

D7.4 Interim Report on dissemination activities and communication strategy update

116020 - ROADMAP

Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform

WP7 – Communication and Patient/Healthcare Provider Engagement

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Document History

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Definitions

- Partners of the ROADMAP Consortium are referred to herein according to the following codes:
 - **UOXF.** The Chancellor, Masters and Scholars of the University of Oxford (United Kingdom) – **Coordinator**
 - **NICE.** National Institute for Health and Care Excellence (United Kingdom)
 - **EMC.** Erasmus University Rotterdam (Netherlands)
 - **UM.** Universiteit Maastricht (Netherlands)
 - **SYNAPSE.** Synapse Research Management Partners (Spain)
 - **IDIAP JORDI GOL.** Fundació Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina (Spain)
 - **UCPH.** Københavns Universitet (Denmark)
 - **AE.** Alzheimer Europe (Luxembourg)
 - **UEDIN.** University of Edinburgh (United Kingdom)
 - **UGOT.** Goeteborgs Universitet (Sweden)
 - **AU.** Aarhus Universitet (Denmark)
 - **LSE.** London School of Economics and Political Science (United Kingdom)
 - **CBG/MEB.** Agentschap College ter Beoordeling van Geneesmiddelen (Netherlands)
 - **IXICO.** IXICO Technologies Ltd (United Kingdom)
 - **RUG.** Rijksuniversiteit Groningen (Netherlands)
 - **Novartis.** Novartis Pharma AG (Switzerland)
 - **Eli Lilly.** Eli Lilly and Company Ltd (United Kingdom)
 - **BIOGEN.** Biogen Idec Limited (United Kingdom)
 - **ROCHE.** F. Hoffmann-La Roche Ltd (Switzerland)
 - **JPNV.** Janssen Pharmaceutica NV (Belgium)
 - **GE.** GE Healthcare Ltd (United Kingdom)
 - **AC Immune.** AC Immune SA (Switzerland)
- **Grant Agreement.** The agreement signed between the beneficiaries and the IMI JU for the undertaking of the ROADMAP project (116020).
- **Project.** The sum of all activities carried out in the framework of the Grant Agreement.
- **Work plan.** Schedule of tasks, deliverables, efforts, dates and responsibilities corresponding to the work to be carried out, as specified in Annex I to the Grant Agreement.
- **Consortium.** The ROADMAP Consortium, comprising the above-mentioned legal entities.
- **Consortium Agreement.** Agreement concluded amongst ROADMAP participants for the implementation of the Grant Agreement. Such an agreement shall not affect the parties' obligations to the Community and/or to one another arising from the Grant Agreement.

Publishable Summary

The present Interim Report on dissemination activities and communication strategy update aims to provide updated information on the communication tools developed early in the project. The achievements of these tools with regard to results of dissemination activities and their impact is evaluated.

The described items were designed in accordance with the initial ROADMAP communication plan, including project branding and policies ([Deliverable 7.2](#)) in order to create a consistent framework which ensures, effective sharing of information with appropriate audiences. As stated in the initial communication plan, the first objective during the initial stages of the project was to raise awareness of ROADMAP to target audience(s). The second objective is to reach out to predefined audiences and highlight the need for real-world evidence (RWE) in the management of Alzheimer's disease (AD) by maximising awareness, use and dissemination of project milestones.

With regard to ROADMAP's communication framework, the underlying strategy is evaluated and improved in order to maintain the attention of target audiences and in order to reinforce on an integrated data environment and framework for RWE in AD.

1. ROADMAP Communication strategy

1.1. Objectives

The communication plan includes four pillars: objectives, target audiences, dissemination actions and tools. The initial communication and dissemination plan as set out in [Deliverable D7.2](#) includes detailed information on the strategy and led to the creation of tools in order to reach out to the identified and appropriate target audiences using the most efficient channels available. The rationale behind the communication strategy is to define an approach that maximises awareness of the project and its achievements to the targeted audiences and increases the understanding of the importance of real-world evidence (RWE) in Alzheimer's disease (AD). In first instance the communication about the project's existence and activities therefore focuses on gathering an audience with particular interest in the potential benefits of the aimed project outputs. This progressively leads to the creation of a "following" that can be effectively targeted using the created tools to highlight the need for RWE in AD, as well as a communication route once the first scientific publications arise from the different work streams and cross work package (WP) collaborations. In order to further tailor the communication strategy to support a 2nd phase of the project, the scientists of the project were asked to highlight the main audiences that should be targeted when communicating about their scientific project outputs.

The agreed upon dissemination objectives consist of two main targets (see Figure 1).

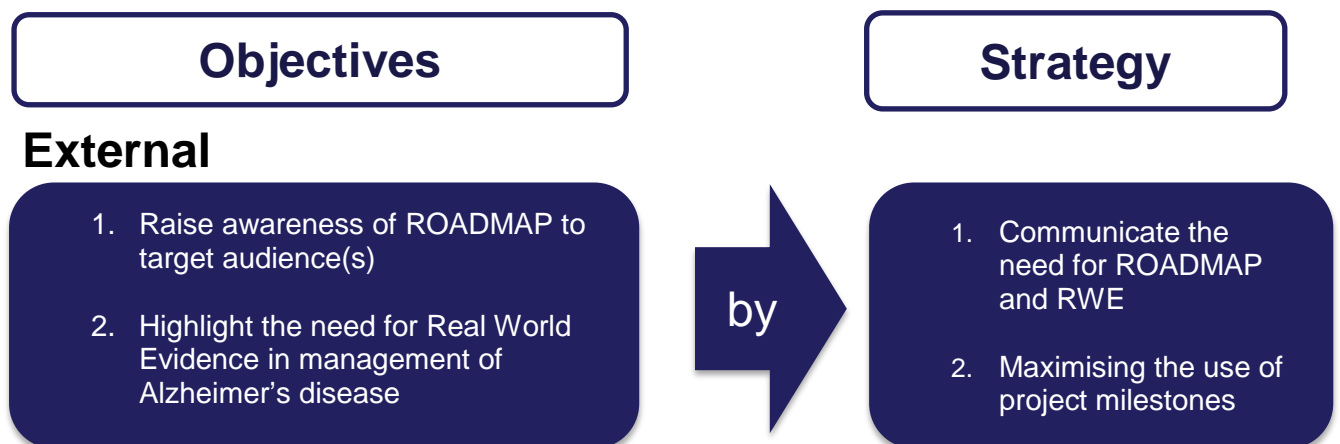


Figure 1. Overview of communication objectives and strategy

1.2. Target audiences

The following table provides a more tailored overview with regard to the target audience, actions and tools.

Target stakeholder	What	When	Responsible	Format
EFPIA upper management	<ul style="list-style-type: none"> High-level summary, with emphasis on strategic progress 	Bi-yearly	WP7 (Lilly)	<ul style="list-style-type: none"> PDF Newsletter, 2 pages max.
Consortium	<ul style="list-style-type: none"> Summary of ongoing work/achievements per WP Project news Upcoming project milestones & deliverables External events Internal meetings (past/upcoming) SharePoint links to documentation 	Monthly	SYNAPSE	<ul style="list-style-type: none"> Formatted email bulletin
IMI/other AD projects (incl. IMI-AD platform)	<ul style="list-style-type: none"> High-level summary, achievements, dissemination 	Quarterly	SYNAPSE	<ul style="list-style-type: none"> PDF external Newsletter
	<ul style="list-style-type: none"> Major achievements Deliverables Interviews with collaborators News and Events 	Quarterly	WP7	<ul style="list-style-type: none"> External Newsletter Website Twitter
HTA / Payer / Regulators / Policy makers	<ul style="list-style-type: none"> Summary of ongoing work with focus on HTA implications 	Tailored to events	WP6 leads (NICE & BIOGEN)	<ul style="list-style-type: none"> E-Mail to EuNetHTA Affiliated communication channels
	<ul style="list-style-type: none"> Spotlight sessions with EXAG members 	Tailored to events	WP6 leads (NICE)	<ul style="list-style-type: none"> Additional section in external Newsletter
	<ul style="list-style-type: none"> Major achievements Deliverables Interviews with collaborators News and Events 	Quarterly	WP7 (AE & Lilly)	<ul style="list-style-type: none"> External Newsletter Website Twitter Dementia in Europe magazine LillyPad Blog Partner channels (http://regulatoryscience.nl/, http://eunetha.eu/)
Ethics Advisory Board	<ul style="list-style-type: none"> Relevant WP ongoing work/documents for ELSI assessment 	As required	WP8 (UOXF & NOVARTIS)	<ul style="list-style-type: none"> Updates through TC's Email bulletin, plain text with relevant documentation links
BD4BO programme	<ul style="list-style-type: none"> High-level summary, achievements, dissemination. Focus on challenges pertaining to Big Data 	Quarterly	WP7 & WP1	<ul style="list-style-type: none"> External Newsletter Website Twitter – once BD4BO handle is active

Target stakeholder	What	When	Responsible	Format
				<ul style="list-style-type: none"> Consolidated feedback on project progress and communication activities (email, LSE internal SharePoint) Monthly TC's
Scientific audience (Academia, scientific community, industry, HCP's, Journalists with interest in AD)	<ul style="list-style-type: none"> Scientific communication 	/	WP2, 3, 4, 5, 8 leads	<ul style="list-style-type: none"> Scientific publications Presentations (oral/poster)
	<ul style="list-style-type: none"> High-level summary Major achievements Deliverables Interviews with collaborators News and Events 	Quarterly	WP7 & Consortium	<ul style="list-style-type: none"> Scientific publications ResearchGate Website External Newsletter Twitter Conference leaflet AE website & newsletter
General public (secondary)	<ul style="list-style-type: none"> High-level summary Presentation of the project Major achievements News and Events 	Quarterly	WP7 (AE) & Consortium	<ul style="list-style-type: none"> Press releases Dementia in Europe magazine Twitter External Newsletter Website AE website & newsletter Partner channels
Dementia community (PwD, their families & carers, Patient & carer organisations, advocacy groups)	<ul style="list-style-type: none"> High-level summary Presentation of the project Major achievements News and Events 	Quarterly	WP7 (AE)	<ul style="list-style-type: none"> Press releases Dementia in Europe magazine Twitter External Newsletter Website AE website & newsletter
ROADMAP com. channels	<ul style="list-style-type: none"> High-level summary Major achievements Deliverables Interviews with collaborators News and Events 	Monthly	WP7 (AE)	<ul style="list-style-type: none"> Email bulletin, plain text with relevant documentation links External newsletter

1.3. Dissemination activities

As part of the broader dissemination strategy, certain activities are conducted during the whole project. These activities include disseminating information generated by and for the ROADMAP project on a constant basis.

Tools	Content	Target group	Responsible	Format
ResearchGate project	High-level summary, scientific publications, poster presentations and public deliverables	<ul style="list-style-type: none"> Scientific audience 	AE	Online account – uploaded PDF files
Twitter account	<ul style="list-style-type: none"> Updates of ongoing work/achievements Project news External events Internal meetings (past/present/upcoming) Links to news related to ROADMAP and to external newsletter 	<ul style="list-style-type: none"> Dementia community HTA/ Payers/ Regulators/ Policy makers Scientific audience General public (secondary) EFPIA & IMI 	AE	Tweets - online
Project website	<ul style="list-style-type: none"> Project summary Summary of ongoing work/ achievements per WP Project news Delivered milestones/deliverables External events Internal meetings 	Potential partners: <ul style="list-style-type: none"> EFPIA Scientific community Regulatory and other authorities Related projects Dementia community General public (secondary)	AE	Plain text, links to partners and affiliated projects, PDF
External Newsletter	Summary of ongoing work with focus on the progression of the project, events and the need for RWE in AD once results arise	<ul style="list-style-type: none"> Scientific audience EFPIA & IMI Dementia community General public 	WP7 leads (AE & Lilly)	Mail with a link to full articles on project website
Press releases	Relevant ROADMAP achievements	<ul style="list-style-type: none"> Media Scientific audience EFPIA & IMI Dementia community General public 	AE	PDF, 1 page max.
Conferences	Project summary Project objectives/ challenges/ results	<ul style="list-style-type: none"> Scientific community EFPIA Dementia community General public 	WP7 leads (AE & Lilly) & Scientific consortium members	Project leaflet and roll-up banner Project relevant presentations: <ul style="list-style-type: none"> Posters Symposia Panel sessions

1.4. Changes from the initial communication plan

This section highlights specific changes from the initial communication plan. In order to not overemphasize the use of project milestones while still maintaining its use in the core strategy, the strategy has been split into two points: i) Communicate the need for ROADMAP and RWE and ii) Maximize use of project milestones. Through the understanding of the need of ROADMAP and RWE the communication of the project milestones becomes more effective, a split of both is therefore more coherent.

Communication with the Big Data for Better Outcomes (BD4BO) programme has been shifted from the Executive Committee as responsible partners to both WP1 (Project Management and Coordination) and WP7 (Communication and Patient/Healthcare Provider Engagement), focussing on their respective tasks in view of management and coordination exercises falling into the scope of WP1 and alignment on communication as well as dissemination tasks being part of the WP7 responsibilities.

Further in the realm of WP7 and WP6 (Regulatory and HTA Engagement) collaboration, WP6 will be contributing to the external newsletter with spotlight sessions with EXAG members to inform the wider audience about their input and current discussions.

The target group “people with dementia, their families & carers, patient & carer organisations” have been clustered to “dementia community” and advocacy groups have been added to the target group as this better reflects the assembly that is targeted with the available tools and channels.

Another target stakeholder has been added to the list, representing the supporting communication channels of the wider ROADMAP network.

2. Activities

2.1. Facilitation of communication outreach

A first step in the facilitation of outreach is the identification of potentially relevant information. All ROADMAP partners are required to inform on their progress, publication plans and planned presentations. In order to facilitate this, a close collaboration of WP1 and WP7 is required to promote a bilateral exchange of information.

Additionally, in order to facilitate communication outreach and gather up to date information on project related dissemination activities of ROADMAP partners, the communication contacts identified (D7.2 section 3.1 Channels and Multipliers) are contacted on a monthly basis via email.

This email is delivered in form of plain text with links to relevant news items at roadmap-alzheimer.org as well as the affiliated [twitter handle tweets](#) this also includes up to date information on ROADMAP representations at conferences with a call for dissemination through their institutional communication channels. Further, it includes a request on information that has been disseminated. The feedback is used to update both the monthly internal bulletin section “dissemination activities” and the [dissemination repository](#). The up to date overview of communication contacts can be found in [SharePoint](#).

Further, WP7 participates in telephone conferences with the SDSG (Scientific Disclosure Strategy Group) this group takes a strategic approach to publications for scientific audiences which fall outside of the WP deliverable publications, these activities are aligned with WP7.

2.2. Big Data for Better Outcomes collaboration

In May 2017, monthly calls (in principle of around 45-60 minutes) between the leads of the communication WP of the disease specific projects (DSP's), which encompass [ROADMAP](#), [BIGDATA@HEART](#) and [HARMONY](#) as well as the communication team of Do-IT, have been set up. The objective of the calls is to update one another on communications efforts, to understand what the other projects are doing in this area as well as to align communication/ dissemination work where possible.

ROADMAP provides the Big Data for Better Outcomes (BD4BO) project, through WP7 in collaboration with WP1, with requested project outputs for their knowledge repository in development, as well as further communication materials for their use when disseminating ROADMAP as part of the BD4BO programme (such as a [one-pager](#), [ROADMAP core slide deck](#) and the project [leaflet](#)).

Further, WP7 supported BD4BO in the development of their BD4BO website, including feedback on structure and design. The website went online on 18 July under the [bd4bo.eu](#) and [bd4bo.org](#) domains. It includes both general information on ROADMAP and a link towards the [ROADMAP website](#).

WP7 also provides BD4BO with website content on an ongoing basis, this encompasses general information on the ROADMAP project and updates on ROADMAP presentations at conferences for the BD4BO event calendar on their website. A [BD4BO section in the London School of Economics and Political Science \(LSE\) SharePoint](#) has been set up for this kind of collaboration and includes an overview of upcoming ROADMAP presentations, maintained by WP7. The information about ROADMAP presentations at conferences is also used for communication support in form of communication before the event, dynamic communication during the event and follow-up communication after the event.

In addition, BD4BO has developed an [internal newsletter](#) which is disseminated on a quarterly basis and aims at raising awareness in all BD4BO group partners (consortium partners and advisors in the existing BD4BO projects) of on-going activities at the programme level and to identify opportunities across projects. WP7 provides BD4BO with news, including consolidated feedback on project progress and communication activities as well as the external ROADMAP newsletter. The next newsletter will go out at the end of October. A first communications and outreach face to face meeting has been organised for 15th November 2017 in London.

2.3. Collaboration with other IMI projects

ROADMAP also collaborates with various IMI projects such as, the European Prevention of Alzheimer's Disease ([EPAD](#)) and its sister project Amyloid Imaging to prevent Alzheimer's Disease ([AMYPAD](#)) through AE's engagement in both projects. Through a dyadic communication using social media, a support in communication efforts and visibility is guaranteed. Further synergies and support are achieved through AE's involvement in [AETIONOMY](#) and [MOPEAD](#) as well as other IMI projects.

Through the connection of BD4BO, WP7 is liaising with [BIGDATA@HEART](#) and [HARMONY](#) communication teams to support each other in communication efforts.

Achievements and announcements of the IMI GetReal project, which are also related to RWE are also supported through ROADMAP's communication channels in order to further support the overarching efforts in the realm of the RWE paradigm.

Through the cross-project engagement of ROADMAP partners in other projects such as EMIF, ROADMAP also participates in joined sessions for example at the EMIF-AD annual general assembly to ensure that the project partners have current state of knowledge about their progress and can liaise on possible learning opportunities from more advanced projects and synergetic efforts. The overarching goal in these efforts is to liaise and establish synergies with and share learnings from neighbouring initiatives.

2.4. General communication

In line with the communication objectives the project and its progress have been featured in a variety of activities through ROADMAP's established communication channels.

This encompasses:

- Two articles in journals including four planned articles.
- Eleven oral presentations at scientific meetings.
- Thirteen representations in external newsletters (Alzheimer Europe newsletter & internal BD4BO newsletter).
- Twenty-seven articles on websites of various ROADMAP partners.
- One article with project manager and project leader interviews in Alzheimer Europe's Dementia in Europe Magazine.

The Dementia in Europe magazine is distributed to all the Members of the European Parliament and many high-level decision makers in the European Commission. It also reaches lawmakers and politicians in the countries of AE's 40 member associations, and is read by research professionals from public and private bodies, such as the JPND and the 2nd European Joint Action on Dementia. It is distributed to academic and scientific partners who work together with AE on various projects. A detailed overview of all communication activities including links to all articles as well as a detailed overview of communication efforts is available in the dissemination activities tracking system in [SharePoint](#).

2.5. Participation in conferences

In order to support ROADMAP representations at scientific events, WP7, WP1 and the Scientific Disclosure Strategy Group (SDSG) work in close collaboration. As a first step, a list of conferences and congresses of possible interest for ROADMAP representations has been made available to the project partners in [SharePoint](#) and researchers are invited to provide their input on potential additional events. ROADMAP partners also can leverage from the [horizontal](#) and [vertical](#) poster presentation templates created by WP7 as a basis for their use.

Abstract submission deadlines, future ROADMAP representations at conferences and other upcoming events are gathered and provided to ROADMAP partners on a monthly basis, through the [monthly internal bulletin](#).

During the first 12 months of the project, ROADMAP has been represented through abstract presentations (orally or poster) and panel sessions in various related conferences. A detailed list of conference attendances can be found in [SharePoint](#). In future, ROADMAP will also be represented at conferences that coincide with scientific publications arising from the project in order to empower outreach to the scientific community.

ROADMAP partners have presented the project on different occasions. All of the ROADMAP presentations coincided with (but were not limited to) the collaboratively agreed conference opportunity overview of WP7 and the scientific disclosure strategy group (SDSG) in the [initial Communication plan D7.2](#) section 2.4.7. The following list gives an overview where ROADMAP has been or will be presented during 2017:

- Panel session: “The state of Alzheimer’s disease in Europe - innovation, value and challenges for HTA”. J. Bouvy, J. Georges, R. Handels, M. Knapp & C. Reed, Health Technology Assessment international (HTAi) Annual Meeting, 17-21 June 2017, Rome (Italy).
- Poster presentation: “Overcoming ethical issues in sharing real-world evidence in Alzheimer’s disease: The ROADMAP Project”. J. Krutzinna, Neuroethics Network 2017, 19-21 June 2017, Paris (France).
- Poster presentation: “Real World Evidence for Alzheimer’s disease Outcomes”, Alzheimer’s Association International Conference (AAIC), 16-20 July 2017, London (UK).
- Oral presentation: “Actualités sur l’Aducanumab et étude ROADMAP”. Journées scientifiques de la fédération nationale des Centres Mémoire Ressources Recherche (FCMRR), 28-29 September 2017, Montpellier (France).
- Symposium: “Engaging with patient organizations within IMI consortia to inform quality, relevance and value in Alzheimer’s research – insights from MOPEAD, EPAD and ROADMAP”. As part of Lilly symposium, Alzheimer Europe Conference, 2-4 October 2017, Berlin (Germany).
- Poster presentation: “Challenges in Optimising Real World Evidence for Alzheimer’s Disease”. C. Reed, F. de Reydet de Vulpillieres, J. Gallacher, Clinical Trials on Alzheimer’s Disease (CTAD 2017), 1-4 November 2017, Boston, MA (USA).
- Oral presentation: “Challenges in Optimizing Real World Evidence for Alzheimer’s Disease”, C. Reed, F. de Reydet de Vulpillieres, J. Gallacher, International Society of Pharmacoeconomics and Outcomes Research (ISPOR) Annual European Congress, 4-8 November 2017, Glasgow (UK).

The following conferences were identified as future key opportunities to present the ROADMAP project, its aims and its achievements:

Title	Date	Location
Lausanne IV OECD/ ADI/ CEOi 2018 the road to 2025: Building the ecosystem for Alzheimer's innovation	13-14 December 2017	Lausanne (Switzerland)
8th International Conference on Pharmacoeconomics of Alzheimer's Disease (IPECAD)	15- 16 February 2018	Paris (France)
AAT-AD/PDTM Focus Meeting on Advances in Alzheimer's and Parkinson's Therapies	15-16 March 2018	Torino (Italy)
23rd Annual International Meeting of the International Society of Outcomes Research (ISPOR)	19-23 May 2018	Baltimore, MD (USA)
HTAi 2018 Vancouver	1-5 June 2018	Vancouver (Canada)
AAIC 2018 Alzheimer's Association International Conference	22-26 July 2018	Chicago (USA)
28th Alzheimer Europe Conference	29-31 October 2018	Barcelona (Spain)
2018 Gerontological Society of America (GSA) Annual Scientific Meeting	14-18 November 2018	Boston, MA (USA)
14th World Congress of Bioethics	4- 7 December 2018	New Delhi (India)

2.6. Involvement of people with dementia and carers

The involvement of people with dementia included the review of a stakeholder survey (Task 2.3) in June, by the Chairperson of the EWGPWD. As part of Task 2.1, Alzheimer Europe (in interaction with WP7) organised a consultation with Alzheimer Europe's [European Working Group of People with Dementia](#) (EWGPWD) to enable the development of a set of consensus outcomes and AD progression criteria, in which the work of WP2 (Outcome Definition) was discussed in the context of ROADMAP. In order to discuss ELSI (Ethical, Legal and Social Implications) issues arising in a RWE approach, Alzheimer Europe is also going to organise a consultation with Alzheimer Europe's EWGPWD for WP8 (Ethical, Legal and Social Implication - ELSI) in December.

3. Dissemination tools

Prior and during the initial stages of the project, different dissemination tools were developed. The materials include the project logo, project launch press releases, website, presentation templates, a general ROADMAP presentation for partners' use, conference leaflets and a roll-up.

3.1. Project website

The temporary ROADMAP website was launched at the beginning of the project. It was replaced by the definitive website at the end of March during the 2nd General Assembly Meeting (24. March 2017) under the registered domain: <https://roadmap-alzheimer.org>. The website serves as main platform for project communication, with emphasis on regular updates. It supports and reinforces the rest of the dissemination activities.

The ROADMAP website was built with WordPress, which allows the content to be easily edited and updated. In addition, a “Subscribe to our newsletter!” form was created on the home page. The website also includes a pop-up sign-up window for the newsletter. These forms both link to Mailchimp and the details of people that completed them are automatically added to the mailing list on Mailchimp. The website is further described in “[D7.1 Project website](#)”. Since submission of the deliverable, the website has been further expanded to comply with communication and consortium needs. It now contains ten main sections at the website navigation menu on top of the website (Figure 2). In order to provide an attractive overview of upcoming events in which ROADMAP will be presented an [events section](#) has been created. Further, the [Expert Advisory Group](#) is also represented on the website and the [Background](#) information has developed. These sections will be consecutively updated throughout the project.

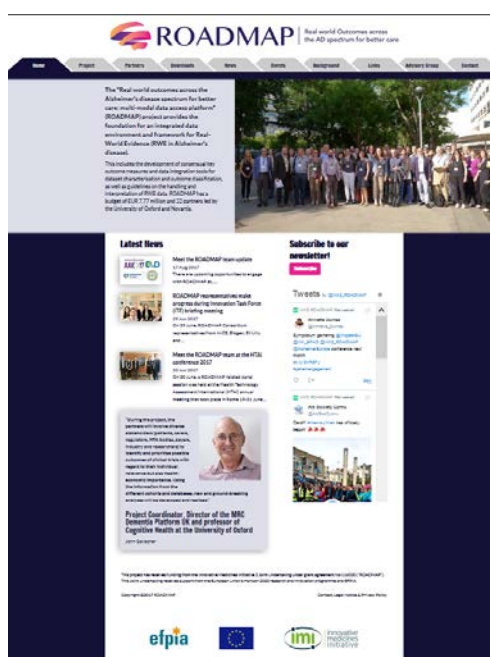


Figure 2. Screenshot of the ROADMAP home page

In order to be able to measure the traffic towards the website, a Google Analytics account was linked to the site shortly after its launch on 30 March. This account is a free online tool generating detailed statistics on the number of sessions (Figure 3), average session duration and the sections/pages most visited (as well as downloads of provided materials on the download section).

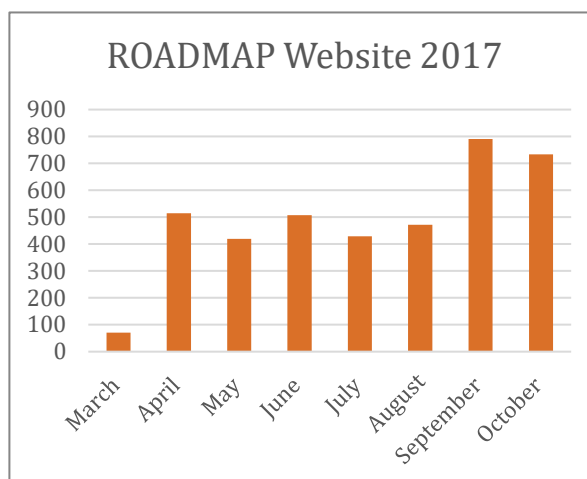


Figure 3. Number of sessions on the ROADMAP website (March-October 2017)

3.2. Press release

Press releases are part of the dissemination strategy and are prepared in accordance with the dissemination calendar (which includes achievements that are part of the feedback from WPLs). Each press release revolves around a specific announcement or achievement of the project. The first press release about the project was disseminated on 16th November 2016 and covered the beginning of the project. In 2017, no additional press releases were launched. WP7 plans to prepare press releases to announce important information or milestones.

3.3. Internal and external communication materials

Different templates with the ROADMAP logo have been produced for communication purposes:

- [Horizontal](#) and [vertical](#) poster presentation template (PowerPoint)
- [Word template](#)
- [Press release](#) (Word)
- [ROADMAP core slide deck](#) (PowerPoint)
- [ROADMAP presentation template](#) (PowerPoint)
- [Deliverable template](#) (Word)
- [Minutes template](#) (Word)
- Updated [one pager](#) (Word)

3.4. Conference leaflet & roll-ups

WP7 has created a conference leaflet and roll-ups for the use of ROADMAP partners when presenting the project at an exhibition and/or presentation opportunities aiming to increase awareness of the project and to reach out to additional database providers, interested universities, institutions as well as companies to further expand its Europe-wide network towards a potential onboarding for a Phase 2. The physical copies were distributed in October at the 4th GAM in Barcelona. It was distributed to all attendees of the 27th Alzheimer Europe Conference in Berlin from 2nd to 4th October 2017.

Furthermore, the flyer has been shared, accompanied by a short article, through partner communication channels to coincide with the third issue of the external newsletter and fourth General Assembly Meeting. Oxford will be featuring a short article about the project on the main University website as well as on the websites of the Medical Sciences Division and Department of Psychiatry.

The ROADMAP leaflet is developed in A5 format and includes (see Figure 4):

- Page 1: ROADMAP logo, challenge of AD and requirement for new models that encompass all available evidence
- Page 2: Information about ROADMAP and its strong data corpus
- Page 3: ROADMAP's objectives
- Page 4: ROADMAP partners and acknowledgement



The Real world Outcomes across the Alzheimer's Disease (AD) spectrum for better care: Multi-modal data Access Platform (ROADMAP) project is a public private consortium with **26 partners** from Europe, coordinated by the University of Oxford and Novartis.

In order to achieve this **ROADMAP** will use and analyse data of subjects from:

75 national databases and clinical registries	$n \approx 80\text{M}$
More than 40 cohorts	$n \approx 2\text{M}$
Several studies using wearables and smart devices	$n \approx 100\text{K}$
5 dementia relevant trials	$n \approx 100\text{K}$

ROADMAP welcomes additional database providers, interested universities, institutions as well as companies to further expand its Europe-wide network towards a potential onboarding for a Phase 2

Contact us at info@roadmap-alzheimer.org

- Define and catalogue scales and consensus-based methodologies for identifying AD outcomes from routinely collected data.
- Identify and pool AD-related RWE data and establish solution options for how to combine different RWE sources with RCT data supporting pharmacoeconomic evaluation.
- Develop and validate a core disease progression model combining diverse datasets to facilitate analysis of disease trajectories and effect of interventions on disease trajectories.
- Develop a proof of concept AD cost-effectiveness and budget impact model for HTA agencies, regulators, service providers, industry, payers and carers.
- Develop guiding principles and recommendations from HTA/payers/regulators for the development and incorporation of RWE into clinical and market access development plans for AD.
- Develop and implement a communication strategy focusing on the needs of patients and professionals.
- Develop an Ethical, Legal, and Social Implications (ELSI) framework with extensive patient involvement for the development and application of RWE in AD.
- Develop a full plan for phase 2 of the ROADMAP initiative that addresses identified gaps and pitfalls, and exploits promising solutions to their full potential for development of a European RWE platform in AD.



ACADEMIA		
 <p>UNIVERSITY OF OXFORD</p>	 <p>THE UNIVERSITY of EDINBURGH</p>	 <p>KHALIFA UNIVERSITY</p>
 <p>Maastricht University</p>	 <p>radboud universiteit nijmegen</p>	 <p>LSE PSSRU</p>
 <p>GÖTEBORGS UNIVERSITY</p>	 <p>UTRECHT UNIVERSITY</p>	 <p>IDAP Jansz-Giel</p>
 <p>Leiden University Medical Center</p>	 <p>ERASMUS UNIVERSITY</p>	 <p>Erasmus MC</p>
EFPIA		
 <p>NOVARTIS</p>	 <p>AC Immune</p>	 <p>Biogen</p>
 <p>Roche</p>	 <p>Lilly</p>	 <p>GE</p>
 <p>Janssen</p>	 <p>janssen</p>	 <p>Takeda</p>
REGULATORY AGENCIES	SMEs	PATIENT ORGANISATION
 <p>c B G M E R</p>	 <p>SYNAPSE</p>	 <p>Alzheimer Europe</p>
 <p>NICE</p>	 <p>IXICO</p>	

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Additionally, ROADMAP roll-ups have been designed and produced to strengthen visibility and recognition of the project at events.

3.5. ResearchGate

As an innovative approach to engage the scientific community, the social network for researchers ResearchGate.net was included into the set of tools to maximise the outreach towards the scientific community. For this purpose, a [project page](#) (see screenshot Figure 5) for ROADMAP was set up. Furthermore, collaborating partners are included and can be followed in order to obtain a deeper insight into the scientific profile of the individual affiliated ROADMAP researchers. This ensured a higher visibility of the project itself, but also raised the impact factor regarding the outreach of future scientific publications in the framework of the project itself.

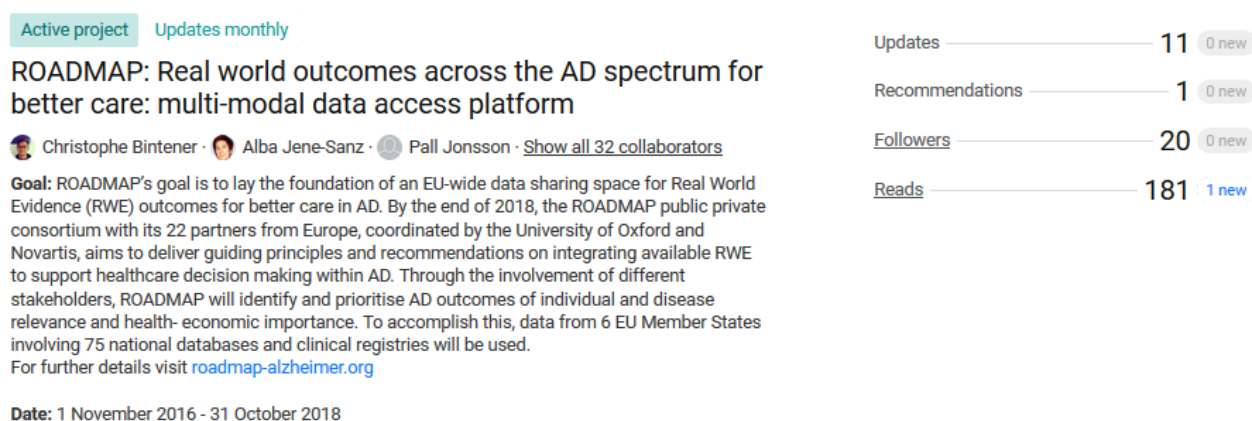


Figure 5. Screenshot of ROADMAP project on ResearchGate

The project currently has a total of 216 reads and 33 members of the consortium are listed as collaborators, since it was launched on 27 March 2017. The project audience consists of project followers, collaborators and followers of collaborators. After the first ROADMAP publication has been published, it will also be possible to assess how often the research items were read and downloaded. The project page also provides all public deliverables, including the publishable summary and a link towards the lead contributor, if a ResearchGate profile of the author is available. In addition, poster presentations held at conferences are also uploaded in order to raise awareness of information highlighted by the contributing researchers (see Figure 6).

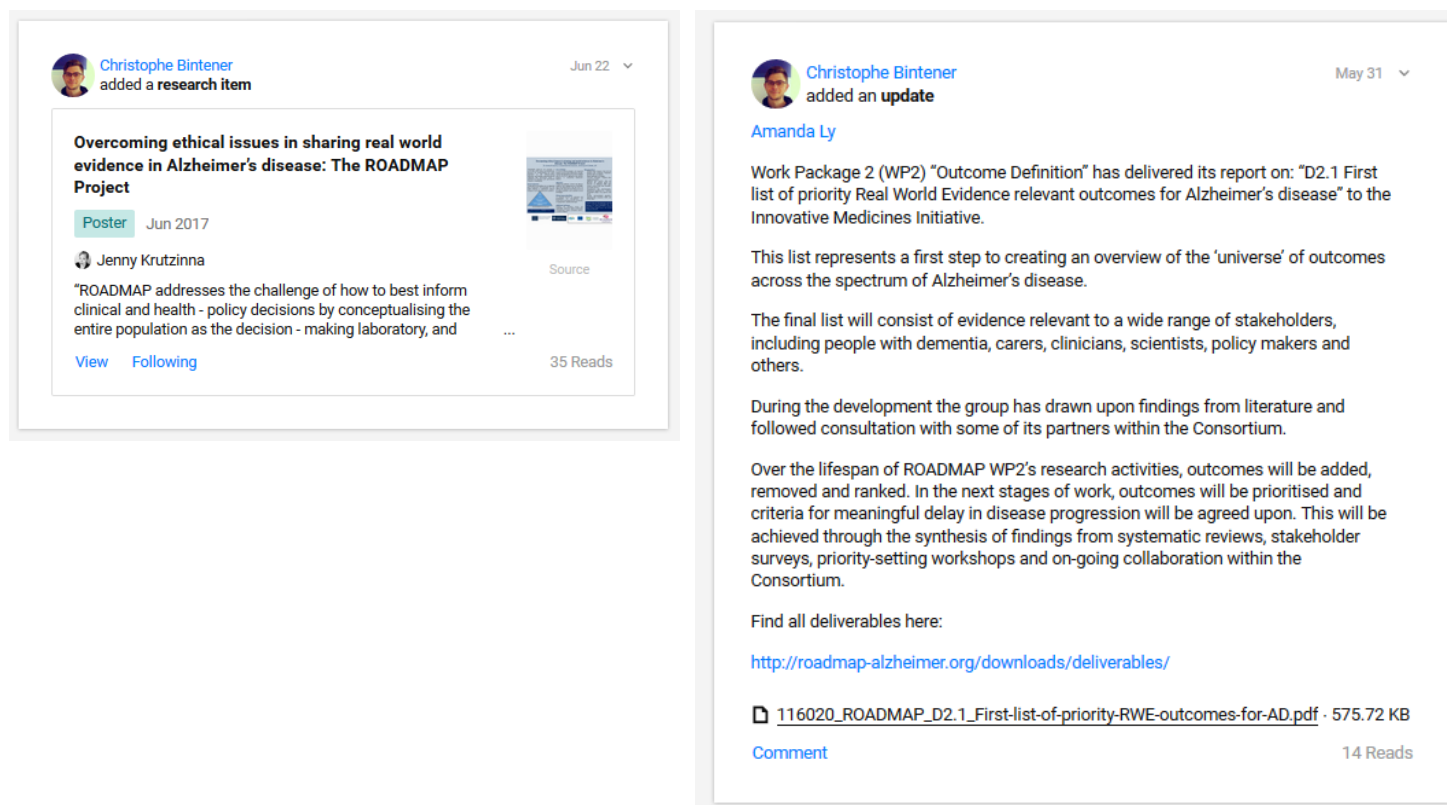


Figure 6. ROADMAP deliverable and poster on ResearchGate

3.6. Twitter

The use of Twitter as a social media tool is appropriate to inform on a regular basis about ROADMAP's progress and disseminate further relevant information. Due to the pronounced interactive nature of the platform it allows the project to reach out to additional stakeholders and connect with thousands of people around the world. A ROADMAP Twitter account was created in January 2017 (@IMI2_ROADMAP). Until the end of October 2017, the account has been used to release 242 tweets, the profile has a current following of 475 Twitter users. The dissemination of activities in form of "tweets" is conducted using partner and funder handles in the tweets or by tagging them in photos that are added to tweets. A [list with project partners and their Twitter handles](#) was also generated to enable visitors to check on updates of contributors in an easy and accessible way.

Figure 7 provides an overview of the so far collected Twitter metrics of the @IMI2_ROADMAP account since January 2017. Below also is a screenshot (Figure 8) of the account on Twitter.

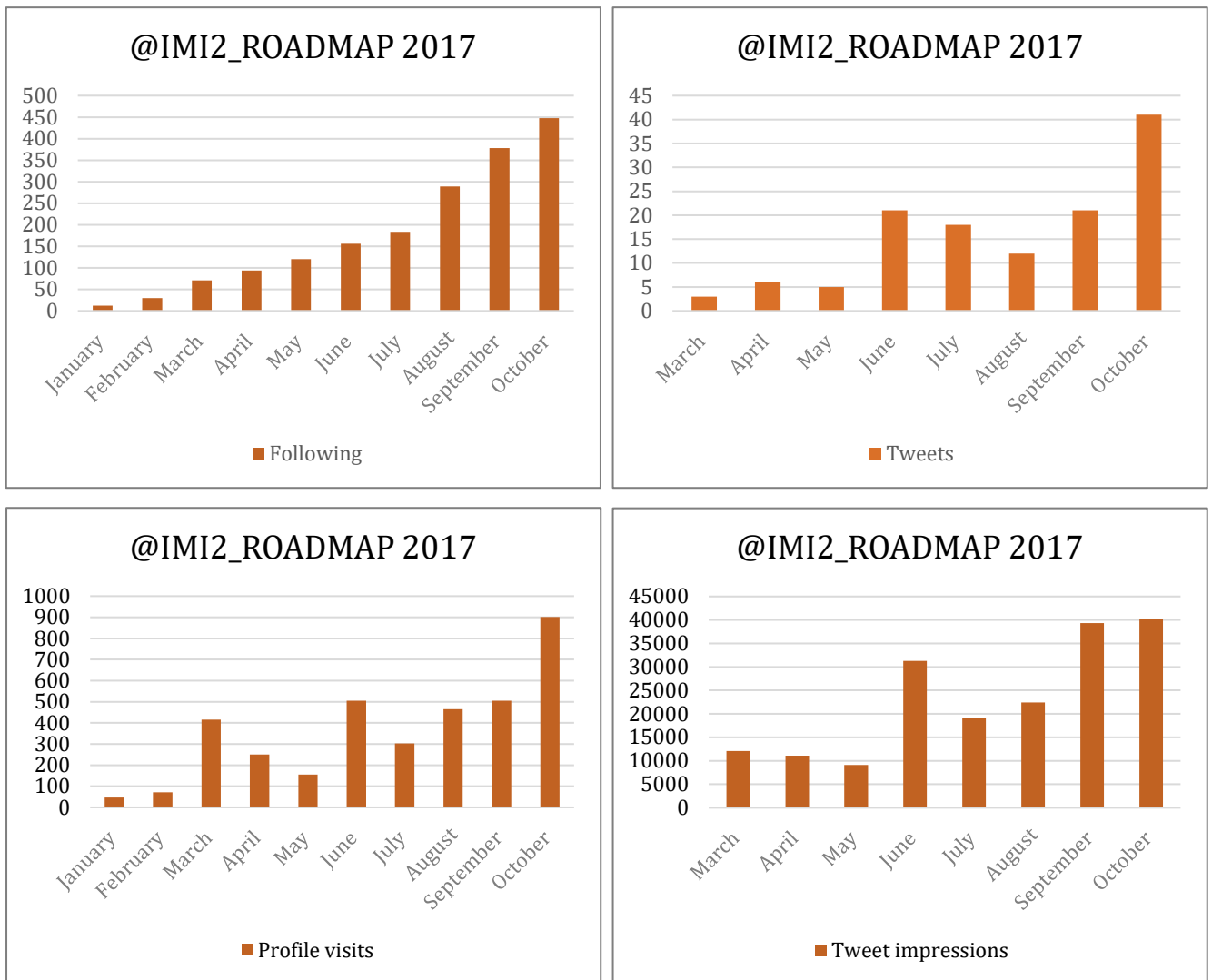


Figure 7. Twitter statistics



Figure 8. ROADMAP project on Twitter

3.7. Newsletters

3.7.1. Internal monthly bulletin

The internal bulletin is circulated on a monthly basis amongst the project consortium via email and uploaded to [SharePoint](#). The aim is to have a summary of the ongoing activities in each WP, an overview on dissemination and external events relevant to ROADMAP, including links to documents in SharePoint. WP1 is editing the bulletin, including feedback from all WP's.

The bulletin sections include:

- Project news
 - WP specific
 - Dissemination activities
 - ROADMAP in the news
- Upcoming milestones and deliverables
- External events
 - Meet the team at XXX
 - Abstract submission deadlines
 - Other upcoming events
- Internal meetings
- Other resources

External events encompass ROADMAP presentations at conferences, abstract submission deadlines for potentially ROADMAP relevant conferences and other upcoming events that could be of interest to ROADMAP consortium members.

3.7.2. External newsletter

The external newsletter aims to increase awareness about the project among external stakeholders and to generate visibility of the project and its progress to all partners, stakeholders and other IMI projects. It is circulated on a quarterly basis to the subscribers, which encompass a broad range of interested stakeholders. Each newsletter features the following sections

- Welcome introduction
- News and Events
- Scientific involvement (Interviews)
- Pick of the season
- After the first publications arise from the ROADMAP project (2018) interviews of external stakeholders' and their point of view on the importance of RWE will be carried out

The design was developed in line with the website and logo in order to provide a consistent corporate design. The first section of the first newsletter includes a welcome introduction from either the Project

Coordinator or by the Project Leader, each includes an introduction in accordance with the achievements disseminated in the specific newsletter.

The quarterly external Newsletter is available on the project website through a subscription option using MailChimp. MailChimp is a web-hosted platform for creating and distributing e-newsletters, it provides excellent functionality and analytics, and also ensures compliance with European and international data protection legislation. The free edition of MailChimp will allow to build a mailing list of up to 2,000 subscribers, and send up to 12,000 emails per month.

Newsletter outreach:

- The [first issue](#) was circulated on 24 April 2017 to 208 people.
- The [second issue](#) was sent out on 5 July 2017 to 289 recipients.
- The [third issue](#) was sent on 29 September 2017 to 324 subscribers

All past editions are available on the [download section](#) of the website. In addition to that the newsletter is also disseminated using Twitter with a direct link towards the [campaign archive](#).

3.7.3. EFPIA partner newsletter

As part of ROADMAP's internal communication on goals and milestones, WP7 also prepares an [EFPIA partner newsletter](#) that is sent to the representatives of their respective companies of the ROADMAP consortium. Its aim is to support internal communication. The first issue provided a brief overview of the project that the recipients were able to share internally with their leaders and team members. This 'EFPIA partners Newsletter' is intended to give a high level update on where we are with ROADMAP and as first step, also to inform on what ROADMAP is as well as its expected goals and next steps.

3.8. Dissemination activities tracking system

WP7, supported by SYNAPSE, keeps track of the project's dissemination activities for the purpose of IMI JU reporting. Participants are asked regularly by the PMO to provide any dissemination activity related to ROADMAP they are involved in. In addition to that, the communication contacts are asked to report on a monthly basis. Participants are also asked to check the list of already reported dissemination activities, in order to ensure the completeness of the information. The template shown below (Figure 9) is regularly updated and used to report and track the project's dissemination activities, and is available in [SharePoint](#). In order to track correctly and efficiently the dissemination activities, we recommend to all ROADMAP partners to share any activities as soon as they are planned. Annex I provides an overview of all communication activities since the start of the project, including type of dissemination activity, audience reached, estimated number of persons reached and date.


		Last update: 06/09/2017 Updated by: Christophe		ROADMAP Dissemination activities and Scientific Publications				<div>Headers legend</div> <div>DISSEMINATION</div> <div>SCIENTIFIC publications</div>					
ID	Title	Type of activity	Status	Description	Location	Partners Involved	Responsible Partner	Date (dd/mm/year)	RP	Type of audience reached	Estimated number of persons reached	Reference (e.g. website)	Contact person
		Please choose from drop-down menu	Please choose from drop-down menu		City, country	Partner(s) (acronym)			IMI Reporting Period	Please choose from drop-down menu			
048	The ROADMAP project updates us on recent progress	External newsletter	Published	News item at AE's newsletter	-	AE, UOKF	AE	31/08/17	RP1	Dementia community	-	http://www.alzheimer-europe.org/content/download/142277/879293	Christophe Bintener
049	The ROADMAP project updates us on recent progress	Website for general public	Published	News item at Alzheimer Europe's website	-	AE, UOKF	AE	31/08/17	RP1	Dementia community	7500	http://www.alzheimer-europe.org/News/EU-projects/Thursday-24-August-2017-The-ROADMAP	Christophe Bintener

Figure 9. Dissemination activities tracking system

Annex I Dissemination Activities



ROADMAP Dissemination Activities RP1

ID	Type of dissemination and communication activities	Type of audience reached In the context of all dissemination & communication activities ('multiple choices' is possible)	Estimated Number of persons reached	Date (dd/mm/year)
001	Website for general public	Dementia community	-	16/11/2016
002	Website for general public	General Public	-	16/11/2016
003	Website for general public	General Public	-	16/11/2016
004	Website for general public	General Public	-	05/12/2016
005	Website for general public	General Public	-	06/01/2017
006	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	50	19/06/2017
007	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	5700	29/01/2017
008	Article in journal	Scientific Community (higher education, Research)		28/03/2017
009	Website for general public	Dementia community	-	31/03/2017
010	Non-scientific and non-peer reviewed publications	Policy makers	2600 issues printed	04/04/2017
011	Website for general public	General Public	-	16/11/2016
012	Website for general public	General Public	-	27/04/2017
013	External newsletter	Scientific Community (higher education, Research)	300	24/04/2017
014	Website for general public	General Public	-	30/11/2016
015	Website for general public	General Public	-	17/11/2016
016	Website for general public	Dementia community	-	03/03/2017
017	Website for general public	Dementia community	-	15/05/2017
018	Website for general public	Dementia community	-	15/03/2017
019	Poster presentation at a scientific meeting	Scientific Community (higher education, Research)	60	06/06/2017
020	Article in journal	Scientific Community (higher education, Research)		13/06/2017
021	Poster presentation at a scientific meeting	Scientific Community (higher education, Research)		08/06/2017
022	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	50	17/06/2017
023	Website for general public	Dementia community		26/06/2017
024	Website for general public	Dementia community		24/04/2017
026	Website for general public	Dementia community		20/06/2017
027	External newsletter	Other	557	22/06/2017

028	Website for general public	General Public		16/11/2016
029	External newsletter	Scientific Community (higher education, Research)	300	07/05/2017
030	Participation in activities organised jointly with other projects	Scientific Community (higher education, Research)	50	24/02/2017
031	Poster presentation at a scientific meeting	Policy makers	140	22/06/2017
032	Other	Scientific Community (higher education, Research)		05/07/2017
033	Article in journal	Scientific Community (higher education, Research)		31/12/2017
034	Website for general public	General Public		16/11/2016
035	Website for general public	Dementia community		16/11/2016
036	External newsletter	Dementia community	7500	16/11/2016
037	External newsletter	Dementia community	7500	24/03/2017
038	External newsletter	Dementia community	7500	24/04/2017
039	External newsletter	Dementia community	7500	15/05/2017
040	External newsletter	Dementia community	7500	13/06/2017
041	External newsletter	Dementia community	7500	20/06/2017
042	Poster presentation at a scientific meeting	Scientific Community (higher education, Research)		28/06/2017
043	Other	Other		15/07/2017
044	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	100	31/07/2017
045	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	30	31/07/2017
046	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	20-30	16/07/2017
047	Oral presentation at scientific meeting	Scientific Community (higher education, Research)		17/08/2017
048	External newsletter	Dementia community	7500	31/08/2017
049	Website for general public	Dementia community	-	31/08/2017
050	External newsletter	Dementia community	7500	19/09/2017
051	Website for general public	Dementia community	-	19/09/2017
052	Website for general public	Investors	-	27/09/2017
053	Website for general public	Investors	-	27/09/2017
054	External newsletter	Dementia community	7500	27/09/2017
055	Website for general public	Dementia community	-	27/09/2017
056	Website for general public	General Public	-	04/10/2017
057	Website for general public	General Public	-	05/10/2017
058	Flyers/brochures	Scientific Community (higher education, Research)	750	04-05/10/2017
059	Flyers/brochures	Scientific Community (higher education, Research)	750	04-05/10/2017
060	Website for general public	Investors	-	05/10/2017
061	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	-	28/09/2017
062	External newsletter	Dementia community	7500	16/10/2017
063	Website for general public	Dementia community	-	31/10/2017
064	External newsletter	Dementia community	7500	16/10/2017
065	Website for general public	Dementia community	-	31/10/2017
066	External newsletter	Other	557	26/10/2017

067	Oral presentation at scientific meeting	Scientific Community (higher education, Research)	80	19/10/2017
068	Participation in activities organised jointly with other projects	Scientific Community (higher education, Research)	-	01/11/2017
069	Other	Other	-	02/10/2017
070	Website for general public	General Public	-	18/10/2017
071	Website for general public	Investors	-	13/10/2017