



Grant agreement no. 668294
PHC-14-2015 'New therapies for rare diseases'

- Research and Innovation Action -

<h2>D6.2</h2> <h3>Tool for Engaging the Public</h3>

WP 6 – Dissemination, Patient Engagement and Ethics

Due date of deliverable: month 18

Actual submission date: 14 / September / 2017

Start date of project: 01/01/2016 Duration: 60 months

Lead beneficiary for this deliverable: UEDIN

Last editor: Jan Barfoot (UEDIN)

Contributors: Jan Barfoot and Clare Blackburn (UEDIN), Paolo Di Coppi, Steven Eaton and Nikhil Thapar (UCL)

Dissemination Level		
PU	Public	X
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
1.0	2/8/17	Jan Barfoot	Release of v 1.0
1.0	14/9/17	Silvia Gigli	Revision of v 1.0

Table of contents

1. Introduction.....	5
1.1 General context	5
1.2 Deliverable objectives	5
2. Methodological approach	5
3. Summary of activities and research findings	6
4. Conclusions and future steps	6

Key word list

Public Engagement, Factsheet, Online Engagement, Video

Definitions and acronyms

Acronyms

Definitions

WP6

Work package 6

SBS

Short Bowel Syndrome

1. Introduction

This deliverable reports on the development of a tool for the engaging non-specialists with the work of the INTENS project (WP6, Task 6.2).

In collaboration with INTENS researchers and the EuroStemCell project (www.EuroStemCell.org) a factsheet, downloadable PDF and three associated videos have been developed on the topics of:

1. The INTENS project
2. Short bowel syndrome and current treatments
3. Short bowel syndrome and stem cell research

These will be disseminated via the well-established EuroStemCell website and social media channels (youtube, twitter and facebook). They will also be placed on the INTENS website and will be available to members of the consortium to use. Viewing statistics will be made available to the INTENS project as appropriate.

1.1 General context

INTENS is partnering with the established stem cell engagement, dissemination, training and outreach initiative EuroStemCell to deliver high quality engagement tools and disseminate INTENS developments and findings to a large international non-specialist audience.

EuroStemCell (funded by the European Commission under Horizon2020) is a co-ordinated public engagement initiative focused on the dissemination of stem cell research results to non-specialists and increasing engagement with stem cell research. This well-established project has been running for >10years and in that time has built up a large network within the stem cell scientific community (<http://www.eurostemcell.org/about-eurostemcell>) and a large number of worldwide visitors to the website (>40,000/month) and social media channels (Youtube - 2200 subscribers, Facebook - 3800 likes and Twitter - 9100 followers).

1.2 Deliverable objective

The aim of this deliverable is to report on the development of the factsheet on Short Bowel Syndrome and stem cells and the associated Videos.

2. Methodological approach

The factsheet has been created according to established EuroStemCell best practice. It contains 'layers' of information and a short summary section structured around three key questions:

- What do we know?
- What are researchers investigating?
- What are the challenges?

For non-specialists who wish for more indepth information there are a further series of 'tabs' covering topics such as the small intestine, current treatments for SBS, current research and clinical trials that can be explored.

The text has been written by professional science communications and reviewed by senior scientists in the INTENS project.

To augment the factsheet, three videos have been produced featuring three INTENS scientists based at UCL. These can be utilized as stand alone videos by project members but have also been incorporated into the factsheet.

3. Summary of activities and research findings

1. Summary of INTENS project on EuroStemCell
<http://www.eurostemcell.org/our-supporting-ec-consortia>

2. Factsheet: Short Bowel Syndrome: how can stem cells help?
www.eurostemcell.org/short-bowel-syndrome

3. Video 1: Short Bowel Syndrome: how can stem cells help?
https://www.youtube.com/watch?v=u2YmQ_Mur2k

How are stem cells be used by stem cell researchers in the laboratory and how might they be used in the future to help people affected by Short Bowel Syndrome.

Credits: Filming and production, Ryan Lewis Scidelight (<http://www.scidelight.com/>). This film was made through collaboration between the INTENS stem cell research consortium (<http://www.intens.info/>) and EuroStemCell (<http://www.eurostemcell.org>). Both projects receive funding from the European Union's Horizon 2020 research and innovation programme under grant agreement numbers 668294 and 652796. We would like to thank the INTENS scientists who contributed to this film.

4. Video 2: Introduction to the INTENS stem cell research consortium
<https://www.youtube.com/watch?v=jdOAKojxUxM>

A short film about the European Commission funded INTENS research consortium. It aims to use tissue engineering to develop sections of functional bowel that could be used in the future as a treatment option for people with Short Bowel Syndrome.

Credits: As above

5. Video 3: Introduction to Short Bowel Syndrome and current treatments
<https://www.youtube.com/watch?v=yrXT3A04Ob8>
An introduction to Short Bowel Syndrome and an overview of the pros and cons of current treatment options.

Credits: As above

4. Conclusions and future steps

A key future step is recruitment of a dedicated public engagement and communications officer. This post will be co-located with EuroStemCell, University of Edinburgh but will liaise closely with the entire INTENS partnership. Future steps 1. and 2. below will occur before this person is in post. The other actions can only be achieved once they are in post.

INtestinal Tissue ENgineering Solution

1. Promotion and dissemination of SBS factsheet (<http://www.eurostemcell.org/short-bowel-syndrome>), downloadable PDF and three videos about the INTENS project (<https://www.youtube.com/user/EuroStemCell>) through EuroStemCell channels (EuroStemCell partner network, EuroStemCell website which has 40,000 visitors a month, Facebook page with more than 3800 likes and twitter account with more than 9000 followers).
2. Participation of two early career INTENS researchers in the Hydra XIII Summer School on Stem Cells and Regenerative Medicine.
3. Recruitment of Part-Time Public Engagement and Communication Officer.
4. Translation of SBS factsheet in to the languages represented by the INTENS partnership (following staff recruitment).
5. Production of lay summaries of INTENS research papers with priority given to papers with a translational theme. These will be connected with the factsheet so that eventually publics will be able to find all the Short Bowel Syndrome information in one place (following staff recruitment).
6. Development (in partnership with stakeholders) of engagement tools and events associated with the science and work of the INTENS Project.