

**Grant agreement no. 668294**

PHC-14-2015 'New therapies for rare diseases'

- Research and Innovation Action -

## D6.4 Report on dissemination of project outcomes, patient engagement and mobility program

WP6 – Dissemination, patient engagement and ethics

Due date of deliverable: month 55

Actual submission date: 30/07/2020

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

Lead beneficiary for this deliverable: UCL

Last editor: Amanda Waite

Contributors: Amanda Waite, Cathy Southworth

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

## History table

---

Version	Date	Released by	Comments
1	27/7/20	Amanda Waite	n.a.

## Table of contents

---

Key word list .....	4
Definitions and acronyms .....	4
1. Introduction.....	5
1.1 General context .....	5
1.2 Deliverable objectives .....	5
2. Methodological approach .....	5
3. Summary of activities and research findings .....	5
4. Conclusions and future steps .....	9

## Key word list

---

Short Bowel Syndrome

Intestine

Patients

Engagement

## Definitions and acronyms

---

### Acronyms

### Definitions

SBS

Short Bowel Syndrome

PINNT

Patients on Intravenous and Naso-gastric Nutrition Treatment

SGSSG

Short Gut Syndrome Support Group

## 1. Introduction

---

Deliverable 6.4 summarises the dissemination of project outcomes, patient engagement and mobility program.

### 1.1 General context

INTENS partners engage with a wide range of stakeholders to communicate and engage with the science and societal issues surrounding the work of the consortia. Stakeholders include general public, policy makers, patient organisations, those affected by SBS, and journalists.

Patient engagement is integral to INTENS work. It provides a flux of two-way feedback between those affected by SBS and the scientific research. It makes the work more relevant, accessible and points to priorities for future work. Indeed, project stakeholders include families and organisations affected by SBS.

### 1.2 Deliverable objectives

- To engage European citizens, in particular patients (key stakeholders), carers and patient advocacy groups, with INTENS research objectives, research outputs and translational human stem cell research more broadly.
- To enhance the career development of INTENS researchers, in particular early career stage researchers.

## 2. Methodological approach

---

INTENS has partnered 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.

INTENS has communicated with patient advocacy groups, including the Short Bowel Syndrome Foundation, PINNT and SGSSG.

A highly experienced dedicated part-time Engagement Manager was in post from January 2018 to September 2019.

## 3. Summary of activities and research findings

---

### Accessible information resources for European citizens

### *Project website*

A dynamic, public-facing website ([www.intens.info](http://www.intens.info)) was created and has been updated with project news, including public engagement activity, consortia meetings, partner information, and documentation for public view.

### *Links between intens.info and eurostemcell.org*

The project website links to accessible, reliable information for citizens on eurostemcell.org, which in turn contains information about and links to the INTENS project.

### *Fact sheet and videos*

A collaboration between INTENS researchers and the EuroStemCell project developed a factsheet, downloadable PDF and three associated videos on the topics of:

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

The fact sheet is disseminated via EuroStemCell's high-profile website (<https://www.eurostemcell.org/short-bowel-syndrome>) and associated social media channels (Facebook, Twitter and YouTube). It has been translated into six additional languages (French, German, Italian, Polish, Spanish and Czech) and has had >4,500 views.

The three videos are hosted on the EuroStemCell website (<https://www.eurostemcell.org/video-short-bowel-syndrome>) and YouTube channel and have had >3,300 views.

## **Tools for public engagement around short bowel syndrome, and potential clinical uses of intestinal stem cells**

### *Workshop for schools*

The 'Stem Cells and the Intestine workshop' was developed and evaluated for use in schools (9-14 year olds). This highly interactive workshop sees the young people explore the topic of stem cells and the intestine through engaging quizzes, stories and activities. The resource was well received by teachers and was iteratively evaluated at partner schools before the final product was designed. The workshop resource was initially used in 25 workshops and has subsequently been shared amongst the consortia partners and for wider dissemination through EuroStemCell (<https://www.eurostemcell.org/stem-cells-and-intestine-workshop> - 362 views)

### *Resources for science festivals and outreach events*

A suite of 'drop-in' style resources for INTENS researchers and science communicators to use at festivals and other outreach events was developed. The resources provide the tools for engaging the general public in the science of INTENS in a highly visual, interactive and engaging way. Using formative

evaluation, the tools have been tried and tested at a UEDIN local community science festival before the final designs were produced. The tools include a life-size body displaying the internal organs, where public can extend the intestine to explore its length; and a game where public generate the cells that are needed to make the intestine before adding them to a collective art work that builds a larger-than-life intestine. The tools have been used at various events and disseminated across the consortia.

### *Equipping labs with resources to engage*

Additional resources from the Eurostemcell 'outreach kit for researchers' (<https://www.eurostemcell.org/start-stem-cell-outreach-kit-scientists>) were disseminated to partner UCL for their use in outreach activity and have been made available for other partners to use for their outreach activities. These resources include Hope Beyond Hype comics, the Start as a Stem Cell floor game and Where are my stem cells? All the resources are highly interactive and engaging for a wide range of audiences and have been extensively used and evaluated across the EuroStemCell network.

### **Direct Engagement Events**

The below events are highlights of the direct engagement activity between INTENS researchers and various stakeholders, making uses of the resources developed for face-to-face engagement.

#### *INTENS workshops for schools*

Using the 'Stem Cells and the Intestine workshop' developed by INTENS, 25 separate workshops were delivered to a mixture of year groups with students aged between 9 and 14. The workshops reached approximately 500 young people and their teachers, raising awareness of the work of INTENS and engaging in the biological concepts and ethical and societal issues.

#### *Edinburgh International Science Festival, April 2018*

INTENS' research was presented to 834 members of the public during one of the largest science festivals in the world – Edinburgh International Science Festival. Over two days the "secrets" of the intestine were disclosed to a wide range of people from 3 to 80 years old. The tools created by INTENS for communicating about their work (see above) were used to facilitate conversations of how INTENS researchers are creating intestine in the lab. Members of the public were given the opportunity to explore the biology of stem cells, the intestine and bio-scaffolding using the fun, engaging and educational tools whilst engaging in conversation about the INTENS project.

#### *Great Ormond Street Hospital Research Trail, May 2018*

Taking place within Great Ormond Street Hospital, INTENS partners from UCL and Francis Crick Institute teamed together to reveal their research to over 50 children, their families and teachers as part of the NIHR's "I Am Research" campaign. A curated trail of activities weaved through the hospital. 6 INTENS partner researchers and the science communicator created Super Stem Cells, a

suite of activities on stem cells, DNA, the intestine and the work of INTENS. The activity hub used some of the tools created by INTENS for engaging with the general public (see above). Particularly relevant for INTENS was that the audience of young people, their families and hospital teachers included those being treated in the hospital with parenteral nutrition.

### *Making Organs Room, Great Ormond Street Hospital, October 2018*

Collaborating with Great Ormond Street Hospital and INTENS partners UCL, UCAM and UEDIN, 7 INTENS partner scientists and the INTENS Science Communicator connected with around 300 general public hosted by the National Institute for Health Research (NIHR) Great Ormond Street Hospital (GOSH) Biomedical Research Centre (BRC). Through a range of stimulating and innovative activities, we revealed our scientific understanding of organs and stem cells and how INTENS scientists are using this knowledge in the lab to create intestine. Activities included the use of a fascinating augmented reality software tool that reveals where the bodies organs are on an augmented reality t-shirt, the making of intestine starting with a stem cell and captivating video from partner KNAW. The large team of scientists connected directly with the public, listening to views on the science, answering questions and raising awareness of the INTENS project.

### *Cambridge Science Festival, March 2019*

Scientists from INTENS participated in the Cambridge Science Festival's family fun day. Interactive activities for families included a 'Future Scientist' photo booth, a USB microscope station, the augmented reality organ t-shirt (see above) and a playdough 'cell differentiation' modelling activity.

## **Patient engagement**

In addition to engaging people affected by SBS both digitally and face-to-face alongside a broader interested public, as outlined above, INTENS has directly engaged with people affected by the condition via patient advocacy groups.

A specific aim was to co-develop an initiative that connected INTENS scientists and their work with those affected by SBS (patients, their families and friends). This is reported on in detail in deliverable 6.5.

In brief, INTENS worked with the Short Gut Syndrome Support Group (SGSSG) to develop a patient-family-led engagement event. The online support group of 3,759 members globally opted for an online Q&A session. The SGSSG facilitators created a thread and posted an introduction to the INTENS project and scientists on their Facebook page, including a link to the videos described above. Members were invited to post questions to be answered by INTENS scientists in a webinar event that would also be recorded. 40 questions were received and sorted by theme. In August 2019 a webinar connected INTENS scientists with the SGSSG. Three INTENS scientists, representing a spread of expertise, joined the event to answer the pre-submitted questions of the group, which were asked by one of the SGSSG facilitators. Post-event, the video audio



was posted to the SGSSG Facebook group. The initiative was successful in engaging members of SGSSG in the work of INTENS and scientific research in general. This was shown by the number of questions submitted by the group, the depth of partnership developed between INTENS and the SGSSG facilitators, and the posts during and post event.

### Training

Capacity has been built within the INTENS consortia for public engagement through establishing a network of communicators, the production of tools to communicate digitally and through face-to-face engagement, and the provision of opportunities to engage with a range of audiences including teachers, school pupils, general public, and families.

The Hydra Summer School on Stem Cells and Regenerative Medicine provides intensive training on fundamental concepts and contemporary issues in stem cell biology and also has sessions on bioethics, public engagement, science writing and patient engagement. Leading experts give an in-depth, week-long programme of lectures and discussion groups. INTENS partners UEDIN and UCPH have been organisers of the summer school. INTENS has supported two researchers to attend each of Hydra XII (2016), Hydra XIII (2017) and Hydra XIV (2019). The summer school did not run in 2018, and has been cancelled in 2020 due to COVID-19.

## 4. Conclusions and future steps

---

As the project approaches its end date, the EuroStemCell team will work with INTENS researchers to update the fact sheet to reflect latest developments and project results in a format that is accessible to people affected by SBS and to the general public.

INTENS researchers will continue and extend the relationship with patient groups to ensure that continued and new trajectories of scientific development are acceptable to the patients who will be the end users of new therapies.

As a rare disease and one that impinges significantly on family time and energy, future projects should continue to seek ways of reaching the geographically dispersed communities affected and modes of communication that would best suit the demands of interested families.

As research moves towards clinical translation and patient enrolment in future trials, a next step for patient engagement would be resources specifically designed for affected children about these aspects.