>

* 13. Research in genetics and physiopathology

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Gene identification and Molecular Mechanisms	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
New database method developments to be applied to omics research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking research	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
High throughput genomics/sequencing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New bioinformatic methods and developments	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
New technologies (e.g., atomic microscopy...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Omics technology (e.g., proteo, metabolo..)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Development of new animal models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New Imaging/Microscopy methods	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Development of new therapeutic tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 14. Pre-clinical therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Proof-of-concept	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Drug libraries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Search for active chemical compounds	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
High throughput drug screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic target identification/validation (e.g., stem cells, systems biology)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Cell therapy research (e.g., viral vectors...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Innovative biotechnological research (e.g., monoclonal antibodies, cell and gene therapy, enzyme therapy...)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Drug toxicology/pharmacology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 15. Therapeutic research

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Drug development	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phase I/II Clinical Trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bioproduction centres	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Epidemiological/clinical/ therapeutical investigations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical devices	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assesment of surgery procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transplants	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharma/academic partnerships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 16. Platforms / Infrastructures development

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Bioinformatics	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacogenomic diagnostic assays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Population Registries	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetically-modified animal model	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	No activity	Low activity	Rather low activity	Rather high activity	High activity
repositories					
GMP platforms	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genomic and proteomic platforms	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-term cohort of patients studies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High throughput drug screening	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 17. Human resources

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Rotational positions for clinicians	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rotational positions for researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specific training in RD	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in bioinformatics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 18. Development and availability of tools needed to accelerate research on rare disease.

	No activity	Low activity	Rather low activity	Rather high activity	High activity
Network development	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Creation of transnational research consortiums	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational calls for projects funding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opening of national research programmes to international collaboration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational research infrastructures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Development of an inventory/directory of databases of experts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transnational collection of funded RD research projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 19. How do you usually conduct your research activities

	Never	Seldom	Sometimes	Very commonly	N/A
Alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Within a research group/team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with colleagues from my institution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with colleagues from other institutions in my country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with international colleagues at EU level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with intercontinental colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with domestic industry/Biotech Company	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Seldom	Sometimes	Very commonly	N/A
Collaboration with international industry/Biotech Company	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with local Patients Organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with international Patients Organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with local Scientific Organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration with international Scientific Organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***20. Do you have access to the following? If yes, how would you rate the quality?**

	International standard or close to it	Good national standard	Insufficient	Do not know	Not applicable
Research support services / unit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Research laboratories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching labs (if different from research Labs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Large research equipment that requires technicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scientific databases (e.g. ISI Web of Knowledge)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowledge Transfer Office	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly agree	Agree to some extent	Disagree to some extent	Strongly disagree	Do not know	N/A
I have the necessary funding to do my research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In my position, I have a high level of autonomy in developing my research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am involved in interdisciplinary research collaboration within my institution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am involved in interdisciplinary research collaboration within colleagues from other institutions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am involved in spin-off activities, research incubators or similar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am/have been involved in patents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I frequently attend international conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am very dedicated to my work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my career	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my salary	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am proud to work at my institution/organisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My working situation is difficult, due to a high workload	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My working situation is difficult, due to bureaucracy, administration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*22. Have you published any of the following over the last 3 years 2014-2017?

	Yes mostly with single authorship	Yes mostly co-authored	Only supervising	No
ISI journal articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*23. If co-authored, who do you write with more often?

	Colleagues from my institution	Colleagues from other institutions	European Colleagues	Intercontinental Colleagues	No co-authoring
ISI journal articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other journal articles (non-ISI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at international conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Papers presented at national conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
PhD. Thesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Colleagues from my institution	Colleagues from other institutions	European Colleagues	Intercontinental Colleagues	No co-authoring
Books	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Book chapters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*24. Have you been involved in applications for research projects (regardless whether successful or not)?

	Frequently as an applicant	Frequently as a partner	Occasionally as an applicant	Occasionally as a partner	No involvement of application
National, involving colleagues from another institution	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Horizon 2020 / FP7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other European project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other International project	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*25. Have you ever worked as a researcher for the following period?

	Less than 1 year	Between 1 and 2 years	More than 2 years
In your country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	very weak	weak	average strong	strong	very strong	don't know
Presenting the results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Critical appraisal of research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orally presenting research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Publishing research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Teaching colleagues and/or students	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Working as a member of a team doing research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accessing resources to undertake research (e.g. money, information, equipment)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undertaking administrative activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***27. How do you rate the following in relation to the motivation to do research abroad?**

	not important	quite important	important	very important	extremely important
Learn different Language	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Career progression goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to knowledge not available in your country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting access to the facilities / equipment necessary to your research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunities to collaborate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	not important	quite important	important	very important	extremely important
with top-class researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More attractive remuneration schemes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities to work in the industry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obtaining funding for own research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Availability of adequate schools you're your children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Work opportunities for your partner (and other family members)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality and cost of accommodation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal interest in the culture of foreign country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***28. Please rank the effect of the international mobility on your research career**

	remained unchanged	a little bit improved	improved	strongly improved	N/A
Publication output	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient output	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to work in the industrial sector	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	strongly agree	agree to some extent	neither agree nor disagree	disagree	strongly disagree	Do not know
The best researchers are leaving the country, which is a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		<input type="radio"/>
The best researchers are leaving the country, but they still continue to Contribute to national research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young researchers are leaving the country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young talented people look for careers outside of the research and higher Education sectors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*31. What do you think are the reasons why people in your Institution are not, or limited engaged in research?

- Not enough time available to engage in research
- Clinical workload pressures
- Lack of support/encouragement
- Lack of funding
- Lack of available resources for research
- Difficulties gaining ethical approval
- Research not valued in organisation
- Weaknesses in research skills
- Personal circumstances (e.g., family commitments limiting time for research)
- Lack of research opportunities
- Lack of supervision/mentorship

	strongly agree	agree to some extent	neither agree nor disagree	disagree	strongly disagree	Do not know
Young researchers are leaving the country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young talented people look for careers outside of the research and higher Education sectors	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*33. Of the changes listed in the table below, indicate how effective you believe they would be for increasing the level of research activity in your Institution

	Would have no effect	Would be somewhat effective	Would be greatly effective
Increased protected working time for research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher levels of ongoing research training	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recruiters in the health service giving more value to research experience when selecting candidates for clinical positions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A more simplified and efficient ethics application process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Greater levels of mentorship and support when conducting research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities to advance one's research qualifications (e.g. post-doctoral fellowships)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More funded research posts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More opportunities for collaboration with other clinical or academic researchers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*34. What is applicable for you in the following list about **Research Infrastructure**.

	Don't know it	Know it	Collaborate with it
BBMRI Biobanking and Biomolecular Resources Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C-ERIC Central-European Research Infrastructures Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLARIN Common Language Resources and Technology Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EATRIS European Advanced Translational Research Infrastructure in Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECRIN European Clinical Research Infrastructure Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ELIXIR The European Life-Science Infrastructure for Biological Information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERA European Research Area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERIC European Research Infrastructure Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESFRI European Strategy Forum on Research Infrastructure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EU-OPENSREEN European Infrastructure of Open Screening Platforms for Chemical Biology	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Euro-BioImaging European Research Infrastructure for Imaging Technologies in Biological and Biomedical Sciences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
INFRAFRONTIER European Research Infrastructure for the generation, phenotyping, archiving and distribution of mouse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISBE Infrastructure for Systems Biology Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MIRRI Microbial Resource Research Infrastructure disease models	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NRRI Research Infrastructure Roadmap	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
PRACE Partnership for Advanced Computing in Europe	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RI Research infrastructure(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*35. What is applicable for you in the following list about **Biobanks**.

	Don't know it	Know it	Collaborate with it
Basque Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobanco.pt (Portuguese National Consortium of Biobanks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank of the Estonian genome center	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BioNER: Biobank of the Institute of Rare Diseases Research/Institute of Health Carlos III	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-net – brain tissue bank Aachen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net – brain tissue bank Munster (pediatric neuropathology)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brain-Net Germany : National network of brain banks in Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cell line and DNA Biobank from patients affected by genetic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CIBERER Biobank (Biobank of rare diseases)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
DNA biobank of the Department of Molecular Genetics and Diagnostics, National Institute of Environmental Health (NIEH) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
EuroBioBank European Network of DNA, cell and tissue banks for Rare Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human DNA and cell biobank of Genethon – genetic diseases, mainly neuromuscular diseases – part of the EuroBioBank network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Human tissue biobank of Neuromuscular diseases (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuromuscular Tissue Bank (NMTB) (EuroBioBank partner)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Telethon Network of Genetic Biobanks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***36. What is applicable for you in the following list about **Registry and database**.**

	Don't know it	Know it	Collaborate with it
(NCARDRS) National Congenital Anomaly and Rare Disease Registration Service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian Country Node of the Human Variome Project (HVP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Austrian registry for inborn errors of metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian Neuromuscular Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Belgian patient database for Wilson disease – contributes to the EuroWilson registry (terminated)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biobank Inherited Metabolic Disorders (blood/urine/liquor/fibroblasts)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Canadian Neuromuscular Disease Registry – part of the TREAT-NMD network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
DDRMD – Dutch Diagnosis Registration Metabolic Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch Neuromuscular Database CRAMP: Computer Registry of All Myopathies and Polyneuropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Fabry disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type B	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dutch patient registry for Niemann-Pick Disease Type C	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ECARUCA: cytogenetic and clinical database on rare chromosomal disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-HOD European Network and Registry for Homocystinurias and Methylation Defects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EIMD: European registry and network for intoxication type metabolic diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English alpha-1 antitrypsin deficiency registry – contributes to the Alpha One International Registry (AIR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English hyperoxaluria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
English phenylketonuria registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EPNET: European porphyria Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E-RARE Consortium	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESNEK – Rare paediatric neurological disease registry Germany	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUNEFRON: registry of the European network for the study of orphan nephropathies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EUROCAT European Surveillance on congenital anomalies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
EUROGLYCANET – International patient registry and cohort for congenital disorders of glycosylation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European cystinosis cohort	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
European Porphyria Registry (EPR)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fabry Disease Registry –DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
FOS : Fabry Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of glycogen storage disease type 2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French certified registry of patients affected by Gaucher disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French cystinosis registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
French registry of neuromuscular diseases from reference centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Galactosemia Patient Registry – part of the Galactosemia Network	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetic alliance Registry and Biobank	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
German mucopolysaccharidosis patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HOS : Hunter Outcome Survey	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
iNTD Network – International Working Group on Neurotransmitter Related Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Collaborative Gaucher Group (ICGG) Gaucher Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Morquio A registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
International Niemann-Pick Disease Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
LOVD: GAA gene (Glucosidase, alpha, acid) variant database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mendelian cytogenetics network online database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
MITOCON: National registry mitochondrial disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mucopolysaccharidosis type 1 (MPS I) Registry –	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NCL-Registry: International neuronal ceroid lipofuscinoses patient registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Neuro-Heart-Registry: Registry for patients with heart involment in neurovascular diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMDcy: Cypriot Neuromuscular Diseases – contributes to TREAT-NMD	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NMD-ES: Spanish Registry of Neuromuscular Diseases	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Norwegian Porphyria Registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pompe Disease Registry – DE	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Portuguese Fabry patient registry – contributing to the international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RAMEDIS : Rare Metabolic Diseases Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
RAMEDIS : Rare Metabolic Diseases mutation Database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Patients with Niemann-Pick Type C Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes – contributing to EURO-WABB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Registry_Biobank Name	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The International Collaborative Gaucher Group (ICGG) Gaucher registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Fabry registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Mps I registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The international Pompe registry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
TREAT-NMD: Accelerating Treatments for Neuromuscular Diseases (registries)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
UK10K RARE NEUROMUSCULAR – Genetic neuromuscular diseases variant database	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
X-ALD: X-linked adrenoleukodystrophy database	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***37. What is applicable for you in the following list about Scientific Organization.**

	Don't know it	Know it	Collaborate with it
AECOM – Asociación Española para el Estudio de los Errores Congénitos del Metabolismo	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
APS – Arbeitsgemeinschaft für Pädiatrische Stoffwechselstörungen (Working group for paediatric metabolic disturbances, Germany)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B4B – Brains for Brain	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
BIMDG – British Inherited Metabolic Disease Group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CLIMB – Children Living with Inherited Metabolic Diseases, UK	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
EBC – European Brain Council	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ERNDIM Quality assurance in laboratory testing for IEM	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
ESGCT – European Society of Gene and Cell Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EURORDIS – European Organisation for Rare Disorders	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fondazione Telethon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Don't know it	Know it	Collaborate with it
IBBS – International Brain Barriers Society	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IRDIRC	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ISNS – International Society for Neonatal Screening	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SEEIM – Sociedad Española de Errores Innatos del Metabolismo	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SFEIM – Société Française pour l'Étude des Erreurs Innées du Métabolisme	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SIMD – Society for Inherited Metabolic Disorders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SISMME – Societa' Italiana per lo Studio delle Malattie Metaboliche Ereditarie	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SPDM – Sociedade Portuguesa de Doenças Metabólicas	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SSIEM – The Society for Study of Inborn Errors of Metabolism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>