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- Research and Innovation Action -

**D6.5 Dissemination event with patient groups**

WP6 – Dissemination, patient engagement and ethics

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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

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Version	Date	Released by	Comments
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## Key word list

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Short Bowel Syndrome

Patients

INTENS

Engagement

## Definitions and acronyms

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### Acronyms

SBS

SGSSG

INTENS`

### Definitions

Short Bowel Syndrome

Short Gut Syndrome Support Group

Intestinal Tissue Engineering Solution

## **1. Introduction**

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### **1.1 General context**

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 partners include families and organisations affected by SBS.

This deliverable – D6.5 – Dissemination event with patients – is part of WP6 which focuses on Dissemination, Patient Engagement and Ethics.

### **1.2 Deliverable objectives**

The aim of the deliverable was to create an initiative that connected INTENS scientists and their work with those affected by SBS (patients, their families and friends).

## **2. Methodological approach**

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- To make the event accessible, relevant and meaningful we planned to work in partnership with those affected by SBS to develop and run the initiative.
- The science engagement manager connected with members of *The Short Gut Syndrome Support Group* (SGSSG) whose main channel of communication is a closed facebook group (<https://www.facebook.com/groups/shortgutsupport/>). The international group is for 'anyone who loves a child with SBS' and provides a network of information, support and advice for approximately 3,759 members.
- We presented some options for the type of event we could create in terms of aims, formats and channels and sought guidance from SGSSG as to what would work best for them. There were three main reasons why we decided upon holding a digital engagement event: (i) SBS is a rare condition so a localised face-face event could be exclusive to a small number of affected families; (ii) the support group represents families from across the globe; (ii) SBS is debilitating and travelling poses problems to families in terms of organisation and management.
- Representatives of SGSSG facilitated the communication between the group and INTENS and we created a plan for the initiative.

## **3. Summary of activities and research findings**

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The initiative composed of three parts:

### **1. Initial engagement**

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The SGSSG facilitators created a thread and posted an introduction to the INTENS project and scientists on the facebook page, including a link to the videos described in D6.2. Members were invited to post questions to be answered by INTENS scientists in a webinar event that would also be recorded. We received 40 questions which were sorted by theme (See Appendix I).

### 2. Connection event



On Friday August 9<sup>th</sup> 7- 8 pm (BST) a webinar connected INTENS scientists with the SGSSG. The time and day had been selected to allow working parents and those in different time zones to connect more easily. Three INTENS scientists, representing a spread of expertise, joined the event

to answer the pre-submitted questions of the group: Professor Paolo De Coppi, (UCL, Project Co-ordinator), Dr Daniel Ortmann (UCAM), and Dr Marianne Terndrup Pedersen (UCPH). The webinar was hosted by the INTENS science engagement manager (UEDIN). One of the SGSSG facilitators based in Dubai asked the questions posed by the group. The event was hosted on *Blackboard Collaborate*, an online software collaboration solution. The software has a recording function and is technically supported by the IT team at The University of Edinburgh, both distinct advantages to the initiative. We had 5 members connecting, with several others trying to connect but struggled with computer software compatability. We had dicussed prior to the webinar that there may be only a small group who connected, whilst many might watch the webinar recording instead which is more compatable to lifestyle flexibility. Our priority of the initiative was a forum for the SGSSG to have their questions answered whether live or recorded.



### 3. Continued dialogue

The recording of the webinar has been posted on the SGSSG facebook page, to share the questions posed and answers provided by the

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INTENS scientists. We have asked for further questions and comments from SGSSG to maintain and deepen the dialogue.

### 4. Conclusions and future steps

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- 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. The event was purposefully personal to the group and so was developed with them and exclusively for them. Facilitators reported that the interaction had raised their awareness of the work, gave a better understanding of the science and affectively empowered, improving their quality of life now, whilst dealing with the condition.
- Feedback questions and comments are being collected to allow for the dialogue to continue for the duration of the project.
- We plan to work with Eurostemcell to disseminate the SBS family – INTENS dialogue more widely. Eurostemcell is the European, 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 (<http://www.eurostemcell.org>) with 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). [#openupstemcells](#) is a Europe-wide digital engagement action that will involve responding to questions posed by the public by releasing recorded or live videos across the partnership's social media channels as a celebration of Stem Cell Awareness Day – 9 October 2019. The recordings of the INTENS patient engagement event described here will be edited to provide material for this action.
- The final year of the INTENS project is a key time for deepening engagement with patient families and friends, to disseminate project results and to prioritise future work. The initiative described here can be re-produced to reach to further networks and groups across the globe effected by SBS.

### 5. Bibliography

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Online collaboration Software “Blackboard Collaborate”

<https://www.blackboard.com/online-collaborative-learning/blackboard-collaborate.html>

## Appendix I

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### Questions from SGSSG

#### About INTENS

Who make up the INTENS team and what are their specialities?

What are the aims and milestones?

Are there promising findings so far?

Are there any unexpected findings? Any that reveal about SBS causes?

Is there any work on patients and what are the timescales for this?

#### How is the intestine being made?

What is tissue engineering? How do stem cells fit into this?

#### About the size and quality of the intestine being made

What size and quality of intestine would a child need to have the treatment? :

- What if the child has no intestine?
- What if the current intestine is dismotile or has poor absorption? Would the new intestine have these problems?
- Will the child need to have all three parts of the intestine present?

#### Post- transplant

- Would immunosuppression / anti-rejection drugs be needed?
- Will it act like a normal intestine?
- Could it die?

#### Safety

- What are the possible risks / side effects?
  - Could they cause cancer?
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