



## VIRTUAL MEETING- GLOBAL STATE OF THE ART RESOURCE

21 April 2021

14.30 – 16.00 (CET)

14.30 – 14.40 10 min	<ul style="list-style-type: none"> <li>Welcome and Presentations</li> </ul>	<p><b>Hlawulani Mkhabela</b> RDI Outreach and Engagement Manager</p>
14.40 – 14.50 10 min	<ul style="list-style-type: none"> <li>What is the Global SoA and why we think it is useful</li> </ul>	<p><b>Flaminia Macchia</b> RDI Executive Director</p>
15.50 – 15.00 10 min	<ul style="list-style-type: none"> <li>Experience from the rare disease community</li> </ul>	<p><b>Charlotte Rodwell</b> Orphanews Partnerships, Business Development &amp; Strategic Communications</p>
15.00 – 15.20 20 min	<ul style="list-style-type: none"> <li>Breakout sessions (all participants):</li> <li>Needs from RDI Members, existing resources, and gaps at national, regional and international levels.</li> </ul>	<p><b>Ellen Coleman</b> CEO &amp; President VOZ Advisors <b>Flaminia Macchia</b> RDI Executive Director</p>
15.20 – 15.40 15-20 min	<ul style="list-style-type: none"> <li>Perspectives from the private sector (users / donors)</li> <li>Case Study</li> </ul>	<p><b>Ellen Coleman</b> CEO &amp; President VOZ Advisors Davide Marchi Patient Engagement Vertex</p>
15.40 – 15.50 10 min	<ul style="list-style-type: none"> <li>Possible framework for collaboration across stakeholders</li> </ul>	<p><b>Flaminia Macchia</b> RDI Executive Director</p>
15.50 – 16.00 10 min	<ul style="list-style-type: none"> <li>Q&amp;A</li> <li>Closure of the Webinar and next steps</li> </ul>	<p><b>All</b> <b>Flaminia Macchia</b> RDI Executive Director</p>