

Dear Participant,

Would you please answer the following questions as best as you can in order for you to help us map in detail the situation across Europe in terms of needs, resources and opportunities regarding relevant Rare Diseases topics. Your collaboration is greatly appreciated.

Participant's Name----- Function-----

Country's name -----

## HAVING A NATIONAL REGISTRY

EXPRESSED NEED FOR REGISTRIES		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

## NOT HAVING A NATIONAL REGISTER

EXPRESSED NEED FOR REGISTRIES		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

Despite the fact that there is no National Registry, are data on RDs currently being collected and, if “yes”, what data is collected, who collects it and where is data conveyed?

Data collected on:	Who collects data	Where is data sent

## CENTRES OF EXPERTISE

N°		YES	NO	Don't know
1.	Have CEs been established in your Country?			
2.	If yes, are CEs based on a multidisciplinary approach?			
3.	Have criteria for designation been adopted?			
4.	Have healthcare pathways for RD patients been organized?			

EXPRESSED NEED FOR CEs		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

## EUROPEAN REFERENCE NETWORKS

N°		YES	NO	Don't know
1.	Have any ERNs been established in your Country?			
2.	Is there a clear designation process for ERNs?			
3.	Is there an ERN cross border from your Country?			
4.	Are there clear regulations in your Country for the payment Cross-border care?			

EXPRESSED NEED FOR ERNs		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

# GUIDELINES

N°	QUESTIONS	YES	NO	Don't know
1.	Are guidelines for RD management developed in your Country?			
2.	Are guidelines for RD management used in your Country			
3.	Are guidelines for diagnostic tests developed in your Country			
4.	Are guidelines for diagnostic tests used in your Country?			

EXPRESSED NEED FOR GUIDELINES		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

# RESEARCH

N°	QUESTIONS	YES	NO	Don't know
1.	Is Research on RDs carried out in your Country?			
2.	Is there a national funding mechanism for RD Research?			
3.	If yes, can Researchers have access to such funds?			
4.	Is there a coordination mechanism for RD research?			

EXPRESSED NEED FOR RESEARCH		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

## SOCIAL SERVICES

N°	QUESTIONS	YES	NO	Don't know
1.	Are there specific Social benefits for school RD children?			
2.	Are there specific Social benefits for adults with RDs?			
3.	Are there any employment benefits for people with RDs?			
4.	Are there social benefits for caregivers of people with RDs?			

EXPRESSED NEED FOR SOCIAL SERVICES		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							

## ORPHACODE SYSTEM

N°	QUESTIONS	YES	NO	Don't know
1.	Do you know the classification/coding for RDs used in your Country ?			
2.	If yes, please specify which ones _____			
3.	Is Orphacode classification/coding used in your Country?			
4.	If not, is your Health System planning to introduce it?			

EXPRESSED NEED FOR ORPHACODE		PREFERRED MODALITY						
		Face-to-face	On the job	Learn by doing	@ learning	Webinar	Distance support	Teleconf.
a.	Training							
b.	Technical support							
c.	Peer support							
d.	Link to Networks							
e.	Supervision							
f.	Monitoring							
g.	Evaluation							
h.	Quality Assessment							
i.	Information							
j.	Other...							