D7.5 Final report on dissemination activities (including impact measures) and project tools developed

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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Table of contents

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V1.2	01/10/2018-05/10/2018	Consortium Review
V1.3	17/10/2018	Final Version

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)
    - **Alzheimer Europe**. AE (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**. Aagentschap College ter Beoordeling van Geneesmiddelen (Netherlands)
    - **IXICO**. IXICO Technologies Ltd (United Kingdom)
    - **RUG**. Rijksuniversiteit Groningen (Netherlands)
    - **Novartis**. Novartis Pharma AG (Switzerland) – **Project Leader**
    - **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)
    - **TAKEDA**. Takeda Development Centre Europe LTD (United Kingdom)
    - **HLU**. H. Lundbeck A/S (Denmark)
    - **LUMC.** Academisch Ziekenhuis Leiden – Leids Universitair Centrum (Netherlands)
    - **Memento**. CHU Bordeaux (France)
- **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

This final report on dissemination activities (including impact measures) and project tools developed provides a compilation of all dissemination activities undertaken in the project, and tools produced to support these activities.

The first section of this Deliverable focuses on the communication and dissemination tools. This includes an overview of the website structure and contents including the most important metrics on website usage. It also gives an overview of other relevant tools and channels such as press releases, the conference leaflet, videos as well as the project's ResearchGate account. Further metrics include the social media account on Twitter and a detailed overview on the external newsletter's subscriptions as well as usage. The external newsletter's open rates are also benchmarked with information from the service provider.

The second section focuses on important activities conducted during the lifespan of the project. This encompasses a comprehensive overview of presentations at conferences, an overview of delivered and upcoming scientific publications and an outline on the real-world evidence (RWE) in Alzheimer's disease (AD) event at Alzheimer Europe's Conference in October 2018. Furthermore, this report gives a brief summary of how the dementia community was engaged as well as involved. Lastly, it provides a brief view into the facilitation of communication outreach as well as the collaboration of ROADMAP within the Big Data for Better Outcomes (BD4BO) programme and with other Innovative Medicines Initiative (IMI) projects.

1. Introduction

This final report on dissemination activities (including impact measures) and project tools developed provides a compilation of all dissemination activities undertaken in the project, and tools produced to support these activities.

ROADMAPs communication team has been involved throughout the lifespan of the project in a variety of activities supporting the project's aims and giving it visibility outside of the Consortium. For that purpose, the group developed and implemented an ambitious communication strategy focussing on the needs of patients and professionals. Keeping in line with the project's aspiration to achieve a step-change in the understanding of Alzheimer's disease (AD) across the disease spectrum, patient/carer advocacy groups and the wider public were involved in providing societal perspectives on data collection needs and requirements for decision-making.

Furthermore, in the spirit of collaboration, the communication team facilitated communication outreach, collaborated with neighbouring initiatives as well as sister projects under the Big Data for Better Outcomes (BD4BO) umbrella (DO->IT, HARMONY, BigData@Heart & PIONEER) and engaged the dementia community. The team has been involving partners from all of the Work Packages (WPs) in these actions, ensuring up-to-date information on progress, securing a maximum of transparency of project activities.

Further activities supported the Consortium in opportunities to present work and results. In addition to this, communication channels and contacts from partner institutions were leveraged to maximise outreach impact. All of these activities were carried out, ensuring unified project branding.

For an overview of the communication strategy, including objectives, target audiences and changes from the initial communication plan please go to section 1. "Roadmap Communication strategy" of Deliverable 7.4 "Interim Report on dissemination activities and communication strategy update", available on the website's "Deliverables" section.

2. Communication and dissemination tools

In order to support external communication and make the most out of the dissemination activities that were planned, a varied and multichannel portfolio of communication tools was jointly designed by partners and developed by WP7.

2.1. Project website

At the very beginning of the project, a temporary website was launched. The definite project website then replaced the temporary website at its launch on 24 March 2017, during the 2nd General Assembly Meeting under the domain www.roadmap-alzheimer.org. The website was developed in line with the requirements from the Communication guide for Innovative Medicines Initiative projects and integrated suggestions and feedback through interactive sessions with WP7 members as well as the project's Executive Committee (ExCom). Alzheimer Europe (AE) has been updating the website since its launch and was the contact for all website-related requests by Consortium partners.

Serving as the platform for project communication with emphasis on regular updates, the website is the go-to-point for all public information about the project. It links up ROADMAPs other communication tools and materials, such as social media platform, newsletter, leaflet and news articles. While updates on developments are added to the news section in a more comprehensive and static way, the implementation of the social media feed on the landing page ensured that the website always provides the most recent information through ROADMAPs tweets, giving daily updates and insights on meetings, presentations and events amongst other activities.

2.1.1. Website content

The website is set up in ten main sections, which are further broken down into subcategories:

1. **Home**
2. **Project**
   a. Structure
   b. Objectives
3. **Partners**
4. **Downloads**
   a. Deliverables
   b. Publications
   c. Newsletters
   d. Videos & Podcasts
   e. Materials
5. **News**
6. **Events**
7. **Background**
   a. What challenge is ROADMAP facing?
   b. What is dementia?
   c. What is Alzheimer's disease (AD)?
   d. What is real-world evidence (RWE)?
   e. What is an Outcome?
   f. What is data pooling?
   g. Big Data for Better Outcomes
8. **Links**
9. **Advisory Group**
10. **Contact**

The different sections provide a clear overview of the project, giving visitors access to all public Deliverables as well as all open access publications. Furthermore, posters and presentations of partners were uploaded when possible. Access to all past external newsletters (2.5.2. External newsletter) helps in ensuring that these materials remain an accessible source of information after circulation.

The videos both from public presentations as well as those produced by WP7 and neighbouring initiatives are another asset that adds to the communication framework in form of a more approachable format than only text and image. Other downloadable materials include ROADMAP articles in other newsletters and magazines such as the Health Economics Research Centre's newsletter (University of Oxford) and the Dementia in Europe Magazine (AE).

Communication also included periodic "recent development update" articles with updates on the WPs. These are based on Work Package Leader (WPL) feedback - updates in bullet point format - provided in the internal bulletin (2.5.1). The final article was checked with WPLs to ensure that only public information is provided. The articles follow the WP structure WP1-WP8, for easier overview, and started to include hyperlinks to interviews with WPLs in April 2018. The DO->IT communication team identified this form of article as a best practice approach in communicating about BD4BO project developments in their external newsletter and encouraged the other disease-specific projects (DSP) in following this example (more information on BD4BO can be found in section 3.5).

The comprehensive list of events is another asset that gave the visitors an immediate overview of upcoming ROADMAP events, but also an insight into all past presentations. The background

information with links to resources gives the visitors the ability to gain a quick introduction about the need for ROADMAP and at the same time access to more in depth information about key concepts.

The website features also a links section, introducing and backlinking affiliations, AD and RWE related projects as well as the EU Research and Innovation Programme. Finally, the project's Expert Advisory Group (EXAG) and its members are introduced in a separate section.

2.1.2. Website metrics

From 29 March until 31 December 2017, the ROADMAP website attracted 2.480 new users. Including returning users, visitors generated 4.876 sessions with an average of 3,61 pages per session, leading to altogether 17.616 page views. The average duration of a session was 3:43 minutes and the total amount of time spent on the ROADMAP website was over 300 hours in 2017.

From 1 January 2018 until 30 September 2018, the ROADMAP website had 3.507 new users. Including returning users, visitors generated 6.527 sessions with an average of 3 pages per session, leading to altogether 19.609 page views. The average duration of a session was 3:33 minutes and the total amount of time spent in 2018 by people on the ROADMAP website was over 386 hours.

Figure 1-4 provide an overview of the monthly statistics for the most useful metrics on website traffic and usage.
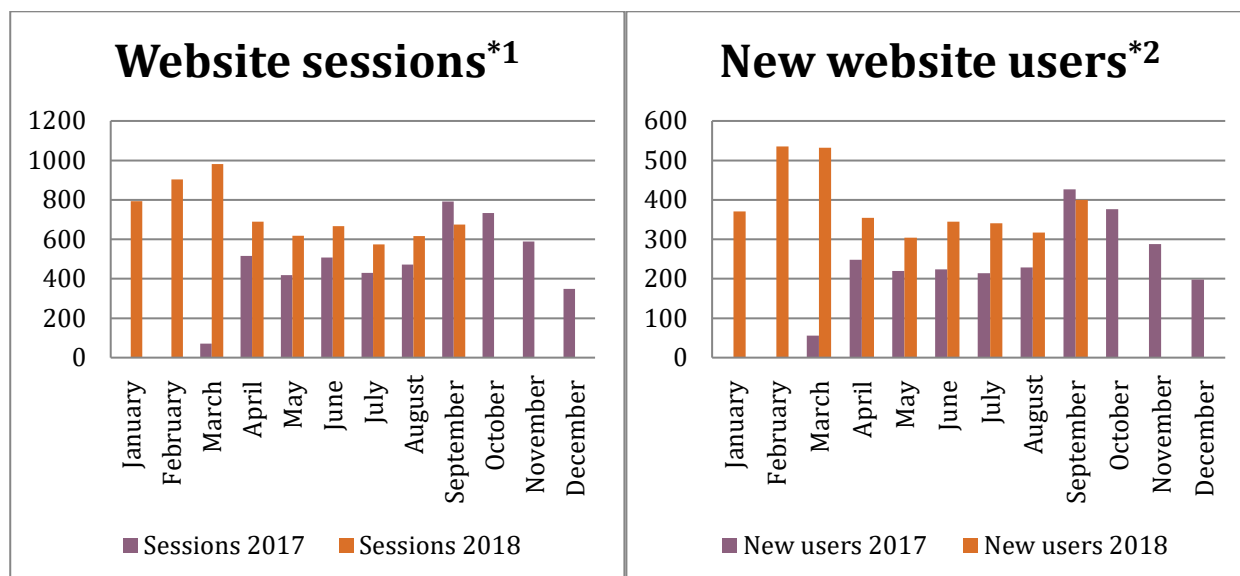
Figure 1. Number of sessions on the ROADMAP website   Figure 2. Number of new users on the ROADMAP website

[*1] A session is the period time a user is actively engaged with the website.

[*2] The number of first-time users during the selected date range. A new user is counted the 1st time a device/browser loads the website and is assigned a client ID. They are considered a returning user anytime a device/browser loads the website and a client ID already exists. Users that already had a client ID in 2017 have not been identified as new users in 2018.

Website users
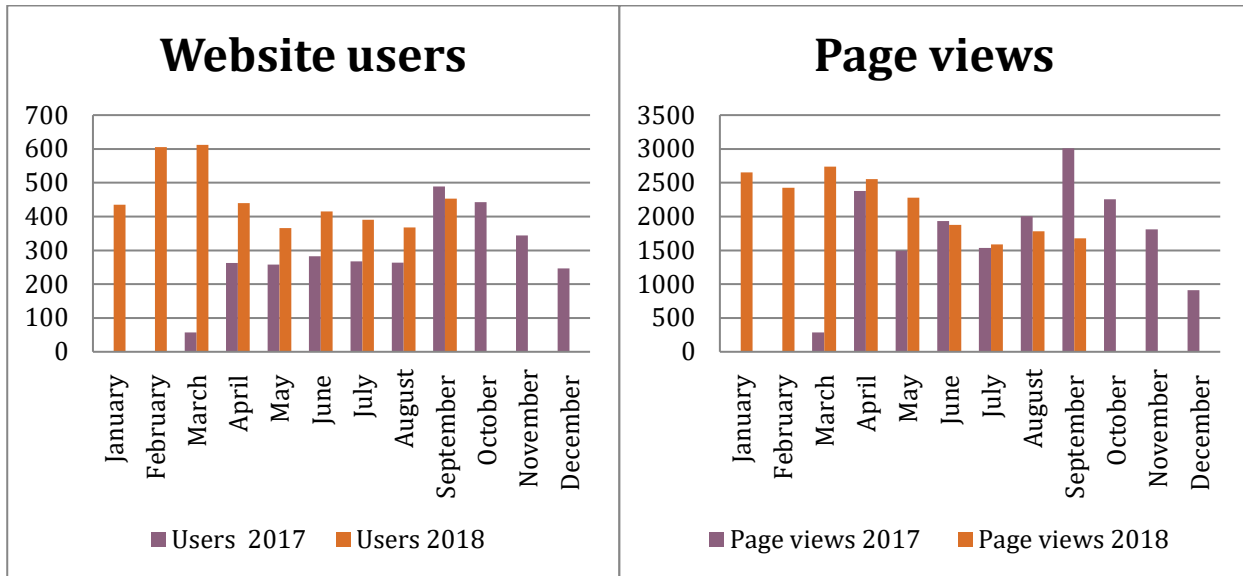
Page views

Figure 3. Number of users on the ROADMAP website

Figure 4. Number of page views on the ROADMAP website

Average session duration
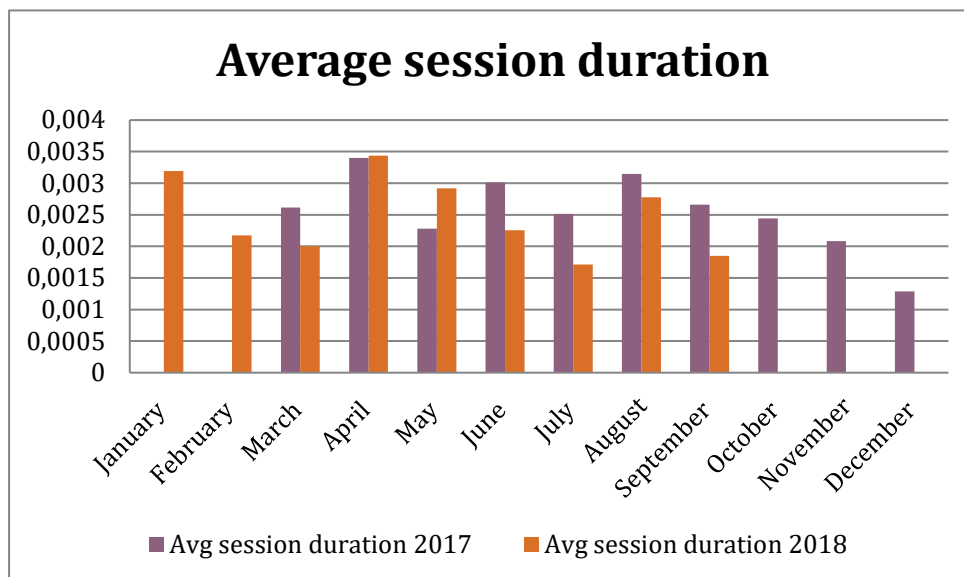
Figure 5. Average session duration on the ROADMAP website in minutes

Apart from the landing page "Home", the section "News" proved to be the most frequented with over 6000 unique page views and more than 8000 views in total (Figure 6). Over the course of the project, more than 60 articles and interviews have been added to the website, which were mostly provided by ROADMAPs communication team as well as partners. Other additions included relevant pieces related to ROADMAP and the BD4BO programme.
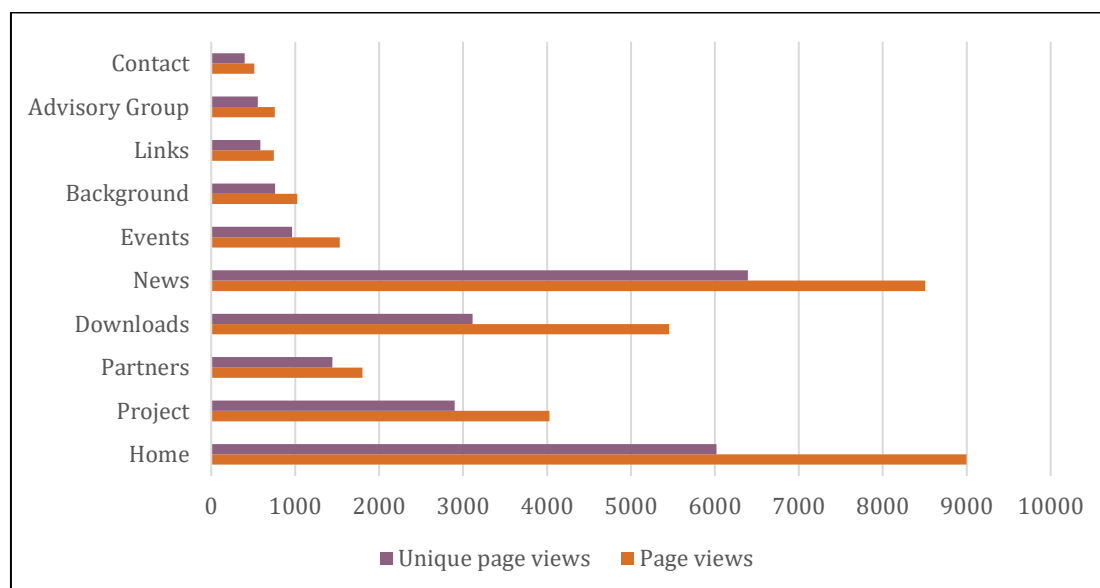
Figure 6. Total page views per main website section - including visits to subpages per section

The article with the highest attention (over 450 page views) was a WP7 interview conducted by AE with Antonella Santuccione Chadha, entitled, "A regulatory perspective on the importance of real-world evidence". It supported the communication strategy in its aim to raise awareness of ROADMAP to target audiences and at the same time highlighted the need for RWE in the management of AD. Table 1 gives an overview of the most visited articles on the ROADMAP website as of 20 August 2018.

Table 1. Overview of most frequented articles on the ROADMAP website

Article	Page views	Unique page views	Average time spent (in seconds)
Interview with Antonella Santuccione Chadha - A regulatory perspective on the importance of real-world evidence	479	435	228,11
Interview with Antje Hottgenroth from Eli Lilly	332	303	254,08
ROADMAP project consultation with people with dementia	243	189	140,27
BIG DATA FOR BETTER OUTCOMES	239	216	110,65
Meet the ROADMAP team at the HTAi conference 2017	229	170	128,42
The value of being involved in research	224	202	223,39
ROADMAP updates on recent and ongoing activities	209	151	121,63
WP5 workshop: modelling the economic value of Alzheimer's disease interventions	199	156	158,49

Worldwide outreach

Figure displays the outreach impact of the project website with regard to the location of users per country. Figure provides an overview with the top ten countries where website users were located. The United Kingdom is the country with the most users, generating almost a quarter (24.30%) of the traffic towards the website, followed by the United States with almost a fifth (19.45%).
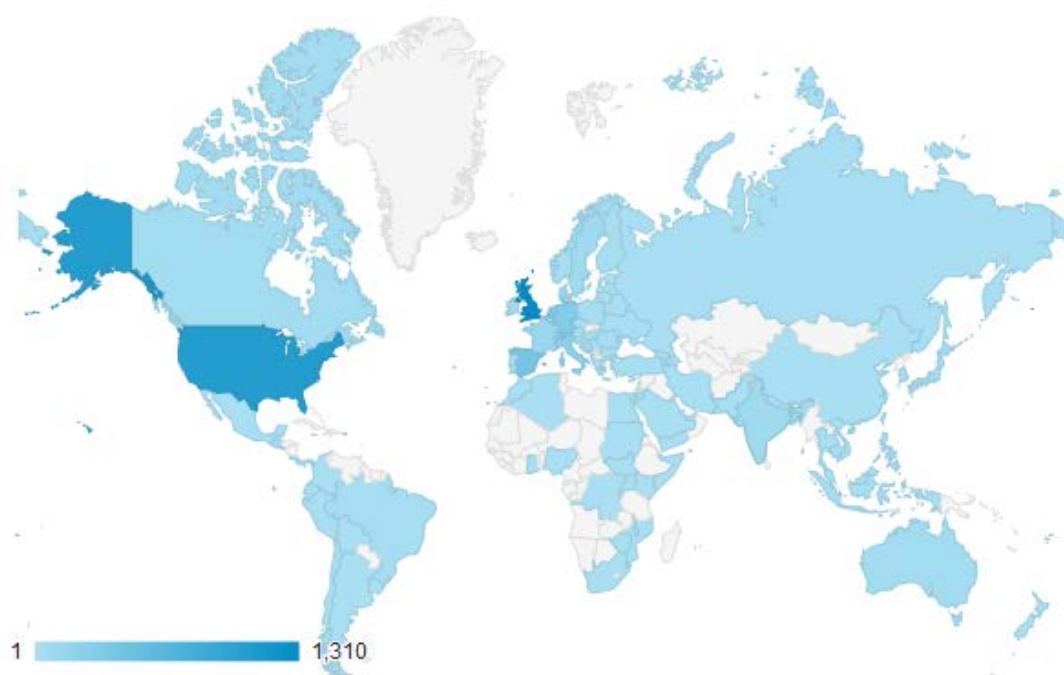
Figure 7. Locations of website users worldwide

1.	🇬🇧 United Kingdom	**1,310**	(24.01%)
2.	🇺🇸 United States	**1,061**	(19.45%)
3.	🇪🇸 Spain	**411**	(7.53%)
4.	🇩🇪 Germany	**303**	(5.55%)
5.	🇨🇭 Switzerland	**295**	(5.41%)
6.	🇳🇱 Netherlands	**260**	(4.77%)
7.	🇮🇹 Italy	**225**	(4.12%)
8.	🇧🇪 Belgium	**213**	(3.90%)
9.	🇫🇷 France	**123**	(2.25%)
10.	🇱🇺 Luxembourg	**115**	(2.11%)

Figure 8. Top 10 locations of website users

2.1.3. Press releases

At the beginning of the project, a press release was launched. This first step in making ROADMAPs start known and widely engage interest of ROADMAPs stakeholders was well covered with strong support from ROADMAP partners such as AE, Lilly, SYNAPSE and NICE amongst others.

Furthermore, ROADMAP Consortium member IDIAP JORDIGOL produced a press release (in both Spanish and Catalan) in April 2018. The press release coincided with the General Assembly Meeting held on 24-25 April 2018. A member of AE whose mother tongue is Spanish reviewed the press release and provided comments for improvement and consistency in messaging.

2.2. Conference leaflet & roll-ups

A leaflet was developed by WP7 (Communication and patient/healthcare provider engagement) to support the project in communicating the need for ROADMAP, its objectives and to attract potentially interested future partners.

All attendees (approximately 1500) of the AE conferences in 2017 and 2018 received a conference bag including the ROADMAP leaflet. The conference is attended by people with dementia, their carers, volunteers and staff of Alzheimer associations, policy makers, health and social care professionals, researchers, academics and industry representatives.

Furthermore, the project Consortium was also encouraged by WP1 (Project Management and Coordination) and WP7 to share the leaflet with potentially interested future partners and colleagues. For this purpose, WP7 also provided an article sent to communication contacts of ROADMAP partners to communicate the launch of the leaflet, including a link towards the digital version. The leaflet is also available on the ROADMAP website and has been downloaded over 50 times.

The two roll-ups were used at internal as well as external events and in the background of videos (see section 2.7. Videos) to strengthen ROADMAPs recognition and branding.

2.3. ResearchGate

The ResearchGate page was set up during the beginning of the project and has been updated continuously. This project page is used as a repository of scientific ROADMAP publications where open access publications are listed and automatically recommended to ResearchGate-account holders with interests in similar topics to ROADMAPs outputs. At the same time, followers of ROADMAP collaborators are also informed about updates of this page, resulting in wider dissemination outreach and visibility of project results. Furthermore, interested scientists can ask questions about the project and its outputs. As of 31 August, the account has:

- 22 updates (recommended 5 times)
- 29 followers
- 361 reads
- 27 consortium members with a ResearchGate account, listed as collaborators.

2.4. Twitter

Social media was utilised throughout the project span to raise awareness about the project and its results, and to engage with additional stakeholders in the discussion on the different topic areas covered by the project. Since the launch of the ROADMAP Twitter account in January 2017, the Twitter handle developed a follower base of over 1.000 accounts and tweeted more than 800 times. The communication activities are in line with the H2020 Programme Guidance "Social media guide for EU funded R&I projects" and respected ROADMAPs Communication Guidelines. Figure 7 is a screenshot of the Twitter account.

Figure 7. Screenshot of Twitter account

The newsletter archive was visited 177 times through the link within the project description on Twitter alone; "Foundation for an integrated data environment and framework for #RealWorldEvidence in #Alzheimer's disease. Visit our newsletter: https://goo.gl/e4MdWD".

Until the end of 2017, the ROADMAP Twitter account tweeted 323 times and produced 163 unique tweets with 235.018 tweet impressions. The account gathered 588 followers and had 4.456 profile visits as well as 262 mentions.

From 1 January 2018 until 30 September 2018, the ROADMAP Twitter account tweeted 509 times and produced 293 unique tweets with 466.500 tweet impressions. The account gathered 561 new followers and had 4.786 profile visits as well as 389 mentions.

Figure 8-14 provide an overview of the Twitter metrics for the account since January 2017.
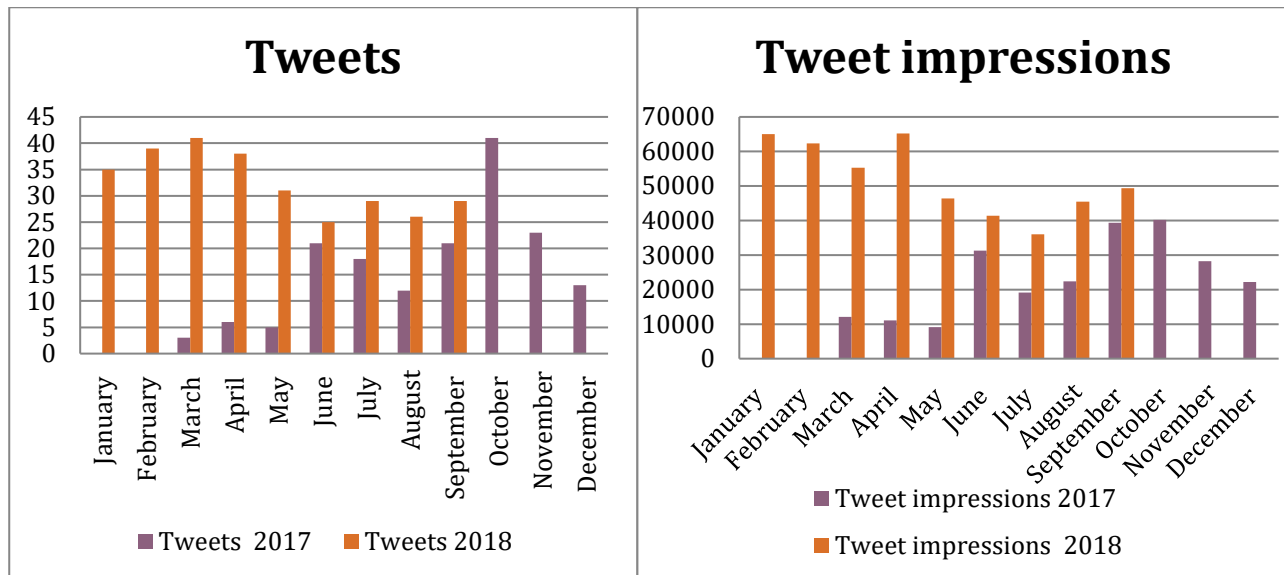
Figure 8. Number of organic tweets per month

Figure 9. Tweet impressions per month
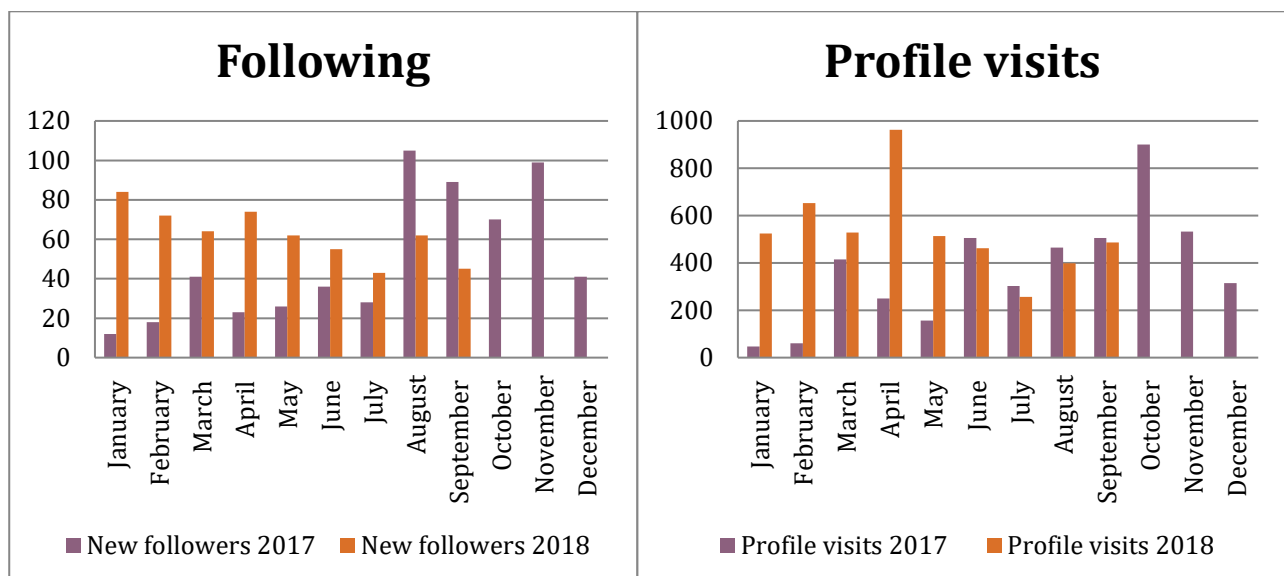
Figure 10. New followers per month

Figure 11. Profile visits per month
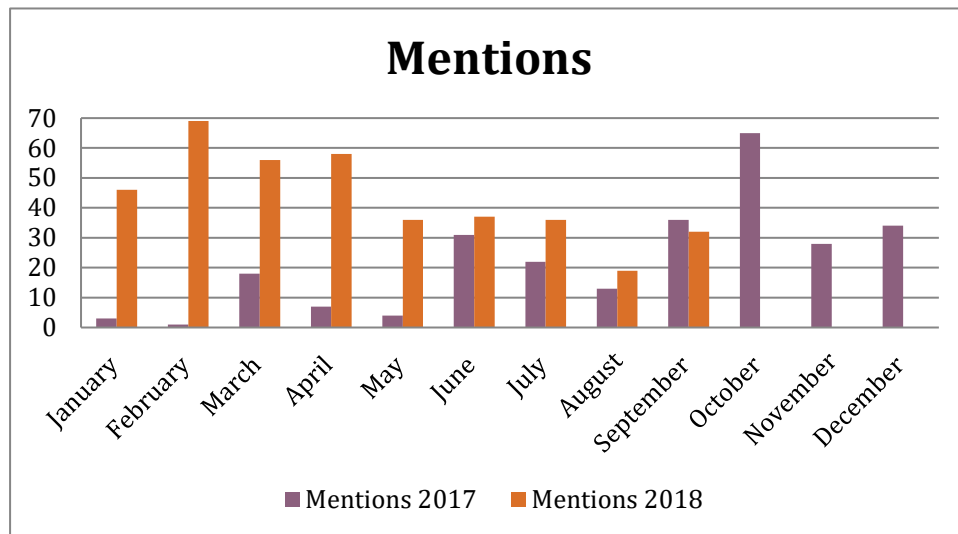
Figure 12. @IMI2_ROADMAP mentions in tweets per month

Outreach

The locations of Twitter followers are quite similar to the visitors of the website; the United Kingdom (40,4%) is the top location for this channel as well, followed by the United States (15,7%), Belgium (5,8%) and Spain (4,5%).

A possible reason for the imbalance towards the United Kingdom might be that it is the third most represented country on Twitter with 18.6 million active users (as of April 2018). In addition to this, there might be some influence by the fact that nine of the Consortium partners are based in the United Kingdom but also because ROADMAP tweets are in English only. Furthermore, the search interest in real world evidence by region is at the highest in the United Kingdom (comparing search queries via Google Trends worldwide).
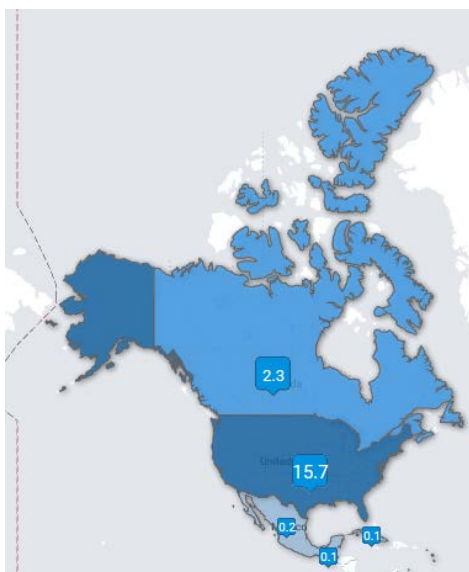
Figure 13. Percentages of followers in the region of the United States and Canada

Figure 14. Percentages of followers in the European region

2.5. Newsletters

2.5.1. Internal bulletin

The internal bulletin was circulated on a regular basis amongst the project Consortium via email and uploaded to SharePoint, regularly providing information on the progress of WPs to the Consortium and further facilitating external communication outreach.

The aim was 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 edited nine issues of the bulletin, including feedback on progress from all WPs and additional input from WP7 on where ROADMAP has been mentioned in the news and external events (where ROADMAP was to be presented, abstract submission deadlines for conferences as well as other upcoming events of potential interest). This also supported the identification of key events for the presentation of the ROADMAP project results, including oral presentations or any other format foreseen as appropriate, by Consortium members.

The bulletin also served as foundation for further communication activities such as the "recent development update" articles, which are based on the WP updates. In addition to the internal bulletin a newsflash was sent to the ROADMAP Consortium, encouraging young researchers to submit an abstract to the Innovative Medicines Initiative (IMI) for its 10th anniversary scientific symposium, to sign up for the final IMI-EMIF symposium as well as the DPUK annual conference and submit an abstract for the upcoming AE Conference 2018.

2.5.2. External newsletter

The quarterly external newsletter is available on the project website through a subscription option using MailChimp. It was sent via email and a link to the campaign archive respectively online versions of the newsletter were shared through the project's Twitter account after circulation of each issue. Furthermore, newsletter referrals can also be found on the project website.

All of ROADMAPs newsletters are over the industry average with up to two-fold higher open rates and more than two-to-four fold higher click rates.

MailChimp reports that (for newsletters sent to at least 1000 subscribers) the average open rate for the pharmaceutical sector is at 18,95% and that the non-profit sector is at 24,11% (as of March 2018). MailChimp categorises ROADMAP as being part of the pharmaceutical industry category. The table below provides an overview with average performance by related industries as well as performance of the ROADMAP newsletters to allow benchmarking of ROADMAPs success in outreach.

Table 2. Open and click rates of MailChimp newsletters per sector

Industry	Open Rate	Click Rate
Pharmaceuticals	18.95%	2.39%
Medical, Dental, and Healthcare	21.09%	2.25%
Education and Training	21.80%	2.48%
Non-Profit	24.11%	2.57%
April 2017 newsletter	37.5%	11.5%
July 2017 newsletter	38.1%	11.2%
September 2017 newsletter	34.9%	9.0%
January 2018 newsletter	32.9%	7.3%
April 2018 newsletter	34.4%	11.3%
July 2018 newsletter	28.5%	7.7%
October 2018 newsletter	28.8%	5.8%

On 24 April 2017, the first issue was sent to **208 recipients** (opened 583 times in total by mailing list subscribers - taking into account multiple opens by the same IP addresses). Further information on an **additional 181 visits** were gathered using google shortened links "goo.gl" and the marketing platform MailChimp (goo.gl, 112 URL clicks; 70 clicks measured via MailChimp). Social media performance to support newsletter outreach marked 3.603 tweet impressions.

On 5 July 2017, the second issue was sent to **289 recipients** (445 total opens by direct recipients). An **additional 84 visits** were recorded as 53 goo.gl URL clicks and 31 clicks recorded with MailChimp. Social media performance to support newsletter outreach marked 2.369 tweet impressions.

On 29 September 2017, the third issue was sent to **324 recipients** (392 total opens by direct recipients). An **additional 339 visits** were recorded as 126 goo.gl URL clicks and 213 clicks recorded with MailChimp. Social media performance to support newsletter outreach marked 4.416 tweet impressions.

On 11 January 2018, the fourth issue was to **408 recipients** (609 total opens by direct recipients). An **additional 196 visits** were recorded as 124 goo.gl URL clicks and 72 clicks recorded with MailChimp. Social media performance to support newsletter outreach marked 6.912 tweet impressions.

On 24 April 2018, the fifth issue was sent to **461 recipients** (624 total opens by direct recipients). An **additional 64 visits** were recorded with MailChimp (no shortened link used in this instance and more than one tweet 1st tweet - 708 tweet impressions, 2nd tweet - 4.756 tweet impressions).

On 9 July 2018, the sixth issue was sent to **513 recipients** (556 total opens by direct recipients). An **additional 111 visits** were recorded as 40 goo.gl URL clicks and 71 clicks reported with MailChimp. Social media performance to support newsletter outreach marked 1st tweet - 2.262 tweet impressions, 2nd tweet 4.973 tweet impressions.

On 08 October 2018, the seventh issue was sent to **532 recipients** (331 total opens by direct recipients). An **additional 51 visits** were recorded as 25 goo.gl URL clicks and 26 clicks reported with MailChimp. Social media performance to support newsletter outreach marked 1st tweet – 2.015 tweet impressions, 2nd tweet 728 tweet impressions.

2.5.3. EFPIA newsletter

Two issues of the EFPIA newsletter have been sent to main Consortium partners in their role as representatives of their respective companies. These issues are also available in SharePoint. The first issue provided a brief overview of the project so that the recipients could share it internally with their leaders and team members. The second issue introduced key achievements at a glance, including an overview of key project outputs produced so far, an overview of key presentations and communication activities as well as an outlook towards future meetings, presentations and articles.

Figure 15. Screenshot of the second EFPIA newsletter (2 pages)

2.6. Other internal and external communication materials

In addition to the newsletters and leaflets, word templates, project poster templates and slideshows to facilitate presentations at events and to support individual meetings were developed, made available to partners and used at various occasions and relevant events for example at the ISPOR and AAIC conferences.

- 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)

2.7. Videos

The communication team also produced four videos with WP leaders and the Project Coordinator during General Assembly Meetings.

The first video introduced the Outcome Definition team (Christin Bexelius - WP2 co-leader).

The second video introduced the Health Economics team (Alastair Gray - WP5 co-leader).

The third video introduced challenges and strengths encountered during the project (Carlos Díaz Project Manager) and the fourth video provided an update from the 5th General Assembly Meeting (John Gallacher - Project Coordinator).

2.8. Dissemination activities tracking system

The dissemination activities tracking system was jointly updated throughout the projects span by WP7 in collaboration with SYNAPSE. The tracking system is available to all partners in SharePoint. Input by partners on plans and activities was collected on a regular basis to ensure the completeness of information. This was supported by the Scientific Disclosure Strategy Group (SDSG), who led the task of developing an upcoming publication overview.

Types of activities include scientific contributions (articles in journals, chapters in books, oral and poster presentations at scientific meetings, publications in conference proceeding…) as well as non-scientific and non-peer reviewed publications, the organisation of conferences/workshops, external newsletters, press releases, flyers/brochures, media (TV, radio, press, multimedia), video/film and participation in activities organised jointly with other projects.

The tracker includes an overall overview of more than 150 activities and is available in ANNEX I.

3. Activities

The crosscutting theme of WP7 "Communication and patient/healthcare provider engagement" involved two overarching tasks including a diverse set of actions throughout the lifespan of the project. The first task focussed on the preparation of a comprehensive communication strategy for a RWE approach to AD. As a second task, the communication strategy, materials and tools for ROADMAP were implemented as described within the previous Deliverables;

- D7.1 Project website
- D7.2 Initial communication plan, including project branding and policies
- D7.3 Initial set of communication tools
- D7.4 Interim report on dissemination activities and communication strategy update

After the identification of all relevant target audiences and key audiences recognising and respecting the role of each audience (including key audiences such as patients, healthcare professionals, regulators, Health Technology Assessment (HTA) bodies, payers, policy makers, professional organisations and the wider dementia community), the Consortium ensured meaningful communication that evolved as the project progressed. This fostered and maintained the relationships with the different stakeholders.

All the dissemination materials generated within the project, including scientific publications and presentations in international events, included the acknowledgement stating that the results were funded by the IMI2/EU and the EFPIA in kind contribution. A procedure for contents approval for publication and other dissemination actions was set up through the Publication Approval Committee (PAC), represented by the ExCom.

The results generated within ROADMAP were shared with the broader community as much as possible. In support of this, ROADMAPs communication team facilitated communication outreach, collaborating with neighbouring initiatives as well as sister projects under the BD4BO umbrella (HARMONY, DO->IT, BigData@Heart & PIONEER). Furthermore, WP7 enabled the involvement of people with dementia and carers through AEs European Working Group of People with Dementia (EWGPWD), the use of AEs channels and tools as well as using the project's developed social media and communication contacts to support outreach.

3.1. Participation in conferences and scientific publications

WP7, WP1 and the SDSG collaborated closely in supporting ROADMAP representations at scientific events. This included the provision of a list of conferences and congresses of possible interest for ROADMAP representations initially made available to the project partners in SharePoint. Researchers were invited to provide their input on potential additional events.

To further ease the overview, abstract submission deadlines for conferences as well as other upcoming events of potential interest were provided to ROADMAP partners on a regular basis, through the internal bulletin as well as an additional newsflash sent via MailChimp to the Consortium (section 2.5.1).

Throughout the project, ROADMAP was represented through presentations (orally and poster) as well as panel sessions in various related conferences and on different occasions. The following list gives an overview where ROADMAP was presented:

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". F. de Reydet de Vulpillieres, M. Pan, C. Díaz, J. van der Lei & J. Gallacher, Alzheimer's Association International Conference (AAIC), 16-20 July 2017, London (UK).

Oral presentation: "Actualités sur l'Aducanumab et l'étude ROADMAP". M. Pan, 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". C. Reed, 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 Vulpilliers, 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 Vulpilliers, J. Gallacher, International Society of Pharmacoeconomics and Outcomes Research (ISPOR) Annual European Congress, 4-8 November 2017, Glasgow (UK). http://www.sciencedirect.com/science/article/pii/S1098301517303716

Poster presentation: "A model for Alzheimer's disease in the prevention setting". N. Hummel, et al., International Society of Pharmacoeconomics and Outcomes Research (ISPOR) Annual European Congress 2017, 4-8 November 2017, Glasgow (UK).

Oral presentation: "The aims of the ROADMAP project". C. Reed, Alzheimer Association Academy, 5-6 December 2017, Brussels (Belgium).

Oral presentation: "The use of real-world data and evidence in regulatory and health technology assessments". M. Dekker, Alzheimer Association Academy, 5-6 December 2017, Brussels (Belgium).

Oral presentation: "Ethical issues raised by big data and real-world evidence projects". A. Turner, Alzheimer Association Academy, 5-6 December 2017, Brussels (Belgium).

Oral presentation: "Expert advisory involvement in ROADMAP". A. Santuccione Chadha, Closed meeting at Lausanne IV, 13 December 2017, Lausanne (Switzerland).

Poster presentation: "Real World Outcomes across the Alzheimer's Disease spectrum for better care: Multi-modal data Access Platform". O. Janssen, S. Vos, R. Handels, F. Verhey, P. J. Vissser, Symposium: The Future of a Data-Driven Society, 25 January 2018, Maastricht (the Netherlands).

Oral presentation: "Real-world evidence in Alzheimer's disease: the ROADMAP collaboration". P. J. Visser, International Pharmaco-Economic Conference on Alzheimer's Disease (IPECAD), 15-16 February 2018, Paris (France).

Oral presentation: "Data sharing in biomedical research: practical questions". C. Díaz, XI Annual Conference of Technological Platforms in Biomedical Research, 5 March 2018, Barcelona (Spain).

Oral presentation: "Real world evidence for investigating AD outcomes: utilising platform resources". N. Vaci, IMI-EMIF Symposium 'Liberating Evidence from European Health Data – the Achievements and Challenges of a Five-Year IMI Project', 18 April 2018, Brussels (Belgium).

Poster presentation: "Predictive modelling for secondary prevention of Alzheimer's disease: Ethical concerns and social implications based on targeted, narrative literature review". Z. Angehrn, et al., International Society For Pharmacoeconomics and Outcomes Research (ISPOR) 23rd Annual International Meeting, 19-23 May 2018, Baltimore MD (USA).

Forum presentation: "Using real-world data to replace missing data for regulatory submissions". H. Kracher, International Society For Pharmacoeconomics and Outcomes Research (ISPOR) 23rd Annual International Meeting, 21 May 2018, Baltimore MD (USA).

Oral presentation: "Regulatory and HTA considerations in Alzheimer's disease". J. Bouvy, HTAi 2018 Meeting, 5 June 2018, Vancouver (Canada).

Roundtable discussion: "Real world data and dementia: contributions from the Information System for the development of primary care research (SIDIAP) and the Girona Dementia Register (ReDeGi)". A. Ponjoan, 11th Research Day of the IDIAPJGol and the 10th Research Day of Catalan Health Institute (ICS), 7 June 2018, Barcelona (Spain).

Oral presentation: "Neuroethics in Dementia Prevention and Treatment: Early intervention for better life long brain health. Findings from the ROADMAP project". A. McKeown, 5th Institute of Medical Ethics Summer Conference, 19-20 June 2018, Oxford (UK).

Oral presentation: "Health-related quality of life in people with dementia measured with preference based instruments: a systematic literature review and meta-analysis". F. Landeiro, et al., XXXVIII Jornadas de Economía de Salud, 21 June 2018, Las Palmas (Spain).

Two ROADMAP teams (Outcome Definition and ELSI) met with the members of the European Working Group of People With Dementia for an interactive feedback session, presenting, discussing and refining conclusions from their consultations in two separate sessions, 27 June 2018, Brussels (Belgium).

Oral presentation as part of "Women and Dementia" parallel session: "Female caregivers' perspectives on the most important outcomes of Alzheimer's disease and dementia". C. Tochel, Alzheimer's Disease International Conference, 27 July 2018, Chicago (USA).

Oral presentation: "Neuroethics in dementia prevention". A. McKeown, 32nd European Conference on philosophy of medicine and health care, 24 August 2018, Lisbon (Portugal).

Poster presentation: "The value of an Expert Advisory Group: Exploration of barriers and facilitators within the ROADMAP international big data project". D. O'Rourke, et al., Guidelines International Network, 12-14 September 2018, Manchester (UK).

Poster presentation: "Identifying priority outcomes and understanding meaningful delay in disease progression for Alzheimer's Disease across the spectrum". A. Ly, IMI 10th anniversary scientific symposium, 22-23 October, Brussels (Belgium).

Poster presentation: "Alignment of European regulatory and health technology assessments: a review of licensed products for Alzheimer's disease". M. Dekker, IMI 10th anniversary scientific symposium, 22-23 October, Brussels (Belgium).

Poster presentation: "Regulatory and HTA considerations for disease-modifying drugs in Alzheimer's disease". D. O'Rourke, IMI 10th anniversary scientific symposium, 22-23 October, Brussels (Belgium).

Oral Presentation: "Challenges of including patient-relevant outcomes in funding decisions for Alzheimer's disease drugs, and consequences – A health technology assessment perspective". A. Bauer & R. Wittenberg, 28th Alzheimer Europe Conference, 29-31 October, Barcelona, (Spain).

In line with the communication objectives, the project and its progress have been featured in a variety of activities through ROADMAPs established communication channels. Dissemination activities primarily entailed scientific interactions including scientific papers.

Publication of papers in journals:

- Systematic literature review of methodologies and data sources of existing economic models across the full spectrum of Alzheimer's disease and dementia from apparently healthy through disease progression to end of life care: a systematic review protocol
- Measuring quality of life of people with predementia and dementia and their caregivers: a systematic review protocol
- Resource utilisation and costs in predementia and dementia: a systematic review protocol
- Big Data for Better Outcomes: Supporting Health Care System Transformation in Europe

As well as three published conference abstracts in journals:

- Gallacher J, ROADMAP Consortium. REAL WORLD EVIDENCE FOR ALZHEIMER'S DISEASE OUTCOMES. Alzheimer's & Dementia. 2017 Jul;13(7):P523.
- Reed C, de Reydet de Vulpillieres F, Gallacher J. Challenges in Optimising Real World Evidence for Alzheimer's Disease. Value in Health. 2017 Oct;20(9):A404.
- Reed C, de Reydet de Vulpillieres F, Gallacher J, ROADMAP Consortium. Challenges in Optimising Real World Evidence for Alzheimer's Disease. The Journal of Prevention of Alzheimer's Disease. 2017 Nov:4(4):P374.

Additional scientific publications are currently underway, including:

- A general ROADMAP introduction focussing on challenges for the optimisation of real-world evidence in Alzheimer's disease (submitted)

WP2 (Outcome Definition) currently produces papers on:

- Priority outcomes for Alzheimer's Disease in European Health Technology Assessments (in process)
- Involving people with dementia, carers and professionals in the development of the ROADMAP data platform (in process)
- What Outcomes Matter to People with Dementia, Their Carers, and Professionals? Insights from ROADMAP Survey (in process)
- Identifying a priority set of stakeholder relevant outcomes: a mixed methods analysis (in process)
- What outcomes are important to patients with Mild Cognitive Impairment or Alzheimer's disease, their caregivers and healthcare professionals? A systematic review (submitted)

WP3 (Identification, mapping and integration of RWE):

- The utility of digital technology in Alzheimer's disease medicine (in process)
- Epidemiology of dementia: prevalence and incidence estimates using validated electronic health records from primary care (submitted)

WP5 (Health Economics):

- Resource utilisation and costs in pre-dementia and dementia – systematic literature review (almost finalised)
- Health-related quality of life in people with pre-dementia or dementia measured with preference based instruments (almost finalised)
- Attributes for an economic model of Alzheimer's Disease: an agreed model specification from academic, industry and reimbursement perspectives (in process)
- Methodologies and data sources of existing economic models across the full spectrum of Alzheimer's disease and dementia from apparently healthy through disease progression to end of life care (in process)

WP6 (Regulatory and HTA engagement):

- Main regulatory and HTA considerations for a disease-modifying drug in AD (accepted)
- Alignment of European regulatory and health technology assessments: a review of licensed product's for Alzheimer's disease (in process)

WP8 (Ethical, Legal and Social Implication [ELSI]):

- A paper entitled: "Clinical trial data sharing: Justifications for increased transparency and access to data in four general medical journals" (submitted)
- A protocol (submitted) of as well as the systematic review on predictive modelling for preventive approaches to Alzheimer's Disease: ethical concerns and social implications (in process)
- A paper on "Trust, Protection and Engagement: The views of the European Working Group of People with Dementia on the sharing and re-use of health data" (submitted)
- Manuscript on reviewing justifications for greater sharing, transparency, and access to clinical trial data (submitted)
- A Landscaping paper on ethics of outcome prioritisation in AD treatment: "Health outcome prioritisation in Alzheimer's Disease: understanding the ethical landscape" (submitted)

3.2. Real-world evidence and Alzheimer's disease event

At the end of the project, WP1 and WP7 jointly organised four public parallel sessions during the 28th AE Conference that took place from 29-31 October in Barcelona (Spain). The participation of the ROADMAP project in this conference represented a major opportunity to target Alzheimer associations/patient groups affiliated with AE.

Briefly, these sessions aimed to present the ROADMAP outputs with higher impact and promote discussions on them, sharing experiences and key learnings:

- Session 1: What matters to whom as AD progresses? Relevant outcomes in disease progression
- Session 2: Ethics challenges for AD research and practice using real-world data
- Session 3: Regulatory and HTA perspectives on real-world data in AD: future of prospective collection and further research
- Session 4: Real-world data availability across Europe: what data are present, missing and heterogeneity of data collected?

In addition to this, John Gallacher joined the Conference as a keynote speaker during the plenary session "PL1 Dementia as a policy priority". His presentation was entitled "Real world data supporting regulatory and health technology assessments: the findings of the ROADMAP project". WP7 developed a Conference brochure that was added to all attendee bags (850) in support of the sessions.

3.3. Involvement of and engagement with the dementia community

AE featured ROADMAP and its results in its e-mail newsletter, its website (over 25 articles) and in 2 issues of the Dementia in Europe magazine. It also involved national patient groups/Alzheimer associations to engage with the dementia community to further communicate and disseminate project results at a national level. ROADMAP partners were also invited to and gave presentations at AEs Alzheimer Association Academy, which took place on 6 December 2017. Participants included 24 representatives from AE member organisations and 4 company representatives.

ROADMAP mainly involved people with dementia and carers in two ways. There was direct involvement through Public Patient Involvement (PPI) as part of the work of WP8 (Ethical, Legal and Social Implications (ELSI)) Task 8.3 and WP2s "Outcome Definition" Task 2.3 that involved both consultations and stakeholder surveys.

AE (in interaction with WP7, jointly with WP2) prepared, organised and carried out a consultation with AEs EWGPWD and a parallel consultation with their companions (as carers) to enable the development of a set of consensus outcomes and AD progression criteria, in which the work of WP2 was discussed in the context of ROADMAP (see Appendix I Patient and public involvement consultations of the COMBINED REPORT D2.3 Stakeholder generated lists of priority RWE relevant outcomes and D2.4 Disease progression and outcomes classification matrix). Furthermore, the participants also gave feedback on a survey for people with dementia. In addition, AE supported the

WP2 survey outreach through its newsletter, website and the involvement of national patient groups/Alzheimer associations who also engaged with the dementia community.

In order to discuss ELSI issues arising in a RWE approach, AE co-organised a consultation with the EWGPWD for WP8 (Ethical, Legal and Social Implication - ELSI) in December 2017. The consultation explored their concerns and expectations about the re-use and combination of health data to create a RWE platform for AD research.

Furthermore, AE facilitated the involvement of advocacy representatives who were individually interviewed as part of Task 2.3. In addition to this, AE also facilitated the participation of a representative from the EWGPWD in the first EXAG face-to-face meeting.

3.4. Facilitation of communication outreach

WP1 and WP7 collaborated closely in cooperation with the SDSG to effectively collect, organise and distribute information on partners' progress, publication plans, planned presentations, ROADMAP surveys as well as the dissemination of results.

The teams ensured the most inclusive reporting of progress in a bilateral way. The communication contacts identified (D7.2 section 3.1 Channels and Multipliers) were contacted before each internal bulletin via email. This email included both updates about ROADMAP and encouraged communication contacts to leverage from the information and articles provided and requested project updates per partner.

Furthermore, the project's communication channels were used in support of the data collection for English language online surveys (professionals, carers and people with dementia) conducted as part of WP2. This resulted in 294 direct clicks towards the survey (opens) through WP7 outreach support in ROADMAP channels such as social media, the project website and Consortium partner newsletters. WP7 reached out to communication contacts and specifically asked to retweet the announcement as well as motivated them to use an attached article announcement in their website/blog. Overall, the survey was opened 425 times due to the additional support of other IMI projects and institutions - 175 of the responses were included in the final analysis.

3.5. Big Data for Better Outcomes collaboration

Big Data for Better Outcomes is a comprehensive European research programme aiming to develop key enablers to support health care system transformation through the use of big data. BD4BO currently comprises of four disease-specific projects (DSP) so far. ROADMAP (Alzheimer's Disease), HARMONY (Hematologic Malignancies), BigData@Heart (Cardiovascular) and PIONEER (Prostate Cancer).

The programme also has a Coordination and Support Action "DO->IT", supporting the work of BD4DO since February 2017. DO->IT is the overall coordinator of the BD4BO activities within IMI and aims to establish the mechanisms for a sustainable focus on outcomes based healthcare delivery.

In May 2017, monthly calls between the leads of the communication WPs of the DSPs as well as the communication team of DO->IT, have been set up. The objective of the calls was to update one another on communications efforts, to understand what the other projects are doing as well as to align

communication/ dissemination work where possible. Furthermore, DO->IT opened its communication WP face-to-face meetings to the representatives of the DSP communication teams.

ROADMAP provided the 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 communicating about 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 and updates of the 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 an introduction ROADMAP and a link towards the ROADMAP website. Since the communication team of DO->IT is also part of the communication contact mailing list, they also receive updates on recently published ROADMAP articles and events, which are featured and backlinked on the BD4BO website's news section. Furthermore, public Deliverables and publications are also listed and available for download in the "publications" section.

Apart from the website, BD4BO also has a social media account on Twitter. WP7 supported this channel through feedback on the social media strategy, tweets (including tweet suggestions) as well as its outreach by re-tweeting relevant messages.

In addition, BD4BO has developed a newsletter (Issue 1, Issue 2 & Issue 3). It aims to raise awareness in all BD4BO group partners (Consortium partners and advisors in the existing BD4BO projects) as well as the wider public 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.

BD4BO also organised a symposium "In data we trust: towards outcomes-based healthcare in Europe", held on 11 October 2018 in Brussels. It brought together key stakeholders of the BD4BO project and beyond who discussed how they can realise the potential of Big Data together and what role each of them could play.

ROADMAP supports the BD4BO initiatives visibility not only on social media, but also in a static way on its website. It is included in the projects background information, backlinked on the links section and meetings. Furthermore, project activities (such as BD4BO webinar invitations and videos, updates on joint meetings as well as project outputs) are featured in articles on the ROADMAP website. AE also covers the involvement through articles in its newsletter and website.

The development of a video to introduce the BD4BO programme, with outreach support through ROADMAP channels (feature on website, social media, external newsletter and inclusion in the internal bulletin) was another activity WP7 was involved in that also supported ROADMAPs visibility.

3.6. Collaboration with other IMI projects

ROADMAP also collaborated with various IMI projects such as EPAD and its sister project AMYPAD through AEs engagement in both projects. Through a dyadic communication using social media, a support in communication efforts and visibility was guaranteed. Further synergies and support have been achieved through AEs involvement in AETIONOMY and MOPEAD as well as other IMI projects.

Through the connection of BD4BO, WP7 liaised with PIONEER, BIGDATA@HEART and HARMONY communication teams to support each other in communication efforts with a focus on social media.

Achievements and announcements of the GetReal project, which were related to RWE, have also been supported through ROADMAPs 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 participated in joined sessions for example at the EMIF-AD annual General Assembly, the final EMIF symposium and DO->IT General Assembly Meetings. This ensured that partnering projects have knowledge about project progression 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.

During the presentation of WP7 progress at the 5th General Assembly Meeting, WP7 also gave ROADMAP partners a benchmark comparison of website performance between HARMONY, BigaData@Heart and ROADMAP in order to provide them with insights on how well communication efforts are going.

3.7. General communication

Furthermore, the project was communicated on other occasions covering a wide audience:

- Over 40 participations in scientific meetings.
- More than 25 representations in newsletters.
- 41 articles on websites of various ROADMAP partners and mentions, without taking articles on the ROADMAP website into account.
- One article with Project Manager and Project Leader interviews in AEs Dementia in Europe Magazine as well as one interview about the involvement of the Vice-Chair of the EWGPWD and his wife in the PPI activities of WP2.

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 AEs 40 member associations from 35 countries, 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 Annex I below.

ANNEXES

ANNEX I. ROADMAP dissemination tracker

Title	Type of activity	Status	Description	Date	Type of audience reached	Estimated number of persons reached	Reference (e.g. website)
New EU project	Website for general public	Published	News item on ROADMAP launch and link to media release (also tweeted from @dceAarhus)	16/11/2016	General Public		http://www.kea.au.dk/news/englishnew
Real world outcomes across the Alzheimer's Disease spectrum for better care: Multi-modal data access platform (ROADMAP)	Website for general public	Published	News item at UOXF's website	16/11/2016	General Public		https://www.oii.ox.ac.uk/research/proje
Current projects: ROADMAP (2016-2018)	Website for general public	Published	News item at Alzheimer Europe's website	16/11/2016	Dementia community		http://www.alzheimer-europe.org/Al
ROADMAP project paves way for sustainable platform for generation and analysis of real world evidence in AD	External newsletter	Published	News item in AE's newsletter	16/11/2016	Dementia community	7500	http://www.alzheimer-europe.org/c
Pathways of care in dementia	Oral presentation at scientific meeting	Presented	Discussion on pathways of care and the potential of dementia data from registries in the Netherlands. PROSPOR working	18/11/2016	Scientific Community (higher education,	15	-
MEB joins European partnership on research into Alzheimer's disease	Website for general public	Published	News item at CBG/MEB website	29/11/2016	Scientific Community (higher education,	-	https://english.cbg-meb.nl/latest
Drawing the Alzheimer's ROADMAP	Website for general public	Published	Article at lillypad blog	05/12/2016	General Public	-	http://lillypad.eu/entry.php?e=3006
NICE takes key role in new European project for faster access to Alzheimer's disease drugs	Website for general public	Published	News item at NICE's website	06/01/2017	General Public	-	https://www.nice.org.uk/news/article/ni
Real World Evidence for Alzheimer's Disease Outcomes	Oral presentation at scientific meeting	Presented	Abstract submitted to the AAIC 2017 conference (16-20 July 2017), Topic Health and Psychosocial theme, Health	29/01/2017	Scientific Community (higher education,	5700	
Roadmap: EMIF contribution	Participation in activities organised jointly with other	Presented	Jointed session at EMIF-AD annual general assembly meeting	24/02/2017	Scientific Community (higher education,	50	
ROADMAP project holds 2nd General Assembly in Barcelona, launches website	Website for general public	Published	News item at Alzheimer Europe's website	03/03/2017	Dementia community	-	http://www.alzheimer-europe.org/N

ROADMAP project holds 2nd General Assembly in Barcelona, launches website	External newsletter	Published	News item in AE's newsletter	24/03/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
Big Data for Better Outcomes: Supporting Health Care System Transformation in Europe	Article in journal	Published	Article written in collaboration with DO->IT partners for EuroHealth	28/03/2017	Scientific Community (higher education,		
ROADMAP (Real world outcomes across the Alzheimer's disease spectrum for better care: multi-modal data access platform)	Non-scientific and non-peer reviewed publications	Published	Interview in Alzheimer Europe's Dementia in Europe Magazine	04/04/2017	Policy makers	2600 issues printed	https://roadmap-alzheimer.org
Cost-utility of CSF biomarkers for AD	Oral presentation at scientific meeting	Presented	Results of a health-economic model for CSF biomarkers and discussion on methodology and assumptions for model	21/04/2017	Scientific Community (higher education,	30	-
ROADMAP project to hold a panel session at HTAi 2017	Website for general public	Published	News item at Alzheimer Europe's website	24/04/2017	Dementia community		http://www.alzheimer-europe.org/N
ROADMAP project to hold a panel session at HTAi 2017	External newsletter	Published	News item in AE's newsletter	24/04/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
Second external newsletter	External newsletter	Published	ROADMAP external newsletter July 2017	07/05/2017	Scientific Community (higher education,	370	http://eepurl.com/cU6BIn
ROADMAP project Work Package 3 submits its first deliverable to IMI	External newsletter	Published	News item in AE's newsletter	15/05/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
Overcoming ethical issues in sharing real world evidence in Alzheimer's disease: The ROADMAP Project	Poster presentation at a scientific meeting	Presented	Poster submitted to the Neuroethics Network 2017 (19-21 June 2017)	06/06/2017	Scientific Community (higher education,	60	http://www.icmbioethics.com/assets/20
Challenges in Optimising Real World Evidence for Alzheimer's Disease	Poster presentation at a scientific meeting	Presented	Abstract submitted to the Clinical Trials in AD (2-4 Nov, Boston), Topic Challenges in Optimising Real World Evidence for	08/06/2017	Scientific Community (higher education,		http://www.ctad-alzheimer.co
BrainAmyloid Pathology and Cognitive Function - Alzheimer Disease Without Dementia?	Article in journal	Published	Editorial published in JAMA	13/06/2017	Scientific Community (higher education,		
News items on 3rd General Assembly and HTAi conference presentation	External newsletter	Published	News item in AE's newsletter	13/06/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
The state of Alzheimer's disease in Europe – innovation, value and challenges for HTA	Oral presentation at scientific meeting	Presented	90 minute panel session at the HTAi conference (Rome, 19-21 June). Five speakers: Martin Knapp, Jean Georges,	19/06/2017	Scientific Community (higher education,	50	

Potential health-economic impact of treating Alzheimer's Disease (AD)	Poster presentation at a scientific meeting	Presented	EBC Value treatment event	22/06/2017	Policy makers	140	
ROADMAP project holds 3rd General Assembly in Barcelona	Website for general public	Published	News item at Alzheimer Europe's website	26/06/2017	Dementia community		http://alzheimer-europe.org/N
Stakeholder views on Alzheimer's disease outcomes and measures of progression. ROADMAP WP2 systematic review protocol	Other	Done	Methodological protocol for undertaking the combined systematic reviews for WP2. [Entry in PROSPERO International	05/07/2017	Scientific Community (higher education,		https://www.crd.york.ac.uk/PROSPERO/d
BD4BO and ROADMAP: a collaborative approach to set new standards for the collation and evaluation of RWE in Alzheimer's Disease	Oral presentation at scientific meeting	Presented	Introduce the BD4BO programme while at the same time speak about ROADMAP, Big data in neurology, Impact on Big Data	31/07/2017	Scientific Community (higher education,	100	https://bigdata.uni.lu/program2/program
ROADMAP update at The Dementia Industry Group	Oral presentation at scientific meeting	Presented	UK Dementia Industry Group update on ROADMAP	17/08/2017	Scientific Community (higher education,		-
The ROADMAP project updates us on recent progress	External newsletter	Published	News item in AE's newsletter	31/08/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
The ROADMAP project updates us on recent progress	Website for general public	Published	News item at Alzheimer Europe's website	31/08/2017	Dementia community	-	http://www.alzheimer-europe.org/N
News items on ROADMAP project consultation with people with dementia and progress update	External newsletter	Published	News item in AE's newsletter	19/09/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
Alzheimer Europe holds ROADMAP project consultation with people with dementia	Website for general public	Published	News item at Alzheimer Europe's website	19/09/2017	Dementia community	-	http://www.alzheimer-europe.org/N
ROADMAP Stakeholder Partnerships: The Importance of regulatory engagement	Website for general public	Published	News item at BD4BO's website	27/09/2017	Investors	-	http://bd4bo.eu/index.php/2017/09/26/
ROADMAP project consultation with people with dementia	Website for general public	Published	News item at BD4BO's website	27/09/2017	Investors	-	http://bd4bo.eu/index.php/2017/09/26/
ROADMAP project progress update	Website for general public	Published	News item at Alzheimer Europe's website	27/09/2017	Dementia community	-	http://www.alzheimer-europe.org/N
Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform	Oral presentation at scientific meeting	Presented	Presentation at the annual meeting of the federation of French memory centres	28/09/2017	Scientific Community (higher education,	-	-

Third external ROADMAP newsletter	External newsletter	Published	ROADMAP external newsletter September 2017	29/09/2017	Scientific Community (higher education,	660	http://eepurl.com/c5jioz
PI John Gallacher introducing the ROADMAP project	Media (TV, radio, press, multimedia)	Published	PI John Gallacher introducing the ROADMAP project	01/10/2017	General Public	52	https://www.youtube.com/watch?v=XZ
Care today, cure tomorrow	Other	Published	Article at lillypad blog	02/10/2017	General Public	-	https://lillypad.eu/entry.php?e=3314
ROADMAP launches public information leaflet	Website for general public	Published	News item at UOXF's website	04/10/2017	General Public	-	https://www.psych.ox.ac.uk/news/road
ROADMAP conference leaflet	Flyers/brochures	Published	ROADMAP leaflets at Alzheimer Europe Conference	04/10/2017	Scientific Community (higher education,	750	_
Engaging with patient organisations within IMI consortia to inform quality, relevance and value in Alzheimer's research – insights from MOPEAD, EPAD	Flyers/brochures	Published	ROADMAP leaflets at Alzheimer Europe Conference	04/10/2017	Scientific Community (higher education,	750	_
ROADMAP launches public information leaflet	Website for general public	Published	News item at UOXF's website	05/10/2017	General Public	-	https://www.medsci.ox.ac.uk/news/roa
What value has being involved in research?	Website for general public	Published	News item at BD4BO's website	05/10/2017	General Public	-	http://bd4bo.eu/index.php/2017/10/05/
ROADMAP project overview	Participation in activities organised jointly with other	Presented	Oral presentation at DO-IT GA	09/10/2017	Scientific Community (higher education,	20	
Engaging with patient organisations within IMI consortia	Other	Published	News item at BD4BO's website	13/10/2017	General Public	-	http://bd4bo.eu/index.php/2017/10/13/
News items on General Assembly Meeting (GAM) and Symposium at AEC	External newsletter	Published	News item in AE's newsletter	16/10/2017	Dementia community	7500	http://www.alzheimer-europe.org/c
ROADMAP holds 4th General Assembly in Barcelona	Other	Published	News item at BD4BO's website	18/10/2017	General Public	-	http://bd4bo.eu/index.php/2017/10/18/
IMI2 Big Data for Better Outcomes (BD4BO) Programme	Oral presentation at scientific meeting	Presented	Oral presentation at IMI Stakeholder Forum	19/10/2017	Scientific Community (higher education,	80	

CP4 - Challenges in Optimising Real World Evidence for Alzheimer's Disease	Publication in conference proceeding	Published	Abstract as part of Value in Health	20/10/2017	Scientific Community (higher education,		-
ROADMAP NEWS	External newsletter	Published	News items in BD4BO Internal Newsletter	26/10/2017	Other	557	
ROADMAP holds 4th General Assembly Meeting (GAM)	Other	Published	News item at Alzheimer Europe's website	31/10/2017	Dementia community	-	http://www.alzheimer-europe.org/N
MOPEAD, EPAD and ROADMAP projects attend the Alzheimer Europe Conference	Other	Published	News item at Alzheimer Europe's website	31/10/2017	Dementia community	-	http://www.alzheimer-europe.org/N
16-17th October, ROADMAP project holds 4th General Assembly in Barcelona 2017	Other	Published	Article in MEB's Regulatory Science Magazine	01/11/2017	Other	-	https://www.regulatoryscience.nl/editio
A model for Alzheimer's disease in the prevention setting	Poster presentation at a scientific meeting	Presented	Poster presentation at the ISPOR Annual European Congress, 2017, Glasgow, Scotland	04/11/2017	Scientific Community (higher education,	5000	https://www.ispor.org/ScientificPresenta
ROADMAP leaflet	Flyers/brochures	Published	Distributed in Maastricht	13/11/2017	Scientific Community (higher education,	50	-
First ROADMAP face to face Advisory Group meeting	Website for general public	Published	News item at Alzheimer Europe's website	19/11/2017	Dementia community	-	http://www.alzheimer-europe.org/N
Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform	Oral presentation at scientific meeting	Presented	Oral presentation at Alzheimer Europe's Alzheimer Association Academy	06/12/2017	Dementia community	50	-
The use of real-world data and evidence in regulatory and health technology assessments	Oral presentation at scientific meeting	Presented	Oral presentation at Alzheimer Europe's Alzheimer Association Academy	06/12/2017	Dementia community	50	-
Ethical issues raised by big data and real world evidence projects	Oral presentation at scientific meeting	Presented	Oral presentation at Alzheimer Europe's Alzheimer Association Academy	06/12/2017	Dementia community	50	-
ROADMAP Christin Bexelius at General Assembly Meeting	Media (TV, radio, press, multimedia)	Published	Introduction by Work Package co-lead (Outcome Definition team) Christin Bexelius.	01/01/2018	General Public	45	https://www.youtube.com/watch?v=SGI
ROADMAP reports on recent progress, submits two deliverables	Website for general public	Published	News item at Alzheimer Europe's website	02/01/2018	Dementia community	-	http://www.alzheimer-europe.org/N

News item on ROADMAP report on recent progress, two deliverables	External newsletter	Published	News item in AE's newsletter	02/01/2018	Dementia community	7500	http://www.alzheimer-europe.org/c
First ROADMAP face to face Advisory Group meeting	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/10/19/
ROADMAP participates in cross-IMI Disease Modelling Workshop	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/10/19/
Meet Roadmap at Alzheimer's Association Academy	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/11/20/
BD4BO meets with sister projects ROADMAP, HARMONY and BigData@Heart in London	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/11/21/
ROADMAP: Communication team reaches milestone	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/11/29/
ROADMAP updates Alzheimer Associations at Alzheimer Europe Academy	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/12/06/
ROADMAP consultation with the European Working Group of People with Dementia	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2017/12/07/
ROADMAP progress report	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2018/01/02/
ROADMAP: Review of past regulatory and health technology assessments of Alzheimer's disease medicines	Other	Published	News item at BD4BO's website	09/01/2018	General Public	-	http://bd4bo.eu/index.php/2018/01/03/
A long standing commitment to R&D	Other	Published	News item at LillyPad blog	09/01/2018	General Public	-	https://lillypad.eu/entry.php?e=3441
Interview with Johan van der Lei from Erasmus University	Other	Published	News item at BD4BO's website	10/01/2018	General Public	-	http://bd4bo.eu/index.php/2018/01/10/
Fourth external ROADMAP newsletter	External newsletter	Published	ROADMAP external newsletter January 2018	11/01/2018	Scientific Community (higher education,	600	http://eepurl.com/dg5e0T

innovative medicines initiative

Resource utilisation and costs in predementia and dementia: a systematic review protocol	Article in journal	Published	WP5 protocol on SLR	15/01/2018	Scientific Community (higher education,		-
ROADMAP leaflet	Flyers/brochures	Published	Distributed at WP3 BD4BO meeting in Brussels	16/01/2018	Scientific Community (higher education,	20	-
BD4BO meets with sister projects ROADMAP, HARMONY and BigData@Heart to discuss communications and outreach activities	Other	Published	News item at Alzheimer Europe's website	16/01/2018	Dementia community	-	http://www.alzheimer-europe.org/N
Several Innovative Medicines Initiative (IMI) projects join forces during cross-Disease Modelling Workshop in Edinburgh	Other	Published	News item at Alzheimer Europe's website	19/01/2018	Dementia community	-	http://www.alzheimer-europe.org/N
PREDICTIVE MODELLING FOR SECONDARY PREVENTION OF ALZHEIMER'S DISEASE: ETHICAL CONCERNS AND	Poster presentation at a scientific meeting	Presented	Z. Angehrn et al., International Society For Pharmacoeconomics and Outcomes Research (ISPOR) 23rd Annual	23/01/2018	Scientific Community (higher education,		-
Real World Outcomes across the Alzheimer's Disease spectrum for better care: Multi-modal data Access Platform	Poster presentation at a scientific meeting	Presented	Poster presentation at Maastricht University Symposium: The Future of a Data-Driven Society	25/01/2018	Scientific Community (higher education,	100	https://www.maastrichtuniversity.nl/eve
Real world Outcomes across the AD spectrum for better care: Multi-modal data Access Platform	Oral presentation at scientific meeting	Presented	OECD regulatory presentation - meeting at OECD about all the IMI Alzheimer's projects contribution to this field	29/01/2018	Other		-
Overview of ROADMAP outreach and engagement with stakeholders	Participation in activities organised jointly with other	Presented	P. Jonsson, A Gustavsson, Overview of ROADMAP outreach and engagement with stakeholders at BD4BO group	29/01/2018	Scientific Community (higher education,		-
ROADMAP launches survey to identify important outcomes in dementia	Website for general public	Published	News item at Alzheimer Europe's website	29/01/2018	Dementia community	-	http://www.alzheimer-europe.org/N
ROADMAP launches survey to identify important outcomes in dementia	Other	Published	News item at AE's website	29/01/2018	Dementia community	-	http://www.alzheimer-europe.org/N
News items in AE newsletter: ROADMAP launches survey to identify important outcomes in dementia, communication team meets with BD4BO	External newsletter	Published	News items in AE's newsletter	31/01/2018	Dementia community	7500	http://www.alzheimer-europe.org/c
Invitation to participate in the ROADMAP survey	Other	Published	Invitation WP2 ROADMAP survey on in news section of british neuroscience association	31/01/2018	Dementia community	-	https://www.bna.org.uk/mediacentre/n
Enquesta ROADMAP	External newsletter	Published	News item in IDIAP's newsletter	31/01/2018	Civil Society	623	http://www.idiapjgol.cat/index.php/ca/

Enquesta ROADMAP	Website for general public	Published	News item at IDIAP's website	31/01/2018	General Public	-	http://www.idiapjgol.cat/index.php/ca/
A systematic literature review of methodologies and data sources of existing health economic models across the Alzheimer's Disease spectrum from	Other	Published	PROSPERO entry on SLR (BMJ protocol 172, article 177)	02/02/2018	Scientific Community (higher education,		https://www.crd.york.ac.uk/prospero/dis
Resource utilisation and costs in predementia and dementia: a systematic review protocol	Other	Published	News item at BD4BO's website	02/02/2018	General Public	-	http://bd4bo.eu/index.php/2018/02/02/
Predictive modelling for preventive approaches to Alzheimer's Disease: ethical concerns and social implications	Other	In preparation	WP2 protocol on SLR	02/02/2018	Scientific Community (higher education,	-	https://www.crd.york.ac.uk/PROSPERO/d
ROADMAP project updates on recent and ongoing activities	Other	Published	News item at AE's website	08/02/2018	Dementia community	-	http://www.alzheimer-europe.org/N
Modelling the economic value of Alzheimer's Disease interventions: How far have we come, and what next	Organisation of a Conference/ workshop	Presented	WP5 workshop in Paris on 14th February prior to IPECAD	14/02/2018	Scientific Community (higher education,		-
Swedish registry data (Svedem, Gothenburg biomarker registry)	Oral presentation at scientific meeting	Presented	R. Handels, International Pharmaco-Economic Conference on Alzheimer's Disease (IPECAD), 15-16 February 2018,	15/02/2018	Scientific Community (higher education,	100	http://www.trippus.se/web/presentatio
Real-world evidence in Alzheimer's disease: the ROADMAP collaboration	Oral presentation at scientific meeting	Presented	P. J. Visser, International Pharmaco-Economic Conference on Alzheimer's Disease (IPECAD), 15-16 February 2018,	15/02/2018	Scientific Community (higher education,	100	http://www.trippus.se/web/presentatio
The ROADMAP project – an EU consortium to improve care in Alzheimer's disease	External newsletter	Published	Article in HERC newsletter	15/02/2018	Scientific Community (higher education,	3600	https://www.herc.ox.ac.uk/about/herc-
BD4BO meets with sister projects ROADMAP, HARMONY and BigData@Heart to discuss	Other	Published	News item at AE's website	16/02/2018	Dementia community	-	http://www.alzheimer-europe.org/N
Invitation to participate in the ROADMAP survey	Other	Published	Invitation WP2 ROADMAP survey on alzheimer forum	16/02/2018	Dementia community	-	https://forum.alzheimers.org.uk/threads
Invitation to participate in the ROADMAP survey	Other	Published	Invitation WP2 ROADMAP survey on website of british college of psychiatry and external newsletter	16/02/2018	Scientific Community (higher education,	-	http://www.rcpsych.ac.uk/workinpsychi
Disease Modeling in AD-ROADMAP Learnings	Participation in activities organised jointly with other	Presented	M. Potashman, EPAD fellow webinar, Review on disease progression models in AD.	20/02/2018	Scientific Community (higher education,	22	-

Involving people with dementia in European research projects	Non-scientific and non-peer reviewed publications	Published	Article in Alzheimer Europe's Dementia in Europe Magazine	20/02/2018	Policy makers	2500 issues printed	https://synapsemanagers.sharepoint.co
ROADMAP NEWS	External newsletter	Published	News items in BD4BO Internal Newsletter Issue 2	22/02/2018	Civil Society	705	
Invitation to participate in the ROADMAP survey	Other	Published	Invitation WP2 ROADMAP survey on BD4BO website and newsletter	22/02/2018	Civil Society	-	http://bd4bo.eu/index.php/2018/01/29/
ROADMAP project updates on recent and ongoing activities	External newsletter	Published	News items in AE's newsletter	26/02/2018	Dementia community	7500	http://www.alzheimer-europe.org/c
February news items: resource use publication, recent updates, modelling workshop	Other	Published	3 news items at BD4BO's website (February)	28/02/2018	General Public	-	http://bd4bo.eu/index.php/2018/02/02/
ROADMAP extends survey to identify important outcomes in dementia until 5 March EOB	Other	Published	News item at AE's website	01/03/2018	Dementia community	-	http://www.alzheimer-europe.org/N
IMI-ROADMAP	Oral presentation at scientific meeting	Presented	ROADMAP project presentation in the framework of the XIth Annual Conference of Technological Platform in Biomedical	05/03/2018	Scientific Community (higher education,	100	https://www.medicamentos-
Carlos Díaz presented the ROADMAP project at the XI Annual Conference of Biomedical Research Technology Platforms in Barcelona	Other	Published	News item at SYNAPSE's website	06/03/2018	General Public	-	https://synapse-managers.co
Brain Awareness Week, 12th – 18th March	Website for general public	Published	News item at SYNAPSE's website	15/03/2018	General Public	-	https://synapse-managers.co
The ROADMAP project – towards patient access to treatments	Other	Published	World Dementia Council Annual Review 2016-2017 document -	19/03/2018	General Public		https://worlddementiacouncil.org/sites/
ROADMAP outcomes definition team meets for data synthesis meeting and publishes deliverable on systematic literature review	Other	Published	News item at AE's website	22/03/2018	Dementia community	-	http://www.alzheimer-europe.org/N
L'IDIAPJGol amb ROADMAP a Amsterdam	External newsletter	Published	News item in IDIAP's newsletter	28/03/2018	Civil Society	623	http://www.idiapjgol.cat/index.php/ca/
L'IDIAPJGol amb ROADMAP a Amsterdam	Other	Published	News item at IDIAP's website	28/03/2018	General Public	-	http://www.idiapjgol.cat/index.php/ca/

ROADMAP outcomes definition team meets for data synthesis meeting and publishes deliverable on systematic literature review	External newsletter	Published	News items in AE's newsletter	29/03/2018	Dementia community	7700	http://alzheimereurope.newsweaver.c
Measuring quality of life of dementia patients and their caregivers: a systematic literature review	Article in journal	Published	WP5 protocol on SLR	30/03/2018	Scientific Community (higher education,		-
Health Economics team of the ROADMAP project publishes two protocols on systematic literature reviews on economic models in Alzheimer's disease	Website for general public	Published	News item at Alzheimer Europe's website	05/04/2018	Dementia community	-	http://alzheimer-europe.org/N
The ROADMAP consortium publishes its second article – a systematic review protoc	Other	Published	News item at SYNAPSE's website	05/04/2018	General Public	-	https://synapse-managers.co
Real world evidence for investigating AD outcomes: utilising platform resources	Participation in activities organised jointly with other	Presented	ROADMAP presentation at EMIF symposium	18/04/2018	Scientific Community (higher education,	110	http://www.emif.eu/assets/e/m/emif_p
Exhibition stand at DPUK conference	Other	Done	WP7 will cover an exhibition stand during DPUK's Annual Conference entitled "Using the power of cohorts" exhibiting the	23/04/2018	Scientific Community (higher education,	200	https://www.dementiasplatform.uk/upc
ROADMAP Newsletter April 2018	External newsletter	Published	ROADMAP external newsletter April 2018	24/04/2018	Scientific Community (higher education,	525	https://us15.campaign-archive.com/
Challenges for Optimizing Real-World Evidence in Alzheimer's Disease: the ROADMAP Project	Article in journal	Submitted	ROADMAP manuscript submitted to the Journal of Alzheimer's Disease	25/04/2018	Scientific Community (higher education,	-	-
L'Institut Universitari de Recerca en Atenció Primària Jordi Gol (IDIAPJGol) participa en el projecte europeu ROADMAP (Real world Outcomes across the AD	Press release	Published	Press release	26/04/2018	General Public		http://ics.gencat.cat/ca/detall/noticia/ID
EL IDIAPJGOL PARTICIPA EN UN GRAN ESTUDIO SOBRE LA ENFERMEDAD DE ALZHEIMER PARA UNIFICAR BASES DE DATOS EUROPEAS	Press release	Published	Press release	26/04/2018	General Public		http://www.news3edad.com/2018/04/2
ROADMAP project holds 5th General Assembly Meeting in Barcelona	Website for general public	Published	News item at Alzheimer Europe's website	26/04/2018	Dementia community	-	http://www.alzheimer-europe.org/N
Generando nuevos datos sobre la enfermedad de Alzheimer: IDIAP Jordi Gol y ROADMAP	Website for general public	Published	News item at IDIAP's website	26/04/2018	General Public	-	http://idiapjgol.org/index.php/en/news-
Investigadors de l'IDIAPJGol participen en el 5th General Assembly Meeting del Projecte ROADMAP	External newsletter	Published	News item in IDIAP's newsletter	30/04/2018	Civil Society	623	http://www.idiapjgol.org/index.php/ca/

Investigadors de l'IDIAPJGol participen en el 5th General Assembly Meeting del Projecte ROADMAP	Website for general public	Published	News item at IDIAP's website	30/04/2018	General Public	-	http://www.idiapjgol.org/index.php/ca/
Synapse gathers the ROADMAP consortium partners for the 5th General Assembly Meeting	Other	Published	News item at SYNAPSE's website	30/04/2018	General Public	-	https://synapse-managers.co
Health Economics team of the ROADMAP project publishes two protocols on systematic literature reviews on economic models in Alzheimer's disease	External newsletter	Published	News item in AE's newsletter	30/04/2018	Dementia community	7700	http://www.alzheimer-europe.org/c
ROADMAP Alastair Gray at General Assembly Meeting	Media (TV, radio, press, multimedia)	Published	Introduction by Work Package co-lead (Health Economics team) Alastair Gray.	02/05/2018	General Public		https://vimeo.com/266877943
ROADMAP Carlos Diaz at General Assembly Meeting	Media (TV, radio, press, multimedia)	Published	Recapitulation of GAM by John Gallacher.	02/05/2018	General Public		https://vimeo.com/266879310
ROADMAP John Gallacher at General Assembly Meeting	Media (TV, radio, press, multimedia)	Published	Introduction by Work Package co-lead (Management team) Carlos Diaz.	02/05/2018	General Public		https://vimeo.com/266879624
Female caregivers' perspectives on the most important outcomes of Alzheimer's disease /dementia	Oral presentation at scientific meeting	Presented	Abstract to ADI Conference	08/05/2018	Scientific Community (Higher		https://www.adi2018.org/sessions/wom
Real-World Evidence for Regulation and Health Technology Assessment of Pharmaceuticals: current use and where do we go next?	Oral presentation at scientific meeting	Presented	Utrecht University will be holding an international symposium on the use of real-world evidence (RWE) in drug	09/05/2018	Scientific Community (higher education,		https://roadmap-alzheimer.org
Incorporating a range of different stakeholder perspectives when identifying and selecting outcomes for Alzheimer's disease Experience from	Participation in activities organised jointly with other	Presented	WP2 presentation DO-IT webinar	15/05/2018	Scientific Community (higher education,	-	http://bd4bo.eu/wp-content/uplo
Workshop on economic modelling in Alzheimer's disease	External newsletter	Published	Article in HERC newsletter	17/05/2018	Scientific Community (higher education,	3600	https://www.herc.ox.ac.uk/news/herc-
Using RWD to Replace Missing Data for Regulatory Submissions	Oral presentation at scientific meeting	Presented	Presentation at ISPOR special interest group: statistical methods in HEOR at ISPOR 2018	21/05/2018	Scientific Community (higher education,		https://www.ispor.org/docs/default-
Complex diseases get the big data treatment	Website for general public	Published	Article in Horizon Magazine - The EU Research and Innovation Magazine	23/05/2018	Scientific Community (higher education,		https://horizon-magazine.eu/
EMIF newsletter	External newsletter	Published	Mention of participation in EMIF symposium	28/05/2018	Scientific Community (higher education,	326	http://www.emif.eu/newsletter-may18

Title	Type	Status	Description	Date	Audience	Reach	Link
The value of being involved in research —Real world Outcomes across the Alzheimers Disease spectrum for better care (ROADMAP)	External newsletter	Published	Interview with Chris Roberts on EWGPWD consultation for WP2 in Dementia Family Support Service Newsletter	30/05/2018	Dementia community		http://www.voluntarycentreservices.org.
News items in BD4BO newsletter	External newsletter	Published	News items in BD4BO's newsletter	31/05/2018	General Public	700	https://mailchi.mp/9f6da8c38ea3/bd4b
News item in AE newsletter: ROADMAP GAM	External newsletter	Published	News item in AE's newsletter	01/06/2018	Dementia community	7700	alzheimereurope.newsweaver.com/New
Protocol on SLR on the ethics of secondary AD prevention using predictive modelling	Article in journal	Submitted		01/06/2018	Scientific Community (higher education,		-
Trust, Protection and Engagement: The views of the European Working Group of People with Dementia on the sharing and re-use of health data	Article in journal	Submitted	Submission to: Sociology of Health and Illness	01/06/2018	Scientific Community (higher education,		-
Regulatory and HTA considerations in Alzheimer's disease	Oral presentation at scientific meeting	Presented	EXAG discussions in year one of the project at HTAi Vancouver (Canada), 1-5 June 2018	05/06/2018	Scientific Community (higher education,	-	https://www.htai.org/meetings/annual-
11th Research Day of the IDIAPJGol and the 10th Research Day of Catalan Health Institute (ICS) organizing by IDIAPJGol	Oral presentation at scientific meeting	Presented	Anna Ponjoan, researcher of the IDIAPJGol involved in the ROADMAP project will participate in one of the	07/06/2018	Scientific Community (higher education,	1000	http://www.idiapjgol.cat/index.php/ca/j
Systematic literature review of methodologies and data sources of existing economic models across the full	Article in journal	Published	Protocol on SLR for BMJ open	08/06/2018	Scientific Community (higher education,		-
Health Economics team of ROADMAP project publishes third review protocol on economic models across the spectrum of AD and dementia	Website for general public	Published	News item at Alzheimer Europe's website	12/06/2018	Dementia community		https://www.alzheimer-europe.org/N
ROADMAP participates in "Women and Dementia" session at Alzheimer's Disease International Conference	Website for general public	Published	News item at Alzheimer Europe's website	12/06/2018	Dementia community		https://www.alzheimer-europe.org/N
The ROADMAP project updates on recent progress and publishes a new scientific article	Website for general public	Published	Article on AE website	25/06/2018	Dementia community		https://www.alzheimer-europe.org/N
Articles on progress and publication in AE newsletter	External newsletter	Published	News items in AE's newsletter	02/07/2018	Dementia community	7700	https://www.alzheimer-europe.org/c
Sixth external newsletter	External newsletter	Published	ROADMAP external newsletter July 2018	09/07/2018	Scientific Community (higher education,	620	https://roadmap-alzheimer.org

Facilitating research with DPUK: ROADMAP and EPAD	Video/film	Published	Interview with Sarah Baumeister on DPUK involvement in EPAD and ROADMAP	13/07/2018	General Public		https://www.youtube.com/watch?v=uE
Neuroethics in Dementia Prevention and Treatment: Ethical Issues Arising from the ROADMAP Project	Oral presentation at scientific meeting	Presented	Oral presentation: "Neuroethics in dementia prevention". A. McKeown, 32nd European Conference on philosophy of	24/08/2018	Scientific Community (higher education,		http://www.espmh.org/
Articles on presentation at ADI in AE newsletter	External newsletter	Published	News item in AE's newsletter	03/09/2018	Dementia community	7700	https://www.alzheimer-europe.org/c
News items in BD4BO newsletter	External newsletter	Published	News items in BD4BO's September 2018 newsletter	06/09/2018	General Public		https://us15.campaign-archive.com/
Epidemiology of dementia: prevalence and incidence estimates using validated electronic health records from primary care.	Article in journal	Submitted	manuscript submitted to Clinical Epidemiology, which contributes to WP3.	13/09/2018	Scientific Community (higher education,		-
External and internal communication - Learnings from the ROADMAP propject	Oral presentation at scientific meeting	Presented	Oral presentation at MOPEAD General Assembly meeting on communication activities within ROADMAP	13/09/2018	Scientific Community (higher education,	25	-
ROADMAP leaflet	Flyers/brochures	Done	Participants of the MOPEAD General Assembly meeting received ROADMAP conference leaflets	13/09/2018	Scientific Community (higher education,	25	-
Projecte per unificar les bases de dades europees de l'Alzheimer	Website for general public	Published	News article on ROADMAP in local press - Diari de Girona	21/09/2018	General Public		https://www.diaridegirona.cat/comarqu
What outcomes are important to patients with Mild Cognitive Impairment or Alzheimer's disease, their caregivers and healthcare professionals? A	Article in journal	Submitted	Academic paper describing the findings of the combined systematic reviews for WP2	04/10/2018	Scientific Community (higher education,		
Seventh external ROADMAP newsletter	External newsletter	Published	ROADMAP external newsletter October 2018	08/10/2018	Scientific Community (higher education,	580	http://eepurl.com/dDhH8H
IMI-2 ROADMAP initiative moves into end of Phase 1 as it holds General Assembly Meeting in Madrid	Website for general public	Published	News item at Alzheimer Europe's website	09/10/2018	Dementia community		https://www.alzheimer-europe.org/N
ReDeGi/SIDIAP validation study	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-
Use Case BESIDE Project	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-

Use Case Estimation duration of AD stages	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-
Publication based on combination of findings from D3.3, D3.4 & D3.6	Article in journal	In preparation	Written combination of; Update on potential data sources with RWE data in Eurpe - D3.3	16/10/2018	Scientific Community (higher education,		-
Comparison of temporal dementia trajectories across Europe (D4.5?)	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-
Stratifying unspecified dementia patients based on disease trajectories (D4.5?)	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-
Philips checklist	Article in journal	In preparation		16/10/2018	Scientific Community (higher education,		-
Alignment of European regulatory and health technology assessments: a review of licensed product's for Alzheimer's disease	Article in journal	In preparation	Based on D6.2 currently under ExCom review	16/10/2018	Scientific Community (higher education,		-
Real world data supporting regulatory and health technology assessments: the findings of the ROADMAP project	Oral presentation at scientific meeting	Accepted	Plenary talk at Alzheimer Europe Conference	30/10/2018	Scientific Community (higher education,		https://www.alzheimer-europe.org/C
Regulatory and HTA perspectives on real-world data in Alzheimer's disease: future prospective collection and further research	Oral presentation at scientific meeting	Accepted	WP6 session at Alzheimer Europe Conference	31/10/2018	Scientific Community (higher education,		https://www.alzheimer-europe.org/C
Real-world data availability across Europe: what data are present, missing and heterogenity of data collected	Oral presentation at scientific meeting	Accepted	Data cube session at Alzheimer Europe Conference	31/10/2018	Scientific Community (higher education,		https://www.alzheimer-europe.org/C
What matters to whom as AD progresses? Relevant outcomes in disease progression	Oral presentation at scientific meeting	Accepted	WP2 session at Alzheimer Europe Conference	31/10/2018	Scientific Community (higher education,		https://www.alzheimer-europe.org/C
Ethics challenges for AD research and practice using real-world data	Oral presentation at scientific meeting	Accepted	WP8 session at Alzheimer Europe Conference	31/10/2018	Scientific Community (higher education,		https://www.alzheimer-europe.org/C
BD4BO meets with sister projects ROADMAP, HARMONY and BigData@Heart to discuss communications and outreach activities in London	Other	Published	News item at Alzheimer Europe's website	15/11/2018	Dementia community	-	http://www.alzheimer-europe.org/N
Disease Modeling in AD-ROADMAP Learnings	Media (TV, radio, press, multimedia)	Published	Record of presentation. M. Potashman, EPAD fellow webinar, Review on disease progression models in AD on youtube.	01/03/2018	Social media	108	https://youtu.be/0DPkpJP8w0c

Harnessing Health Technology Assessment (HTA) knowledge and expertise in an innovative, pan-European big data project	Poster presentation at a scientific meeting	Rejected	Abstract to ISPOR Europe 2018	10-14/11/2018	Scientific Community (higher education,		https://www.ispor.org/Event/EventInfor
Neuroethics in dementia prevention: ethical issues in early intervention for better life long brain health – findings from the ROADMAP project	Oral presentation at scientific meeting	Accepted	Oral presentation: "2018 INS Annual Meeting - Cutting Edge Neuroscience, Cutting Edge Neuroethics, 1-2 November, San Diego, CA (USA).	1-2/11/2018	Scientific Community (higher education, Research)		http://www.neuroethicssociety.org/annual-meeting
The value of an Expert Advisory Group: Exploration of barriers and facilitators within the ROADMAP international big data project	Poster presentation at a scientific meeting	Presented	Poster presentation at Guidelines International Network, 12-14 September	12-14/09/2018	Scientific Community (higher education,		-
ROADMAP project Work Package 2 delivers report on priority Real World Evidence for Alzheimer's disease to Innovative Medicines Initiative	Website for general public	Published	News item at Alzheimer Europe's website	15/03/2017	Dementia community	-	http://alzheimer-europe.org/N
ROADMAP project Work Package 3 submits its first deliverable to IMI	Website for general public	Published	News item at Alzheimer Europe's website	15/05/2017	Dementia community	-	http://alzheimer-europe.org/N
23-24 March, ROADMAP project holds 2nd General Assembly in Barcelona 2017	Other	Published	Article in MEB's Regulatory Science Magazine	15/07/2017	Other		https://www.regulatoryscience.nl/editio
Real world outcomes across the Alzheimer's disease spectrum for better care: multi-modal data access platform	Oral presentation at scientific meeting	Presented	Meredith of GE gave a short 2-minute presentation about ROADMAP WP2 and WP2 surveys to the AMYPAD consortium	16/07/2017	Scientific Community (higher education,	20-30	-
ROADMAP project paves way for sustainable platform for generation and analysis of real world evidence in AD	Website for general public	Published	News item at Alzheimer Europe's website	16/11/2016	Dementia community	-	http://www.alzheimer-europe.org/N
New IMI-JU project to pave the way for a sustainable platform for the generation and analysis of real world evidence in Alzheimer's disease	Website for general public	Published	News item at SYNAPSE's website	16/11/2016	General Public	-	http://synapse-managers.co
Public-private European partnership (ROADMAP) paves the way for sustainable platform for the generation and analysis of real world evidence in	Website for general public	Published	Press clipping at University of Groningen's website	16/11/2016	General Public	-	http://www.rug.nl/research/portal/clipp
IXICO to receive €100k funding to provide digital technologies for "real world" study	Website for general public	Published	News item at IXICO's website	16/11/2016	General Public	-	https://ixico.com/ixico-to-receive-

Gerontology Future Day	Oral presentation at scientific meeting	Presented	Presentation of ROADMAP project and communication tools at the University of Vechta's "Gerontology future day"	17/06/2017	Scientific Community (higher education, Research)	50	https://www.facebook.com/events/1751414196832208/
New grant to kickstart international research into Alzheimers	Website for general public	Published	News item at CPR website	17/11/2016	General Public	-	http://www.cpr.ku.dk/cpr-news/2016/n
Neuroethics in Dementia Prevention and Treatment: Ethical Issues Arising from the ROADMAP Project	Oral presentation at scientific meeting	Presented	Oral presentation: "Neuroethics in Dementia Prevention and Treatment: Ethical Issues Arising from the ROADMAP	19-20/06/2018	Scientific Community (higher education,	25	ime.datawareonline.co.uk/Event-
Meet the ROADMAP team at the HTAi conference 2017	Website for general public	Published	News item at Alzheimer Europe's website	20/06/2017	Dementia community		http://www.alzheimer-europe.org/N
Health-related quality of life in people with dementia measured with preference based instruments: a systematic literature review and meta-analysis	Oral presentation at scientific meeting	Presented	Abstract submitted with the results of the SLR on quality of life to the XXXVIII Spanish Health Economics Conference 20-	20-22/06/2018	Scientific Community (higher education,		http://www.aes.es/jornadas/es/
ROADMAP NEWS	External newsletter	Published	News items in BD4BO Internal Newsletter	22/06/2017	Other	557	
Effect of acetylcholinesterase inhibitors in clinical trials and cohort studies	Oral presentation at scientific meeting	Rejected	Abstract submitted to the IMI Symposium for session 'New targets, tools and pathways'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-
Alignment of European regulatory and health technology assessments: a review of licensed products for Alzheimer's Disease	Poster presentation at a scientific meeting	Accepted	Abstract submitted to the IMI Symposium for session 'New clinical and regulatory paradigms'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-
Identifying care transitions and durations of different care trajectories of persons with dementia	Oral presentation at scientific meeting	Rejected	Abstract submitted to the IMI Symposium for session 'New targets, tools and pathways'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-
Validation of predictive disease models of the AD on real-world evidence data	Poster presentation at a scientific meeting	Rejected	Abstract submitted to the IMI Symposium for session 'New targets, tools and pathway'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-
Identifying priority outcomes and understanding meaningful delay in disease progression for Alzheimer's Disease across the spectrum	Poster presentation at a scientific meeting	Accepted	Abstract submitted to the IMI Symposium for session 'From Concep to Trial'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-
Regulatory and HTA considerations for disease-modifying drugs in Alzheimer's disease	Poster presentation at a scientific meeting	Accepted	Abstract submitted to the IMI Symposium for session 'New clinical and regulatory paradigms'	22-23/10/2018	Scientific Community (higher education,		https://www.imi.europa.eu/news-

First external newsletter	External newsletter	Published	ROADMAP external newsletter April 2017	24/04/2017	Scientific Community (higher education,	380	http://eepurl.com/cMe0xj
Newsletter from IMI project about Alzheimer's disease	Website for general public	Published	News item at AU website	27/04/2017	General Public	-	http://www.kea.au.dk/news/englishnew
Challenges in Optimising Real World Evidence for Alzheimer's Disease	Oral presentation at scientific meeting	Presented	Abstract submitted to ISPOR in Glasgow (UK), 4-8 November	28/06/2017	Scientific Community (higher education,		https://www.ispor.org/Event/index/201
The most important outcomes of Alzheimer's disease (AD) from the perspective of people with the disease and their supporters, collating a decade of published	Oral presentation at scientific meeting	Cancelled	Abstract for Alzheimer Europe Conference Barcelona 29-31 October	29-31/10/2018	Scientific Community (Higher		http://www.alzheimer-europe.org/C
Challenges of including patient-relevant outcomes in funding decisions for Alzheimer's disease drugs, and consequenes - A health technology assessment	Oral presentation at scientific meeting	Accepted	Abstract for Alzheimer Europe Conference Barcelona 29-31 October	29-31/10/2018	Scientific Community (higher education,		-
New European cooperation for better measurement of the effects of Alzheimer medicines	Website for general public	Published	News item at UGOT website	30/11/2016	General Public	-	http://www.akademiliv.se/en/2016/11/3
ROADMAP project holds 2nd General Assembly in Barcelona, launches website	Website for general public	Published	News item at Alzheimer Europe's website	31/03/2017	Dementia community	-	http://alzheimer-europe.org/N
ROADMAP: best use of Real World Evidence to address specific healthcare challenges	Oral presentation at scientific meeting	Presented	Engaging with patient organisations within IMI consortia to inform quality, relevance and value in Alzheimer's	31/07/2017	Scientific Community (higher education,	30	http://www.alzheimer-europe.org/C
Systematic literature review of methodologies and data sources of existing economic models across the full spectrum of Alzheimer's disease and dementia	Article in journal	In preparation	Anticipated Journal: Alzheimer's & Dementia (PROSPERO entry 104)		Scientific Community (higher education,		-
Clinical trial data sharing: Justifications for increased transparency and access to data in four general medical journals	Article in journal	Submitted	Submitted to Journal of Bioethical Enquiry	Submitted April 2018	Scientific Community (higher education,		-
Regulatory and health technology assessment considerations for disease-modifying drugs in Alzheimer's disease	Article in journal	Rejected	ROADMAP manuscript to be submitted at the journal Value in Health		Scientific Community (higher education,		-
Mapping algorithms from real world outcomes to preference-based measures	Article in journal	Planned	Potential publication based on D5.3		Scientific Community (higher education,		-
Health-related quality of life in people with pre-dementia or dementia measured with preference based instruments: a systematic literature review	Article in journal	In preparation	Anticipated Journal: Alzheimer's & Dementia		Scientific Community (higher education,		-

Resource utilization and costs in pre-dementia and dementia – a systematic literature review – 2nd draft sent by medical writers to UOXF for review	Article in journal	In preparation	Anticipated Journal: Alzheimer's & Dementia		Scientific Community (higher education,		-
Attributes for an economic model of Alzheimer's Disease: an agreed model specification from academic, industry and reimbursement perspectives	Article in journal	In preparation	Anticipated Journal: Alzheimer's & Dementia		Scientific Community (higher education,		-
Results of the SLR on the ethics of secondary AD prevention using predictive modelling	Article in journal	In preparation	Data analysis and drafting the manuscript with the results is ongoing (part of D8.5).		Scientific Community (higher education,		-
Landscaping paper on ethics of outcome prioritisation in AD treatment	Article in journal	In preparation	Paper for philosophy / bioethics audience. This is D8.4., the manuscript is due to be submitted.		Scientific Community (higher education,		-
Involving people with dementia, carers and professionals in the development of the ROADMAP data platform	Article in journal	In preparation	Target journal Dementia		Scientific Community (higher education,		-
Priority outcomes for Alzheimer's Disease in European Health Technology Assessments	Article in journal	In preparation	Academic paper describing the findings of WP2 LSE part on health technology assessment		Scientific Community (higher education,		-
What Outcomes Matter to People with Dementia, Their Carers, and Professionals? Insights from ROADMAP Survey	Article in journal	In preparation	Research article describing the results of ROADMAP WP2 online and paper surveys. Target journal tbd.		Scientific Community (higher education,		-
The utility of digital technology in Alzheimer's disease medicine I	Article in journal	Planned	TC to discuss publication plan with those involved in drafting the report on/around the 11 October. There will be two publications with the same authors based on the report.		Scientific Community (higher education, Research)		-
Regulatory and health technology assessment considerations for disease-modifying drugs in Alzheimer's disease	Article in journal	Accepted	ROADMAP manuscript submitted to CNS drugs		Scientific Community (higher education,		-
Identifying a priority set of stakeholder relevant outcomes: a mixed methods analysis	Article in journal	In preparation	Alzheimer's & Dementia or BMJ or The Gerontologist		Scientific Community (higher education,		-
The utility of digital technology in Alzheimer's disease medicine II	Article in journal	Planned	TC to discuss publication plan with those involved in drafting the report on/around the 11 October. There will be two publications with the same authors based on the report.		Scientific Community (higher education, Research)		-