

Developing collaboration with EU Life Science Infrastructures within ERA-NET scheme



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Info Day

Horizon 2020 - 'Health, demographic change and wellbeing'

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Major facts about E-Rare

- ERA-NET for research programmes on rare diseases
- Created in 2006 (E-Rare-1) renewed in 2010 (E-Rare-2) at present funded under Horizon 2020 ERA-Net Co-fund

E-Rare-3 (2014 - 2019)

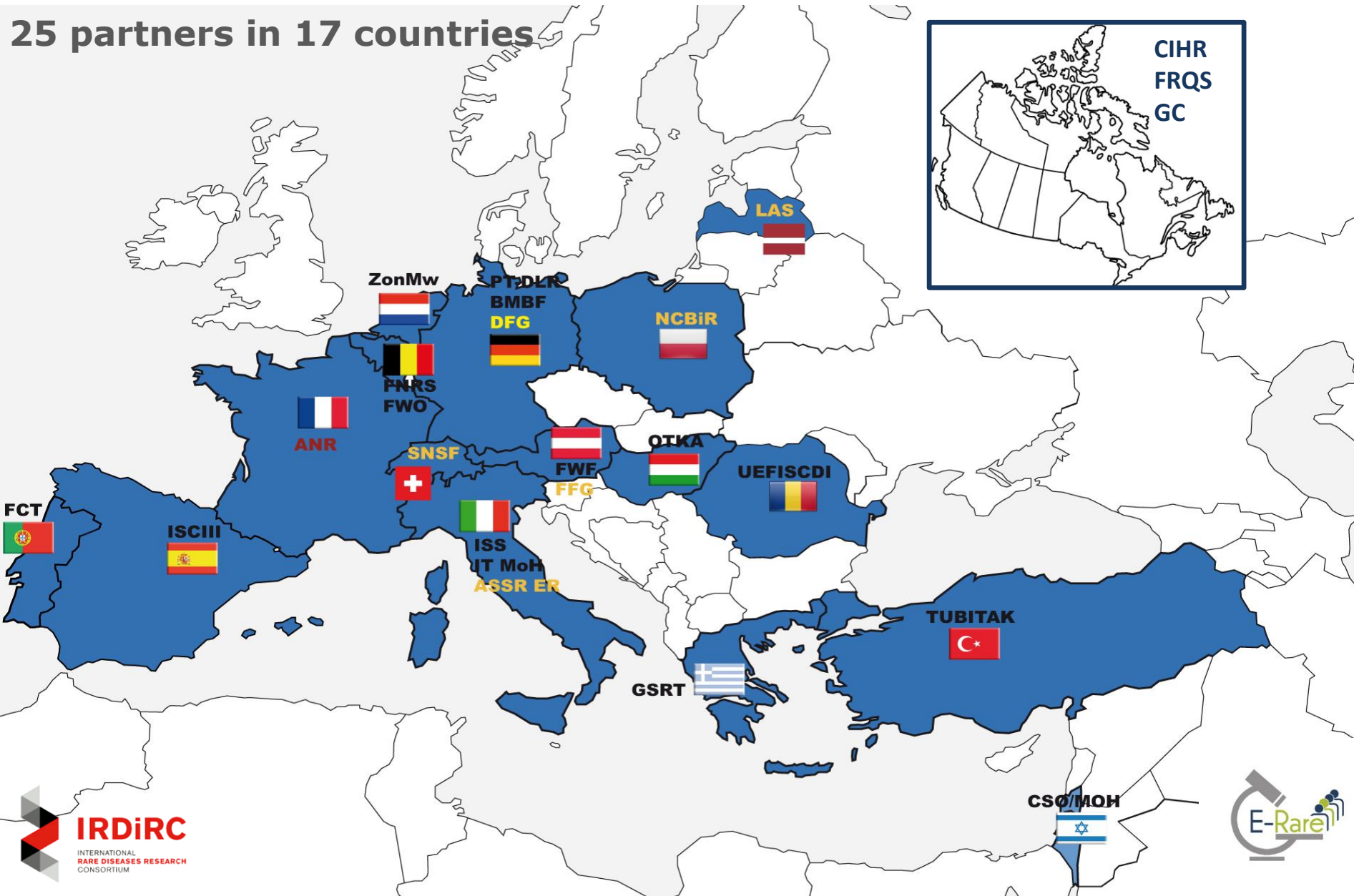


- 25 partners from 17 European, Associated and non-European countries (AT, BE, CA, CH, ES, FR, GR, HU, IT, IL, LV, NL, PO, PL, RO, TR)
- **Objective: coordinate and promote European and international efforts for funding research on rare diseases**
- E-Rare is mentioned in more than half of National Plans for Rare Diseases



E-Rare-3: beyond Europe

25 partners in 17 countries



E-Rare activities

Coordination & support activities

- Harmonization of national research programmes
- Development of strategic agenda & contribution to IRDiRC
- Development of common funding mechanisms
- Monitoring and assessment of funded research projects
- Collaboration with relevant stakeholders: **EU research infrastructures/POs/EMA/RD JA/JRC/RE(ACT)**
- Communication & dissemination

Joint Transnational Calls

- No cross-border funding
- Virtual common pot = each agency funds its own national research teams (except co-fund)
- Launched with regular periodicity (yearly)
- Topic to be defined: open vs focus

E-Rare Joint Transnational Calls: FUNDING



	Belgium	Germany	Spain	France	Italy	Israel	Hungary	Turkey	Austria	Greece	Portugal	Poland	Canada	Romania	Hungary	Switzerland	Denmark	USA
E-Rare-1		X	X	X	X	X		X										
JTC 2007		X	X	X	X	X		X										
JTC 2009		X	X	X	X	X	X	X	X	X	X	X						
E-Rare-2																		
JTC 2011	X/X	X	X	X	X	X		X	X	X								
JTC 2012 (YI)	X	X	X	X		X	X	X	X		X	X						
JTC 2013	X/X	X	X	X	X	X		X	X		X	X	X/X	X	X/X	X		
JTC 2014	X	X	X	X	X	X	X	X	X		X	X	X/X	X	X	X	X	X
E-Rare-3																		
JTC 2015	X/X	X/X	X	X	X/X	X	X	X	X/X	X	X	X	X/X/X	X	X	X	X	X
JTC 2016	X	X/X	X	X/X	X	X		X	X/X		X	X	X/X/X	X	X	X	X	X

● JTC 2007: 6 call partners from 6 countries → JTC 2015: 23 call partners from 17 countries

- Up to 230 applications in open calls / 35 – 80 applications in focused calls
- The global success rate of E-RARE proposals is 10%
- Average budget per call: 14 Mio€ Average budget per project: 800 K€
- Since January 2008 we implemented 7 joint calls:
78 Mio. € to support 449 research groups in 98 research consortia
- JTC 2015 with co-funding from European Commission of about 3 M€

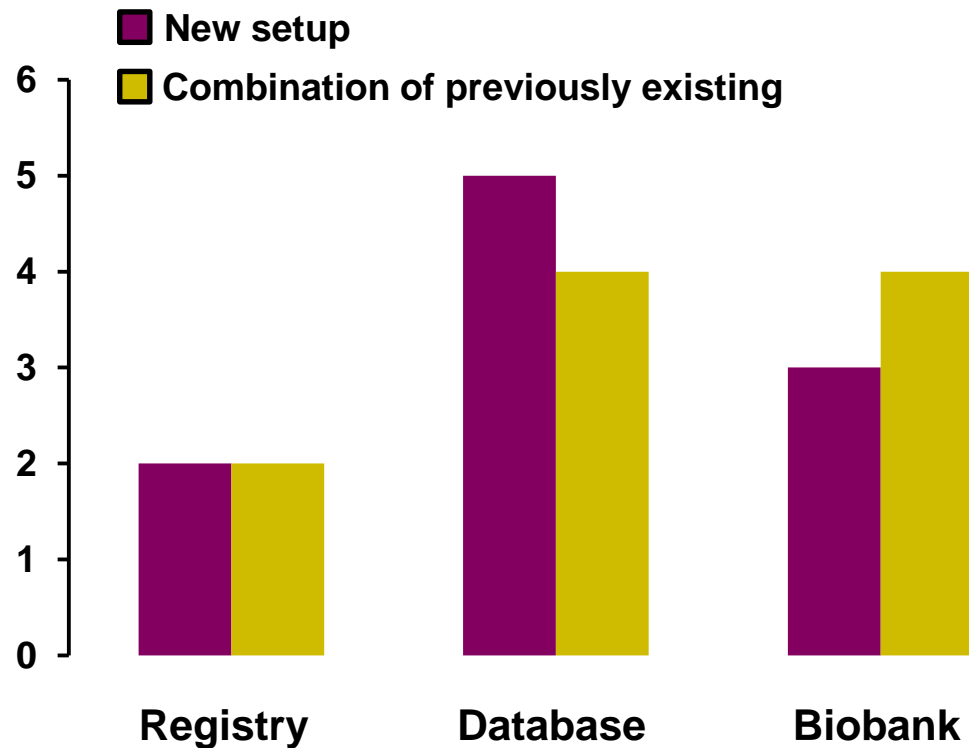


E-Rare funded projects: CRITICAL MASS

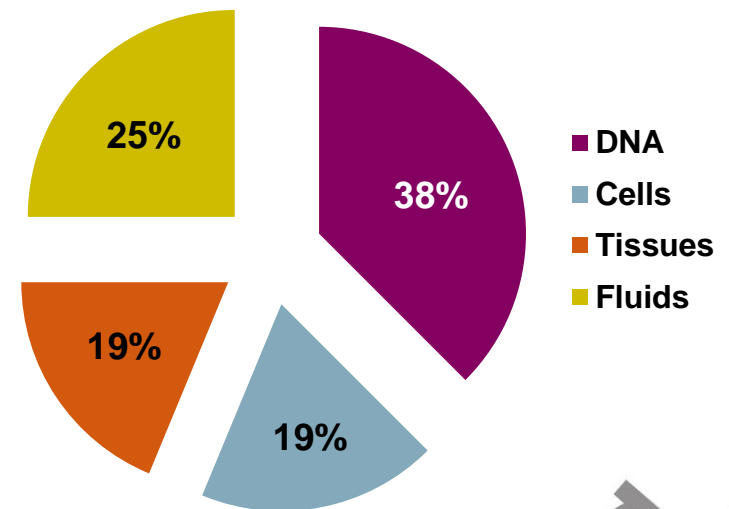
Assessment of JTC 2007 & 2009 funded projects

ALL funded consortia achieve critical mass necessary for the development of the scientific project

Infrastructures initiated by consortia:



Nature of the samples in biobanks



E-Rare funded projects: INFRASTRUCTURE/SUSTAINABILITY

Assessment of JTC 2007 & 2009 funded projects

Registries

	Nb	%
Registries	4	31*
New	2	50
Existing	2	50
Harmonisation	4	100
Critical mass	4	100
Sustainability**	4	100

Databases

	Nb	%
Database	9	69*
New	5	56
Existing	4	44
Harmonisation	9	100
Critical mass	9	100
Sustainability**	7	78

Biobanks

	Nb	%
Biobank	7	54*
New	3	43
Existing	4	57
Critical mass	7	100
Sustainability**	5	71

* Expresses the proportion of all JTC2007 consortia able to establish the concerned facility

** At least one option/scenario of sustainability is envisaged

Use of infrastructures in research projects

What type of infrastructure will you use for your project?

- High throughput genomics or sequencing
- Proteomics
- Metabolomics
- Transcriptomics
- Imaging
- Animal models facility
- Biobank
- Registry

**ONLY 5% OF PROJECTS DOES NOT INDICATE
THE USE OF ANY INFRASTRUCTURE**

Why to collaborate with EU Research Infrastructures?

Research community needs:

- Rapid access
- Sustainability of results
- Regulated (legally) data sharing
- High quality service

Funders community needs:

- Optimization of funds → (fees for infrastructures + expected results)
- Clear outcomes → faster bench to bedside
- Sustainable results
- Regulated data sharing



E-Rare-3 collaborations: Infrastructures

EUROPEAN RESEARCH INFRASTRUCTURES:

BIOBANKS, CLINICAL TRIALS, TRANSLATIONAL MEDICINE, MOLECULE SCREENING, MOUSE MODELS, DATA

- Facilitated access
- Exchange of best practices
- Models for sustainability
- Establishment of new funding mechanisms
- Communication & training
- Creation of dedicated module on E-Rare website

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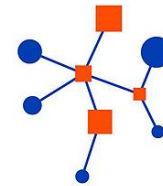


orphanet

RD Connect



INFRAFRONTIER
mouse disease models



BBMRI
Biobanking and
Biomolecular
Resources Research
Infrastructure



ECRIN
EUROPEAN CLINICAL RESEARCH
INFRASTRUCTURE NETWORK

EATRIS

European Infrastructure for
Translational Medicine



EU-OPENSREEN

Chemical keys for life's locks



BOTTLENECKS:

- Lack of information on RI services & fees
- Geographical coverage
- Potential Conflicts of Interest

EU Infrastructures: geographical coverage

E-Rare																	
BBMRI	X	X		X	X		X	X	X	X		X					X
EATRIS		X	X	X	X		X										
ECRIN	X	X	X	X	X		X	X	X			X		X	X	X	X
EU-Opensc.	X	X	X	X	X		X		X			X		X	X	X	X
ELIXIR	X		X	X	X	X	X			X	X						X
Infrafrontier	X	X	X	X	X	X	X		X	X	X			X			
RD-Connect	X	X	X	X	X		X		X	X	X			X		X	X
Orphanet	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X



UK



USA



SE



SV



SB



MT



LX



NO



JP



IR



IC



FI



ET



DK



CZ



AU



✓ - IRDiRC member

Infrastructure	Cost for:			Comments
	Full member	Observer	Non-member	
BBMRI	Free	Free	Under discussion	Depending on the service provided: ex. sample storage – fee may apply
ECRIN	Free (for coordination service only)	Free (for coordination service only)	Full cost	Special fee for E-Rare member countries may apply
EATRIS	Full cost excluding depreciation of machines	N/A	Full cost	Special fee for E-Rare member countries may apply
INFRAFRONTIER	Free/Cost recovery/Scientific collaboration	Free/Cost recovery/Scientific collaboration	Free/Cost recovery/Scientific collaboration	
ELIXIR	Free	Free	Free	Depending on the service provided: ex. large data sets storage – fee may apply



EU Infrastructures: Capacity & delivery

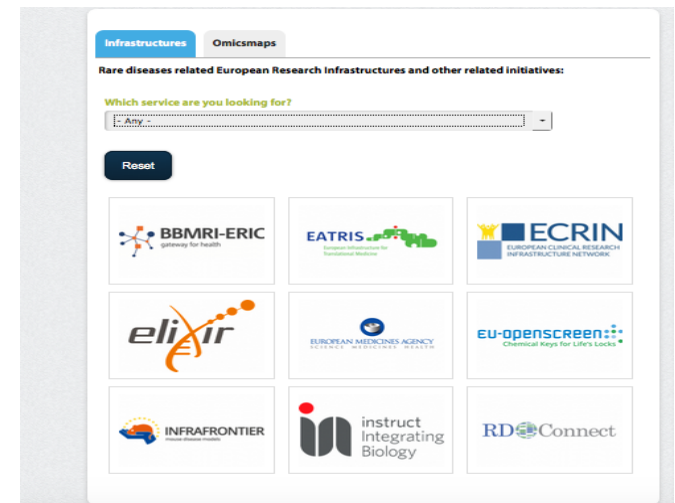
Infrastructure	Capacity per year	Projects completed/run within last year	Delivery timeline
BBMRI	In progress, not defined	N/A	In progress
ECRIN	10 -20 projects	20	6 – 8 weeks for protocol review 3 – 5 years for project
EATRIS	100	12	2 weeks – 3 months
INFRAFRONTIER	+/- 1400	+/- 1400	Service specific
ELIXIR	unlimited	hundreds	24h/24h
RD-CONNECT	unlimited	7 (on going)	Project specific
EU-OPENSREEN	30 - 40	N/A	12 months

EU Infrastructures: Conclusions

- Out of 7 infrastructures analysed 4 are fully operational (ECRIN, EATRIS, ELIXIR, INFRAFRONTIER)
- BBMRI service capacity is growing rapidly
- The geographical coverage between E-Rare and Infra members is not complete
- Most of the Infras have defined cost for their services
 - For non-members full costs apply or a reduction fee could be negotiated in case if E-Rare funded project
 - Use of operational infrastructures should be defined and negotiated (→E-Rare calls)

www.erare.eu

- Focus information provided:
 - Short description
 - Leaflet/PDF document
 - Which services are provided?
 - Why to work with RI?
 - How much does it cost?
 - Countries involved
 - Headquarters contact point



You have not found answers to your question, please send us your request and we will help you

My request



E-Rare-3: collaboration with EU Research Infrastructures

Inclusion of RIs in E-Rare calls

■ **Joint Transnational Call 2015:**

- The use of **existing European health research infrastructures** is strongly encouraged when appropriate
- Projects are invited to identify the existing European research data infrastructures that may be used and how these may be mobilised, in particular for long-term data curation and preservation (in accordance with EU and IRDiRC recommendations, www.irdirc.org).

E-Rare-3: collaboration with EU Research Infrastructures

Inclusion of RIs in E-Rare calls

- **Joint Transnational Call 2016 (repurposing & clinical research – trials):**
 - The use of **existing European health research infrastructures** is strongly encouraged when appropriate, e.g. research infrastructures established as an European Research Infrastructure Consortium (ERIC) or identified on the roadmap of the European Strategy Forum on Research Infrastructures (ESFRI).
 - The following ESFRI European Research Infrastructures were identified as potentially useful for this kind of study: ECRIN, EATRIS, BBMRI, INFRAFRONTIER, ELIXIR, EU-OPENSREEN
 - The costs of use of the EU INFRASTRUCUTRES are eligible for the projects
- **ECRIN implemented ECRIN on Board service for E-Rare applicants = fast track access**
 - *Out of 30 applications 8 declared to use ECRIN service and 7 were successful to pass the first evaluation stage (note that use of ECRIN was not mandatory and not giving extra points at the evaluation stage)*

E-Rare-3: collaboration with EU Research Infrastructures

Inclusion of RIs in E-Rare calls

■ **Bottlenecks identified:**

- High level complexity for both funding bodies and infrastructures to include multinational RIs into project funding:
 - The legal status of ERIC type infrastructures is “centralized” and the budget of ERA-NET calls is a virtual common pot → to be able to include RI in the projects they need to be « de-centralized » + the cost of the central office cannot be covered easily
 - There is a need for mutual training (infrastructures and agencies) on the organization and mechanisms of action to be able to advise to researchers who want to profit from this new scheme
 - There is a need for more communication and education of research community that is not aware about the existence and potential of the RI

E-Rare-3: collaboration with EU Research Infrastructures

Inclusion of RIs in E-Rare calls

- **Next possible steps:**

- Continue to integrate EU RI in E-Rare calls BUT:
 - Implicate them from the start of the call preparation and develop partnering schemes whenever relevant
 - Make clearer incentives for the use of EU RI → specific funding rates
 - Require detailed description on the use of (any) infrastructure and plan for sustainability and sharing of results

THANK YOU



WWW.ERARE.EU