



Grant agreement no. 666918
PHC-14-2015 'New therapies for rare diseases'

- Research and Innovation Action -

<p style="text-align: center;">D9.1 Website pages, Facebook & Twitter feeds established for all stakeholders & wider public</p>

WP 9 – PATIENT ORGANISATION INVOLVEMENT

Due date of deliverable: month 6

Actual submission date: 25/08/2016

Start date of project: 01/01/2016 Duration: 36 months

Lead beneficiary for this deliverable: Batten Disease Family Association (BDFA)

Last editor: Sara Mole, Cristina Soriano

Contributors: Heather Band, Laura Codd

Dissemination Level		
PU	Public	
PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

History table

Version	Date	Released by	Comments
01	24/08/2016	Heather Band / Laura Codd	
02	25/08/2016	Sara Mole	

Table of contents

1. Introduction	4
1.1 General context	4
1.2 Deliverable objectives.....	4
2. Summary of activities.....	4
3. Conclusions and future steps.....	5

1. Introduction

This deliverable is the result of the tasks carried out within WP9 entitled “Patient organization involvement”, whose lead beneficiary is partner 14 (BDFA, WP leader: Heather Band).

1.1 General context

Online platforms and social media are fundamental in enabling patients, patient groups and stakeholders to participate in the BATCure project. Website pages, a Facebook account and Twitter feeds for BATCure have now been established with the aim of encouraging and enabling this participation.

1.2 Deliverable objectives

The goal of this deliverable is to report on the different range of social media resources that BATCure will use throughout the project in order to inform on the progress of the project with professionals, patients and the wider public and promote participation by patients and affected families.

2. Summary of activities

As part of a solid and well-defined dissemination/communication plan, BATCure recognizes the important role that social media plays on patient involvement and engagement. In line with this, the different social media tools used by BATCure will be listed as follows:

- The BATCure website (www.batcure.eu) was launched in May 2016. The content has been reviewed and edited by BDFA to ensure it is accurate, relevant and intelligible to all audiences. The website contains detailed project and partner information and also has a BATCure Twitter feed to provide latest news and updates. A link to our Facebook account has also been included in the homepage. The website has a ‘Dissemination’ area where resources are shared and made accessible to the public. The BATCure information leaflet has been added here.
- A [BATCure Twitter account](#) was created in January 2016 and the BDFA is also using the existing ‘BDFA Research’ Twitter account to raise the profile of the project by sharing news/updates and retweeting relevant information.

The BDFA tweet daily, with at least three weekly posts relating to BATCure. The frequency of tweets will increase as the project progresses and consortium members have research findings to share. The Twitter accounts will also be used to raise awareness of the family survey and to encourage participation.

- A [BATCure Facebook](#) account was established in January 2016 with the goal of raising awareness of the project and sharing news among stakeholders, families and the wider public.

The page currently has 94 likes, predominantly from consortium partner organisations and their contacts in a range of European countries. Those currently following the page are encouraged to like and share any posts. 39 people shared the post containing the BATCure flyer in July, thereby reaching 1,875 people.

Previous posts have also directed visitors to the BDFA website and BATCure website as sources of further information. The BDFA anticipate that the number of likes from European patient groups and affected families will increase as we begin raising the profile of the family survey and identifying potential survey participants.

A procedure has been established for dealing with any personal or medically related comments or queries added to BATCure social media sites by the families and/or the general public. This ensures that queries are directed to the appropriate professional and adequate support is given to the individual or organization involved.

3. Conclusions and future steps

Online platforms and social media are established and are being monitored and updated effectively, thereby enabling a range of audiences to participate in BATCure.

Future steps include increasing the frequency of social media posts as the family survey is launched and research findings emerge. A patient/family area of the BATCure website is also planned with the aim of engaging this audience with the project and encouraging participation in the family survey. It is envisaged that this area will contain a link to the online survey.

A BATCure YouTube channel is also planned with the aim of encouraging public engagement with the project. The channel will provide a 'face' for the project, with content including short interviews with key members of the BATCure Consortium in which they describe their role in the project.

Clips from laboratory open days and progress meetings could also be shared on this channel to provide a look 'behind the scenes' at BATCure.

In parallel, this content could also be used to develop podcasts in the major EU languages.