



Deliverable

D6.4 Solve-RD communication and dissemination tools

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Explanation according to GA Annex I:

Solve-RD communication and dissemination tools like press releases, research briefs, research summary documents, policy brief, newsletter, publication in popular press, peer-reviewed journals, wide-audience journals with a high impact factor, publication of papers, reviews on different topics, organisation of symposia and presentation meetings, outreach to patient community and health care provider (networking).

Abstract:

This deliverable report includes the Solve-RD communication and dissemination plans and describes the tools Solve-RD uses to implement both.

Introduction:

Excellent science needs effective communication and dissemination. Bridging research and its outcomes to the attention of non-scientific audiences, scientific peers, and industry or policy makers fosters collaboration and innovation. Strategic communication and dissemination increase the impact of research and innovation in many ways.

Communication on Solve-RD aimed at promoting the project and its results. It requires strategic and targeted measures for communication about a) the project itself, and b) the projects results to a multitude of audiences. Dissemination on the other hand, aims at disclosing the results we achieved by any appropriate means, including by scientific publications.

Report:***Communication plan***

Communication about the project – aiming to promote the project itself – has already been started before the project start. Communication can be divided in three parts:

- a) Internal communication,
- b) External communication, and
- c) Communication with the EC.

Internal communication mainly aims to update partners on project results and developments, keep them engaged with the project, and ensure an efficient project execution and an understanding of EC regulations. External communication has a different objective: it aimed at promoting the action itself by informing a variety of stakeholders about the project aims, objectives and work plan, promote its tools and services, raise awareness for the results Solve-RD is going to achieve and finally establish Solve-RD as a main player in the field of rare diseases.

The stakeholder inventory in Table 1 lists all key stakeholders we identified in Solve-RD: consortium partners, members of Solve-RD Advisory Boards (the Scientific Advisory Board and the Independent Ethics Advisory Board), partners of the European Reference Networks (ERN; the four core ERNs as well as all other ERNs), clinicians and basic scientists, patients and patient organisations, diagnostics labs, Omics service providers, the rare disease community at large, policy makers, the European Commission, and last but not least the general public. By an efficient communication strategy, we will ensure that the Solve-RD objectives, activities and methodologies are widely promoted and that Solve-RD's visibility remains high at all times. The Solve-RD communication plan is shown in Table 2.

Table 1: Stakeholder inventory for the Solve-RD communication plan.

	Website	Document repository	Twitter	Newsletter	Mailing lists	F2F meetings	Tele-/ Webconference	Press release	Publications	Presentation at conference	Project Manual	Factsheet
Consortium partner	●	●	●	●		●					●	
WPs	●	●	●	●	●	●	●				●	
Advisory board members (SAB, IEAB)	●	●		●		●					●	
Steering Committee	●	●		●	●	●	●				●	
Core ERNs	●		●	●		●	●		●	●		●
ERNs	●		●	●		●			●	●		●
Clinicians	●		●			●			●	●		●
Patients	●		●						●	●		●
Patient associations	●		●						●	●		●
Diagnostic labs	●		●					●	●	●		●
Omics service provider	●		●					●	●	●		●
RD community	●		●					●	●	●		●
Basic scientists	●		●	●					●			
Policy makers	●		●					●	●	●		●
General public	●		●						●			●
EC	●		●			●		●	●	●		●

Table 2: Solve-RD communication plan.

Audience	Objective	Measure	Timing/Frequency	Responsibility
Consortium partner	Update partners on project results & developments	F2f meetings	Annually	EKUT
	Keep partners engaged with the project	Project updates via internal newsletters, website and Twitter	If required	EKUT
	Ensure efficient project execution	Project manual	Project start, annual updates	EKUT
	Understand EC regulations	Provide repository for	Project	EKUT, WP

		project-related documents (cloud)	start, updates if required	leader
WPs	Facilitate communication between partners Efficient project execution	F2f meetings	Annually, and if required	WP leader
		WP mailing lists	If required	EKUT, WP leader
		Tele-/ webconference	Monthly	WP leader
Advisory board members (SAB, IEAB)	Update on project results/ developments Keep engaged with the project	F2f meetings	Annually	EKUT
		Project updates via internal newsletters, website and Twitter	If required	EKUT
	Understand EC regulations and the project structure	Provide repository for project-related documents (cloud) Project manual	Project start, updates if required	EKUT
Steering Committee	Facilitate communication between partners Efficient project execution	SC mailing list	If required	EKUT
		F2f meetings	Biannually	EKUT
		Tele-/ webconference	Monthly	EKUT
Core ERNs	Update on project results/ developments Keep engaged with the project	Project updates via newsletters (specifically for core ERNs), website and Twitter	If required	EKUT
		F2f meetings: Solve-RD Annual Meeting, ERN meetings	Annually	EKUT
		Tele-/ webconference with the ERN coordinator	Quarterly	EKUT
	Inform about the project Contribute unsolved exomes	Publication of overview articles in ERN newsletters and in scientific journals	Annually	EKUT
		Presentation (oral and poster) of Solve-RD at scientific conferences and ERN meetings	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
ERNs	Inform about the project	Project updates via newsletters (specifically for core ERNs), website and Twitter	If required	EKUT
		F2f meetings: Solve-RD Annual Meeting, ERN meetings	Annually	EKUT
	Inform about the project Contribute unsolved	Publication of overview articles in ERN newsletters and in scientific jour-	Annually	EKUT

	exomes	nals		
		Presentation (oral and poster) of Solve-RD at scientific conferences and ERN meetings	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
Clinicians	Inform about the project Support and tools available for data analysis	Project news via website and Twitter	If required	EKUT
		Presentation (oral and poster) at Solve-RD or ERN Annual Meetings or scientific conferences	Annually	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
Patient associations	Inform about project and its benefit for patients	Project news via website and Twitter	If required	EKUT, EURORDIS
		Presentation (oral and poster) at scientific conferences	Annually	EKUT, EURORDIS
		Publication of overview articles in newsletters and the lay press	Annually	EKUT, EURORDIS
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
	Get involved in the Community Engagement Task Force	Personal communication	Year 1	EURORDIS
	Inform about winter school on genome diagnostics	Website (Solve-RD and EURORDIS), Twitter, newsletters	Weekly (01/2018-03/2019)	EURORDIS, EKUT
Patients	Inform about project and its benefit for patients	Project news via website and Twitter	If required	EKUT, EURORDIS
		Publication of overview articles in newsletters and the lay press	Annually	EKUT, EURORDIS
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
	Inform about winter school on genome diagnostics	Website (Solve-RD and EURORDIS), Twitter, newsletters	Weekly (01/2018-03/2019)	EURORDIS, EKUT
Diagnostic labs	Inform about project (e.g. work plan, omics strate-	Project news via website and Twitter	If required	EKUT

	gies)	Press release	If required	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Presentation (oral and poster) at scientific conferences	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
Omics service provider	Inform about project (e.g. work plan, omics strategies, planned omics analyses, market consultation)	Project news via website and Twitter	If required	EKUT
		Press release	If required	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Presentation (oral and poster) at scientific conferences	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
RD community	Inform about project Establish Solve-RD as main player in the field	Project news via website and Twitter	If required	EKUT
		Press release	If required	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Presentation (oral and poster) at scientific conferences	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
Policy makers	Raise awareness that Solve-RD is working on recommendations for genomic diagnostics and explores clinical utility and cost-effectiveness of NGS diagnostics	Project news via website and Twitter	If required	EKUT
		Press release	If required	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Presentation (oral and poster) at scientific conferences	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
EC	Solve-RD is a successful research project	Project news via website and Twitter	If required	EKUT
		Invitation to Annual Meet-	Annually	EKUT

		ings		
		Press release	If required	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
		Presentation (oral and poster) at scientific conferences	Annually	EKUT
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT
Basic scientists	Register in RDMM-Europe database Raise awareness for the brokerage service and seeding grants Solve-RD will offer	Project updates via website and Twitter	If required	EKUT
		Newsletter: directly contact basic scientists	Monthly	EKUT
		Publication of overview articles in newsletters or scientific journals	Annually	EKUT
General public	Raise awareness for undiagnosed RD patients as specific population that have a major medical need in common: obtain a diagnosis	Project updates via website and Twitter	If required	EKUT
		Publication of overview articles in the lay press		EKUT, all partners
		Factsheet on specific topics (e.g. project objectives or services)	Annually	EKUT

Dissemination plan

For the dissemination plan (see Table 3), we listed the expected project outcomes in the first column and the target audience to which we would like to disseminate our results in the last column. In between those two columns are a number of different dissemination measures we will use to make our key stakeholders aware of Solve-RD outcomes:

- *Workshops*: can be organized as stand-alone workshops, linked to a project meeting or scientific conference (such as ESHG, ECRD, ERN meetings) or provided as an online webinar.
- *Publications*: publication of project outcomes includes publication in scientific journals but also publication in the lay press, newsletters or blogs.
- *Presentation at conferences*: project outcomes will be presented via oral or poster presentations at scientific conferences, ERN meetings, or patient organization meetings (such as ECRD, EURORDIS Council of National Alliances and European Federations, etc.).
- *Twitter, news item*: project outcomes will be tweeted using the Solve-RD Twitter account, re-tweeted by partners and published as a news item on the Solve-RD website www.solve-rd.eu.
- *Press release*: selected high impact publications or findings will be selected for dissemination via press releases by the responsible partner organization.

Dissemination of project results is relevant during the project but usually gains more momentum towards the end of the project. We will disseminate project outcomes as soon as they have been achieved.

Table 3: Solve-RD dissemination plan

Project outcome	Dissemination measures					Target audience
	Workshop	Publication	Presentation at conference	Twitter, news item	Press release	
Solve-RD tools Such as GPAP, PhenoTips, Sandbox	●	●	●	●		Researchers Clinicians Bioinformaticians ERNs Patients ¹
FAIR data collection Standardized genomic, phenotypic and additional omics data from unsolved RD patients		●	●	●		Researchers
New genes and mechanisms		●	●	●	●	Clinicians Researchers Diagnostic labs
Novel diagnostic omics strategies		●	●			Clinicians Diagnostic labs
Diagnostics recommendations		●		●	●	Clinicians Diagnostic labs ERNs Patients ¹
RD3 system Data management system for rare disease research	●	●	●	●		Bioinformaticians Clinicians Researchers
Treatabome	●	●	●	●		Clinicians Diagnostic labs ERNs Patients ¹
Improved ways to communicate (gen)omic test results		●	●	●		Clinicians ERNs Patients ¹
An ontology-based pipeline for diagnostic hypothesis generation (ORDO)		●	●			Clinicians Researchers Diagnostic labs
Winter School on genome diagnostics	●			●		Patients ¹

Conclusion:

Implementation of the communication and dissemination measures described above will help that Solve-RD's objectives, activities and methodologies are widely promoted, that Solve-RD's visibility remains high at all times and that the project outcomes are disseminated to the relevant stakeholders. Transfer of knowledge and results to other users will maximize the impact Solve-RD can achieve.

¹ The term "patients" used here includes patients, patient associations and ePAG (European Patient Advocacy Group) representatives.