Rare Best Practices

RB-DEL.6.5

Website content

Platform for sharing best practices for management of rare diseases

(*RARE-Bestpractices*)

Author

Cristina Morciano

Beneficiary in Charge
ISS

Revision date
20 June 2013

Dissemination level
Public

Reference WP(s)
6-Dissemination

Index

1. Executive Summary

A Project website has been created to publicize the RARE-Bestpractices project, to keep informed the community about project activities/advancements and to constitute a bridge with other interesting WEB sites in the field of the rare diseases and guidelines.

The website has also functionalities to permit the community to benefit of the platform resources of the project and to access to the science journal *Rare diseases and orphan drugs. An international journal of public health* which is one of the project deliverables.

In the present document the organization, the development and the management of the of the website content are described. It is also provided a brief description of the website architecture. The technical description of the website infrastructure is considered in the deliverable 2.1 corresponding to task 2.3 (1 - 48) - Realize and manage the project website.

2. Website description

The website have been organised into the two following sections:

- o public section with general info on the project (project activities, information on project partners, events and main project outputs), links to related websites and to the aforementioned science journal. The section includes also the platform resources (database of guidelines, database of research recommendation, web community and an area dedicated to the training activities and learning tools which are both project deliverables).
- o private section (only for partners) for the project management. The private section is described in the deliverable 2.1 corresponding to task 2.3 (1 - 48) - *Realize and manage the project website*.

1.1 The public section

The contents of the website is mainly based on texts written by members of the respective RARE-Bestpractices partners and on the RARE-Bestpractices description of work (DoW) Annex I of the Grant Agreement. It has been edited and uploaded into the website by Cristina Morciano.

The website home page is logically and graphically sub-divided in three mayor areas which are organised around a carousel of pictures:

1) **From the main menu** it is possible to access to the sections related to project description and deliverables:

   a. overview of the **project** which includes pages related to the following contents: project description, work plan, work packages, organisation, events (past events and upcoming events);

   b. **participants' description** with links to institutions and contains biosketchs of the project collaborators;

   c. **platform resources** which include the guideline database, the research recommendations database, the web community and the training tools (which hosts information about training activities);

   d. **publications** where are uploaded any type of publications (press releases, popular articles, scientific articles) produced by the RARE-Bestpractices consortium.

Figure 1 - The Website homepage

Figure 2 – Project Description

Figure 3 – Project Description (continued)

2) **The second area** is related to the editorial outputs of the project which include:

    a. A link to the science journal *RARE Diseases and orphan drugs. An international journal of public health* which is one of the deliverable of the project;

    b. A link to the project leaflet with a summary of the goals and outputs of the project, project participants and contacts;

    c. The newsletter.

3) **The third area** which is on the footer of the home page is about:

    a. Links to external relevant website in the field of rare diseases and guidelines

Category	Link
Funders	Rare Diseases-European Commission http://ec.europa.eu/health-eu/health_problems/rare_diseases/index_en.htm
Relevant websites	
	Guidelines International Network http://www.g-i-n.net/
	International Rare Diseases Research Consortium http://www.irdirc.org/

    b. News and events will be suggested by partners and to the Project management team to be charged on the website; news and events will be characterized by the following information: date and time, place, title, link to event/news website.

1.2 Logos and acknowledgement

The project logo has been prepared by Fabiola Gnessi (*OPI services srl*) and is reported in the following figure.

Acknowledgement of the EC funding is displayed on the project website with the following phrase *The RARE-Bestpractices project is funded by the European Union Seventh Framework Programme. Project Ref.: n° 305690* and the European Emblem and FP7 logo are also displayed.

1.3 Privacy issues

The privacy issues will be managed according to the Italian Law D. Lgs 196/03 – "Codice in materia di protezione dei dati personali" that acknowledges the directives 95/46/CE and 2002/58/CE of the European Parliament and of the Council.

The ISS will be responsible of the data.

1.4 Legal Notice

The content of the legal notice has been developed around three main sections:

1. Disclaimer

2. Privacy policy

A copyright notice will be soon developed as one of the IPR issues managed in the Work package 8, Task 8.3 - *Manage intellectual property rights (IPR) issues*.

1.5 Role for the content management

Role	Paola Laricchiuta (ISS) in collaboration with partners	Paola laricchiuta (ISS)	Giorgio Vincenti, Linda agresta (ISS)
WEB content planning and updating	✔		
Content updating notification (new documents, new versions)		✔	
WEB pages management (adding / removing content)			✔

3. Document History

Date	Author	Changes
07/06/2013	Cristina Morciano	Insert the content of the all paragraph
17/06/2013	Pierpaolo Mincarone	Formatting and minor revisions