IDEA-FAST

Identifying Digital Endpoints to Assess FAtigue, Sleep and acTivities in daily living in Neurodegenerative disorders and Immune-mediated inflammatory diseases.

Grant Agreement No. 853981

WP9 – Dissemination, Impact, Sustainability and Exploitation

D9.1: Detailed Dissemination Plan

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Other contributors	P18 EMP

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1 Abstract

The objective of IDEA-FAST is to identify digital endpoints that provide reliable, objective and sensitive evaluation of, fatigue, sleep, activity of daily living (ADL), and health-related quality of life (HRQoL) for patients with chronic diseases such as neurodegenerative disorders (NDD) and immune-mediated inflammatory diseases (IMID). A critical part of the work plan is to ensure that IDEA-FAST is disseminated to stakeholders in the most effective and timely way. Deliverable D9.1 Detailed Dissemination Plan develops an implementable strategy with related methodologies to maximise the impact of IDEA-FAST. The strategy is built around providing key knowledge at the right time in the most appropriate format to stakeholders including the general public. For each stakeholder group key objectives and messages are identified together with their timing. In addition, the dissemination methodologies have been identified and roles and responsibilities assigned to IDEA-FAST participants.

2 Objectives

The objective of this dissemination plan is to develop an implementable strategy with related methodologies to maximise the impact of IDEA-FAST. The strategy will be built around providing key knowledge at the right time in the most appropriate format to stakeholders including the general public.

To ensure wider dissemination of the project and to increase its impact and outreach, the IDEA-FAST Detailed Dissemination Plan will undertake the following activities:

1. Develop and deploy media planning to ensure that all the project outputs reach the appropriate audience and have the expected impact.

2. Monitor the achieved impact of the dissemination and adjust methodologies as appropriate.

3. Organise the involvement of all partners to ensure correct and full to ensure a correct deployment of the dissemination strategy.

4. Coordinate with external stakeholders (patients, regulatory bodies, healthcare providers, decision makers), as well as other related projects and institutions to ensure a high outreach of the communication activities.

3 Methodology

The dissemination plan is being developed within the first 6 months of the project. As such there are currently no key project outputs available for dissemination. Thus, during the early stage of the project, activities will focus on raising awareness of the project with the various stakeholder groups present within the scope of the project as well as the general public. As the work develops, this plan will be updated to include specific events and their timing.

Each partner within IDEA-FAST has a specific geographical and societal sphere of operation as well as specific technical, legal, commercial or clinical expertise. Therefore, they have a unique set of circumstances that provides for their own methodology for dissemination to various audiences and each partner has a role to play in disseminating the aims and outcomes of the project.

This dissemination plan aims to integrate the uniqueness of each partners abilities and situation with the global dissemination objectives for the project.

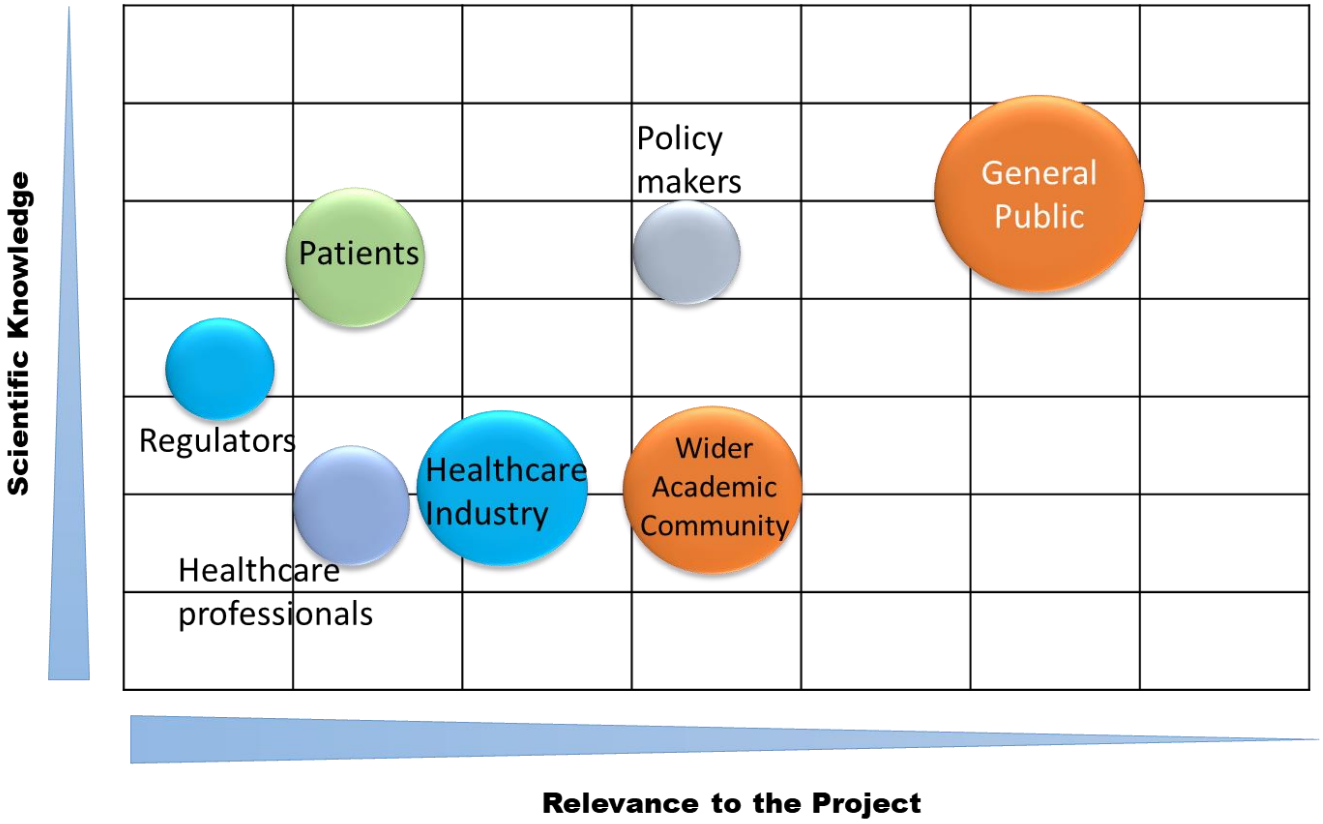
IDEA-FAST will develop a framework for communication and dissemination that encompasses the following key stakeholder groups.

- Patients, carers, support groups
- The general public
- Governmental policy makers and NGO’s
- Regulatory authorities and other interested groups.
- Healthcare professionals and providers

- Academic community
- Industrial end-users, pharmaceutical companies, device manufacturers and emerging digital health providers

For each of the groups, the methods, timing and messages will be developed into an implementable plan, taking into account each group's needs, understanding, nomenclature and media delivery requirements.

The graph below shows the IDEA-FAST understanding of a number of stakeholder groups, their scientific knowledge and their relation to the project.



4 Roles and Responsibilities

Although each partner within IDEA-FAST has a key role and responsibility for dissemination, partner IXS will oversee the implementation of the dissemination and communications strategy. The following table details the key dissemination activities and highlights the partner who will lead that activity and who will contribute to it.

Dissemination Activity	**Lead**	**Contributors**
Website		
Management and Maintenance	EMP	
Content	EMP	All partners
Newsletter		
Content	UNEW, IXS	All partners

Dissemination Activity	Lead	Contributors
Dissemination	EMP	All partners
Social media		
Twitter	EMP	All partners
LinkedIn	EMP	All partners
Printed and Digital materials		
Printed materials (flyers, brochures)	UNEW	All partners
Stakeholder video updates and project information	UNEW	All partners
Publications		
Scientific publications	All	
Trade and other journals	All	
Project Events		
Conference	UNEW / Janssen	
Workshops for stakeholders. Also within WP8 for patient feedback	UNEW & UKSH	MLCF
External Events		
Conference attendance and presentations	All	
Interaction with education	All	
Assessment and Strategy Revision		
Recording of dissemination events	IXS	All partners
Monitoring of performance and impact	IXS	
Assessment and revision of dissemination plan	IXS	

5 Dissemination Activities

The image below shows in a visual way, key dissemination methodologies to be employed in IDEA-FAST.

5.1 Website

The website is aimed to reach all the audiences relevant to the IDEA-FAST project, although a greater number of visits is expected from those groups that are more technical and related to the subject matter of the project. The main communication objectives of the IDEA-FAST website are:

- To provide relevant and current information to a wide audience.
- To ensure information is provided in an accessible and usable manner.
- To be a documentation base, containing publicly available documentation about the project and public deliverables.
- To provide a specific focus for patient information and diseases covered by IDEA-FAST.
- To provide links to other IDEA-FAST dissemination media such as Twitter and LinkedIn.

The public deliverables of the project will be available at the project Website (www.idea-fast.eu).

In addition, the website will provide regular updates on progress and major achievement and outcomes from the project.

5.2 Newsletter

To keep the interested audiences informed about the progress of the project, a newsletter will be addressed every quarter to all the consortium members. In addition to increase the impact of the project there will be a public newsletter containing the main news and information about the project.

5.3 Social Media

IDEA-FAST will generate project profiles on social media including Twitter and LinkedIn. These networks will provide a multiplier effect to the dissemination of the project enabling access to a wider audience.

The presence of the project on social media is important to maximise its impact and reach to key stakeholder groups. It will be used as a relevant tool to reach third parties, the research community and to interact with the general public. The availability of new project results will be communicated informing stakeholders about progress and major achievements.

The content for social media will be generated by EMP with the collaboration of other consortium members. The consortium members will also publish the relevant information in their own social networks.

5.4 Academic and other Publications

Project results will be also disseminated in the form of scientific publications targeted at peer-reviewed professional journals. In addition to this IDEA-FAST commits itself to producing plain English summaries of publications to make them more accessible to patients and the general public. These will be made available on the project website. The main scientific journals identified as potential disseminators of IDEA-FAST results are shown below. IDEA-FAST will ensure that all publications will be open access.

Journal
Movement Disorders Journal
Neurology
IEEE Journal of Biomedical and Health Informatics
Journal of Huntington's Disease
The Lancet Digital Health - Journal
International Journal of Human-Computer Interaction
JMIR - Journal of Medical Internet Research
Annals of Neurology
Annals of Internal Medicine
Sensors
BMJ
Frontiers Group
BMJ Open
npj Digital Medicine
European Journal of Health Law
Medical Law Review
European Data Protection Law Review
Journal of Medical Ethics
BMC Medical Ethics
Annals of rheumatic diseases
Arthritis and Rheumatology
The Lancet
The Lancet Rheumatology
New England Journal of Medicine
Gut
Gastroenterology
Science Translational Medicine
Nature Medicine
Nature Review Rheumatology
Journal of Clinical Medicine
The Lancet Gastroenterology and Hepatology

5.5 Participation in committees and editorial boards

Through their participation in various program committees and editorial boards, IDEA-FAST personnel will be able to play a role in setting the agenda and organising special sessions at conferences or special journal issues.

In addition, partners because of their standing in various communities are able to influence a wider agenda related to the background issues and needs that have driven the creation of IDEA-FAST and similar initiatives. This is an important activity because it raises awareness of digital medicine and the needs of patients within many spheres.

A few examples of relevant affiliations are given below:

- Member of the Executive Committee of the European Huntington Disease Network (EHDN)
- Member of the Executive Committee of the Huntington Study Group (HSG)
- Co-Chair of the Task Force on Huntington Disease of the Movement Disorders Society
- Member of the Task Force on Technology of the Movement Disorders Society
- Associate Editor of the Journal of Huntington's Disease
- Member of the Program Committee of the EHDN Meeting
- Member of the Program Committee of the German Society for Parkinson Disease and Movement Disorders
- Member of the Advisory Boards and Scientific Writer of the German Huntington Association (Patients)
- Theme Chair and Editor of the theme "Biomedical & health informatics" for the Annual IEEE Engineering in Medicine and Biology Conference
- Research Integrity Adviser at VTT for Finnish National Board on Research Integrity, TENK
- Member of IEEE Engineering in Medicine and Biology Society
- advisory board member of the Critical Path for Parkinson's Consortium
- Co-chair of the MDS Technology Task Force.
- Trustee of the British Sjogren's syndrome Association
- Committee member of the Sjogren's Foundation (USA) clinical trial steering group
- Editorial Board member, IEEE Pervasive Computing
- Advisory Board Member, Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies (ACM IMWUT)
- Associate Editor, ACM Transactions on Intelligent Systems and Technology (ACM TIST)
- Steering committee member for international conferences: IEEE UIC, ICOST
- Co-chair of the UK & Ireland Vasculitis Society also associate editor of Arthritis & Rheumatology
- Member of the BMJ advisory board
- Vice-President of the Human Frontier Science Programme Organization
- Scientific advisor at the French Ministry of higher education, research and innovation
- Chair of ERA-PerMed evaluation panel (2018)
- Invited Chair of the national Parkinson's UK Evidence Based Practice committee
- Invited member of Parkinson's UK College of Experts

5.6 Other Materials and Events

To contribute to the promotion and communication of the project objectives and its outcomes, a number of brochures, presentations, leaflets, posters, roll-ups and other materials will be produced.

To provide broader knowledge of the project results and related challenges, the project will arrange two open workshops (UNEW & UKSH). The purpose of these workshops is so that the relevant stakeholders can get information of overall challenges and project progress related to the field.

IDEA-FAST will develop a network of PhD students, post-doctorate researchers and their supervisors involved in the IDEA-FAST consortium in line with the Horizon 2020 Marie Sklodowska-Curie actions. Moreover, we will include the project results in the graduate and postgraduate courses and invite EFPIA partners to

demonstrate how this Public Private Partnership drives drug discovery and development and ultimately enhances patient care.

IDEA-FAST will engage in outreach activities with local schools to enthuse young scientists. For example, through "Leading Edge", a joint initiative between UNEW and the City Council provides opportunity for school students to participate in on-going research projects and present their projects to peers, family, council members and industry.

IDEA-FAST will generate a range of video updates focused towards stakeholders, especially patients to inform them about the project, its objectives and expected impacts as well as progress.

Members of the IDEA-FAST consortium will attend a range of conferences and events where they will present or discuss the project. At these events they will interact with a range of stakeholders. To assist in this IDEA-FAST will produce a generic project presentation that provides an overview of the project thatpartners can modify to change the focus to the topic they are presenting. In addition, a powerpoint presentation template has been produced which will reinforce IDEA-FAST branding and contain logos' for all partners and acknowledge IMI funding.

Consortium partners foresee attendance at the following conference or event.

Conference or Event
Annual International Congress of Parkinson's Disease and Movement Disorders to be presented for the research community (in 2019, 6.000 people were registered at Nice Congress from 106 countries, 38 companies and 12 non-profit organizations and 33 representatives from the press attended).
Conference on Human Factors in Computing Systems (CHI)
Human-Computer Interaction with Mobile Devices and Services (MobileHCI)
International Conference on User Modeling, Adaptation, and Personalization (UMAP)
Intelligent User Interfaces (IUI)
ISPGR conference
EULAR Annual Congress
Annual IEEE Engineering in Medicine & Biology Conference (EMBC)
British Society for Rheumatology Annual Conference
American College of Rheumatology Annual Conference
European Academy of Neurology https://www.ean.org/
United European Gastroenterology
British Society of Gastroeneterology Annual Meeting
American College of Gastroeneterology Annual Scientific Meeting

6 Key Messages by Stakeholder Group

The following identifies key messages for each of the key stakeholder groups identified by IDEA-. This has been collated from 2 perspectives. Firstly, what IDEA-FAST would like to tell the group by secondly and as equally important what the group would like to know. It is often the case that when information is provided to a group of stakeholders it generates more questions. IDEA-FAST will address this in our communications and as necessary use smaller stakeholder focus groups when producing materials.

Patients, carers, support groups

- Discussion of target diseases and their relation to sleep and fatigue
- Challenges of the current state of measuring sleep and fatigue, and how it affects the development of effective treatments
- Benefits of IDEA-FAST outcomes for assessing sleep and fatigue and benefits for patients in the respective disease areas
- How technology can reduce the burden for patients and improve outcomes

- How patients can participate in the project Clinical Validation Study (CVS), testing sites
- Results of the CVS
- Ambulatory monitoring in real life conditions
- Ambulatory clinical monitoring for improvement in personalized medical care
- How the results of IDEA-FAST will be implemented in clinical practice
- How patients will benefit from IDEA-FAST
- Close contact with clinical teams

The general public

- Aims and goals of the project, relationship between sleep and fatigue and the disease areas – educational
- Information about devices used in the project / study
- Information on the burden of fatigue and sleep to the patients and the society
- The impact of fatigue and sleep to the healtheconomic and healthcare providers
- The challenges of measuring fatigue and sleep
- Improvement of personalized medical care
- Improvement of medical care in a system that is traditionally overlooked due to difficulty quantifying and monitoring

Governmental policy makers and NGO's

- Evaluation results, outcomes of the CVS
- Demonstrate the value for patients, health professionals, and health systems
- Knowledge components of IDEA-FAST
- Development of guidelines for new devices
- Implications for the provision of healthcare, disease monitoring and diagnostics
- Health Technology Assessment and impact

Regulatory authorities and other interested groups.

- Results of the CVS, regulatory approval
- Guidance on secure, FAIR and compliant research data platforms governance
- How can regulators participate
- Regulatory approval methodologies and wider digital medicine
- Broader ethical issues in ambulatory monitoring with digital technology
- Digital security and privacy

Healthcare professionals

- The value of empowering patients by using technology responsibly, decreasing the patient burden, increase in availability (and accuracy) of data
- Evaluation results and results of the CVS
- Impact of new treatments and benefits to patients
- How new measurement methods can be implemented and included in clinical practice

Academic community

- Interoperability and standards
- Knowledge base
- Evaluation results, methodology
- Advances in the state of the art

- Regulatory approaches
- Insight into the mechanisms of fatigue
- Exploitation of the digital bioresource generated by IDEA-FAST for future research

Industrial end-users, pharmaceutical companies and device manufacturers

- IDEA-FAST database, patient-facing portal
- Future commercial relationships
- Guidance and experience in device data sharing
- Specifications and standards
- Treatment or drug development impacts
- Integration of data and records into Electronic Healthcare Records

7 Targeted Audiences

7.1 Internal

Internal communication within IDEA-FAST has two main objectives. Firstly, to ensure that all members of the consortium are aware of progress within the work program, to provide contextual awareness and understand their role within the work. Secondly to inform the consortium of events, publications, conferences etc that are relevant.

The main internal dissemination mechanism will be the project share point site. This contains a file repository, project calendar and news.

In addition, the project will produce a quarterly update on progress and other project related events and items for consortium partners

7.2 External

External dissemination will be focused on different stakeholder groups. The information being presented, how it is presented and the level of technical detail and focus will depend of audience type. It will also ensure that the specific audience will receive the information most relevant to it. For example, detailed technical information aimed at regulators or healthcare providers may not be relevant for the general public.

The table below shows a breakdown of audience segmentation, its composition, key objectives for dissemination and what the key messages are:

Group	Composed of	Objective	Key Messages
Clinical / academic Community (fatigue and sleep)	Clinicians, and academics.	Sharing achievements Key outcomes & results Methodologies Advances in the state of the art	Evaluation and results Key outcomes and advances Standards, regulatory approaches Key knowledge base Sensors and data analysis methods. The value of empowering patients by using technology responsibly, decreasing the patient burden, increase in availability (and accuracy) of data
Ethics and legal /	Ethicists, lawyers and legal scholars	Sharing experiences	Guidance on secure, FAIR and compliant research data platforms governance

Group	Composed of	Objective	Key Messages
academic community	working on digital health	Contributing to and reflecting on development of guidance How patients data will be protected	Guidance and experience in device data sharing Interoperability and standards Advances in the state of the art
Industry	Measurement device manufacturers Pharmaceutical companies Software producers	Definition of standards for hardware and software. Data standards and specification development Understanding of new opportunities from the work in IDEA-FAST	Pharma companies benefiting from new, more specific and measurable outcomes that will allow better clinical trials design and being able to reduce cohorts to be included in trials. As such pharma companies benefit from improved trials feasibility and lower costs. How device manufactures can supply the need generated and take part in standards definitions. Software requirements for patients, clinicians and clinical trials
Regulators and clinical guidance	Professional bodies EMA / FDA HTA entities Standardisation entities Data protection authorities	Understanding and interaction with regulatory authorities. Impact on healthcare providers – provision, data platforms, HTA etc.	Guidance on secure, FAIR and compliant research data platforms governance. Methodology for attaining regulatory approval. Guidance and experience in device data sharing
Healthcare Providers	Healthcare trusts Insurance companies	Impact on healthcare providers – provision, data platforms, HTA etc. Potential benefits to patients. Budget implications for adoption	Cost benefits to adoption of new digital technology Ability of new technology to impact healthcare.
Policy makers	Governments Local authorities	New technologies can revolutionise healthcare delivery in a cost-effective way. Demonstrate the benefits to patients and healthcare delivery	Ability of new technology to impact healthcare. New methods of working and interacting with patients Societal benefits Cost benefits to adoption of new technology
Patients and Patient Groups	Patients	What the project is trying to achieve and why.	Patients may participate in the project by contacting collaborating clinical sites – official contacts of each centre in website

Group	Composed of	Objective	Key Messages
	Patient representative groups Carers	Potential benefits and impact on their conditions	Expected outcomes from the research How it will benefit them
Public and other non-technical groups	General public Entrepreneurial players and investors	Publicise aims, objectives and benefits of IDEA-FAST. How new digital technology can be used for better clinical outcomes	Personalised medical care Aims of the project and its benefits The vision for future medicine

8 Collaboration with other Initiatives and IMI projects

To maximise the impact of IDEA-FAST the consortium will interact with other initiatives and IMI projects.

High level communication has already begun with IMI projects Neuronet and Mobilise-D.

One of the most inter initiative collaborations is around regulatory methodology and approval for Digital Healthcare Measures. IDEA-FAST will build strong relationships with Transcelerate, CTTI and C-Path to help develop a common regulatory approach with EMA and FDA.

9 Recording, Monitoring and Assessment

The main objective of monitoring and evaluation is to record what information has been disseminated and to whom and to ensure a high-quality of the material.

Reporting

All partners will be required to report and record their dissemination activities as well as providing to the project record a copy of the material.

To enable this a spreadsheet has been setup which is located in the WP9 area of the project share point. Within this there are two sheets, one for recording scientific peer reviewed publications and the second to record all other dissemination. The images below show the layout of these. All partners are required to add the specific information to these spreadsheets at the point of dissemination. Partners are also reminded of the requirements within the Consortium Agreement for publication clearance.

Scientific Publication data

Publication Activities - Project Continuous Report

Author(s)	Title publication	Type of publication	Title journal/proceedings/book/maga	Year, Issue/Date	Pages	Publisher, Place	Peer reviewed	Partners involved	Partner short name	WP's involved	Open Access	Embargo length if Green Access	Cost if Gold Access	DOI	Link to publication	Comments

Other Dissemination data

Dissemination & Communication Activities - Project Continuous Report

Date of activity	Type of dissemination/ communication activity	Title dissemination/communication activity	Event name; location; other details	Presenter/person responsible	Partner short name	Additional partners involved	Main type of audience reached	Additional type of audience (see G)	Estimated size of audience reached	WP's involved	Presentaion received

The collection of the data above also forms the basis for the period reporting requirements.

Monitoring and Assessment

On an annual basis a process of monitoring and assessment will take place to evaluate the relevance and impact of the dissemination strategy and its implementation. This will be fed back into an updated dissemination plan to ensure the project continually strives for improvement.

Areas for monitoring and assessment include:

- Website and social media – visits to the website and followers on social media
- Scientific publication and impact factors
- Number of dissemination events and types to key stakeholder groups
- Feedback from the stakeholder groups on the information provided.

10 Conclusions

IDEA-FAST has the possibility of maximising the impact of its work by considered and effective communication to stakeholders.

This document develops an implementable strategy with related methodologies to maximise the impact of IDEA-FAST. The strategy is built around providing key knowledge at the right time in the most appropriate format to stakeholders including the general public. For each stakeholder group key objectives and messages are identified together with their timing. In addition, the dissemination methodologies have been identified and roles and responsibilities assigned to IDEA-FAST participants.

IDEA-FAST within the document developed a framework for communication and dissemination that encompasses the following key stakeholder groups.

- Patients, carers, support groups
- The general public
- Governmental policy makers and NGO's
- Regulatory authorities and other interested groups.
- Healthcare professionals
- Academic community
- Industrial end-users, pharmaceutical companies and device manufacturers

During the implementation of the project additional detail and plans will be added on a regular basis so that the plan is a living document. Monthly meetings will identify new dissemination events and the WP leads will collaborate to develop the correct timings and messages for stakeholders and ensure they are implemented on the most appropriate media.