HARMONY

Best Practice
IMI project
‘HARMONY’

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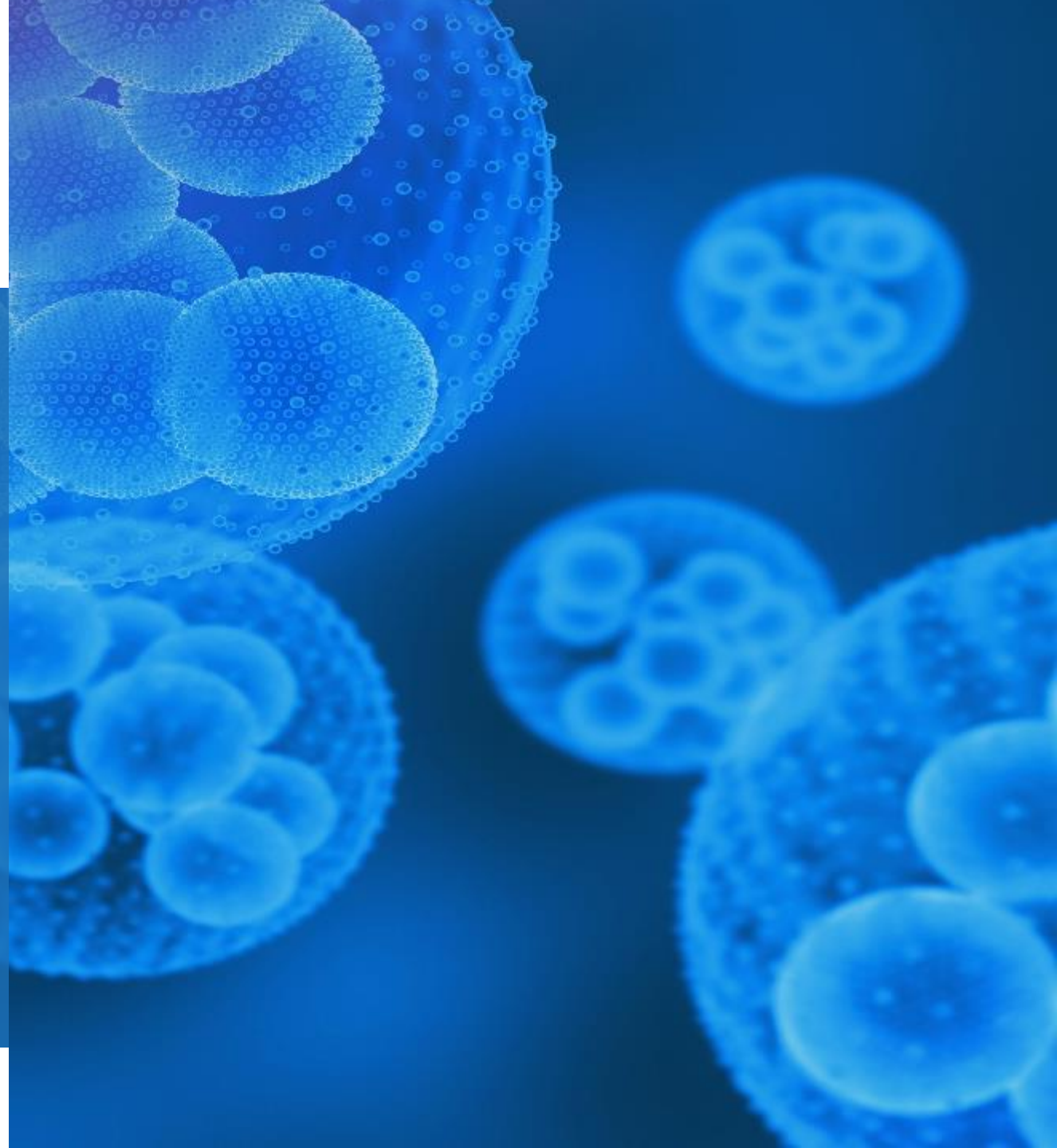
HARMONY Communication Manager

European Hematology Association

IMI Project Communications Event

2 April 2019, Brussels, Belgium



HARMONY

Communicating

on behalf of IMI projects

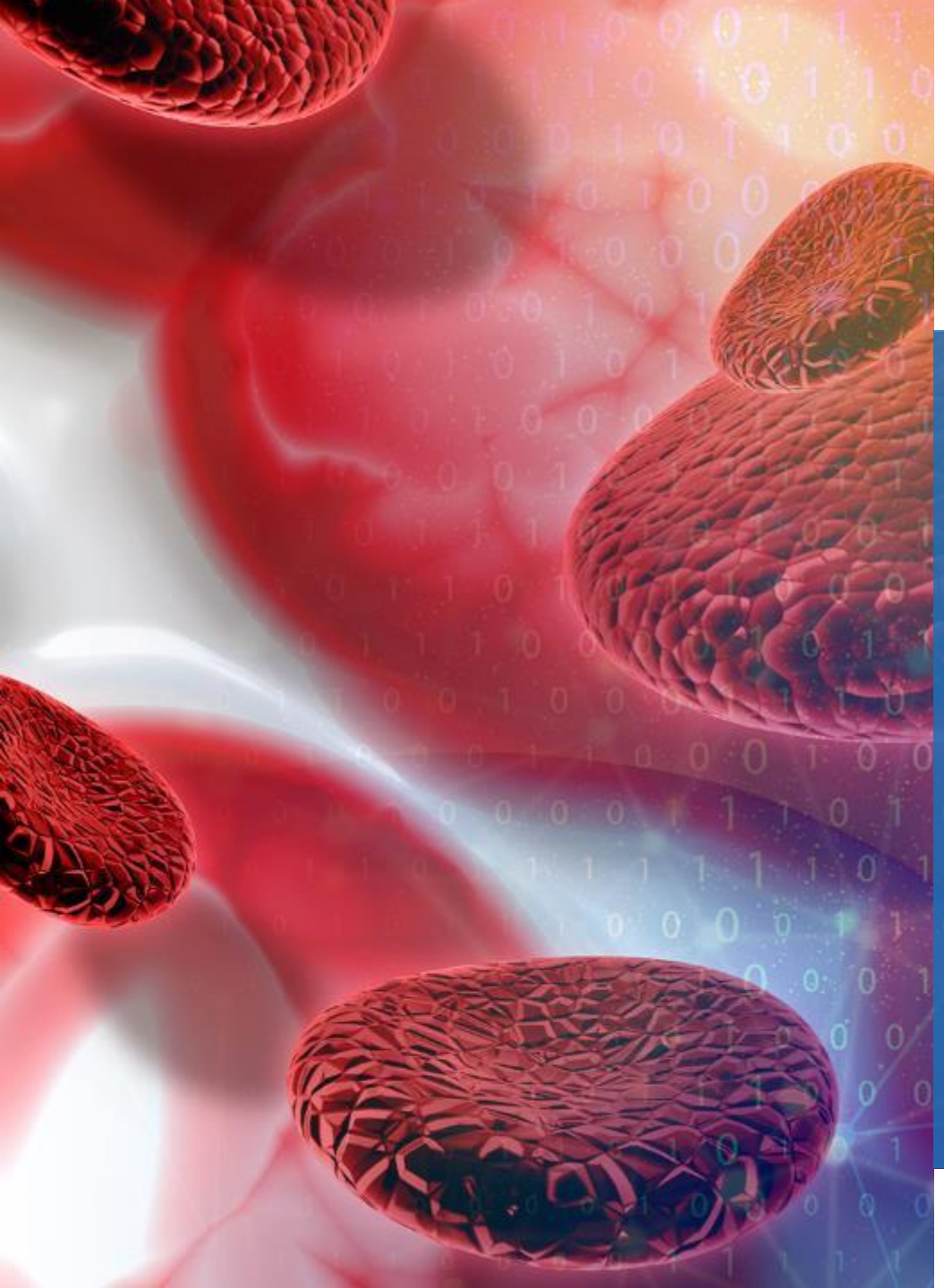
Public-Private-Partnerships

Communication managers in IMI projects ….

- have a unique position – they play a central role
- represent important organizations - the Project Partners
- will - together with Project peers - to bring the (virtual) ‘organization’ to life and keep it vibrant
- are always on the look-out for content to translate in to clear messages
- need to be sure to balance the public-private elements of the partnership in outreach activities
- know that internal communications is as important as external comms and will do what is in their power to build and maintain a committed community
- seek for all kinds of opportunities to engage the right external interest

- *think big but spent little | keep cool and dare to take decisions*

- About HARMONY
- Becoming the Communication Manager > Where to start
- The Objectives
- The Strategy
- The Channels > Content
- Patient Involvement
- What went well > What could go better
- Wrap up



HARMONY

Healthcare Alliance for Resourceful Medicines Offensive against Neoplasms in Hematology

Enabling Better and Faster Treatment for Patients with Hematologic Malignancies by using big data technologies

imi innovative medicines initiative

efpia

Our reason for being

- Blood cancers, or hematologic cancers, account for about 40% of cancer cases in children and about one third of all cancer deaths. Important blood cancers are leukemia, lymphoma, and myeloma. There is a need for improved treatments for blood cancers. Individual cancers usually need specific therapies. As many blood cancers are rare and healthcare practice varies across Europe, a lack of data on relevant outcomes represents a challenge for clinicians, researchers, and other decision-makers like regulators and HTA bodies, resulting in limitations for patient access to the best healthcare.

- The key outstanding questions in this field can only be answered by studying large numbers of patients.

- We aim to use Big Data technologies to deliver information that will help to improve the care of hematology patients - it will allow us to reliably predict the course of the disease course and drug response - ultimately, this should result in tools to rapidly select the most promising treatment strategy for a particular patient.

HARMONY Alliance

Healthcare Alliance for Resourceful Medicines Offensive against Neoplasms in Hematology

WHO WE ARE

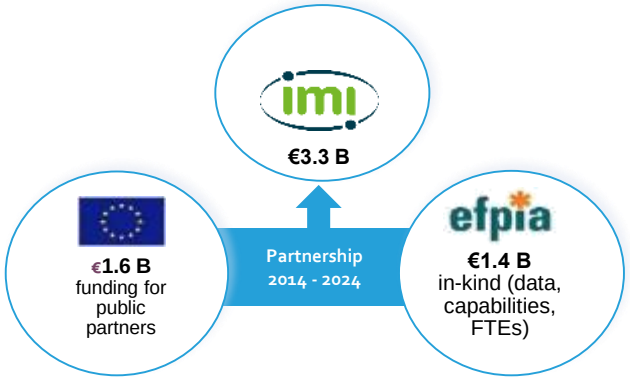
- A pan-European IMI project uniting and aligning healthcare system stakeholders and key opinion leaders in the field of Hematologic Malignancies (blood cancers)
- The first and largest Public Private Partnership in Hematology
- 40 M€ | 2017-2021
- The largest project within IMI Big Data for Better Outcomes program

WHAT WE OFFER

- The HARMONY Big Data Platform: high-quality multidisciplinary sources platfrom that integrates outcome measures and endpoint definitions
- Big Data ‘Tools’ to empower clinicians and other Healthcare system stakeholders to improve decision-making

HARMONY is the Key Initiative within IMI

Europe's largest public-private partnership in healthcare to speed up development of and patient access to new medicines



During first phase (2008-2013), IMI budget of €2 billion: 50% EU FP7, 50% in kind contributions EFPIA companies

BD4BO: An IMI program seeking to leverage big data to improve outcomes:

- Design sets of standard outcomes and demonstrate value;
- Increase access to high quality outcomes data;
- Use data to improve value of HC delivery;
- Increase patient engagement through digital solutions

Connected in BD4BO: IMI projects in different disease areas addressing key enablers in different therapeutic areas.

Involving every stakeholder group is necessary to **meet patients' needs**

53 Partners and 32 Associated Members from 22 European countries and still growing. Patient Groups are involved as Alliance Partners.

What makes us unique?

- Focus on 7 Hematologic Malignancies
- Access to skilled data scientists/statisticians
- Access to data-mapping tools and data analysts
- Access to ethical and legal guidance for pooling data
- Opportunities to get involved in projects that cover multiple diseases, are drug-specific, and incorporate information on quality of life, common genes, common targets, etc.
- Opportunities to interact with >80 stakeholders from all healthcare-related areas

Expected Results

- A clinical data-sharing platform including Big Data series from patients with Hematological Malignancies
- Meaningful and harmonized clinical endpoints and outcome measures in Hematological Malignancies
- Tools for analyzing complex data sets including genomic data
- Biomarkers that will contribute to timely patient access to more effective and better tolerated innovative therapies
- A framework for legal, ethical and governance issues
- A community of European stakeholders

8 Work Packages

www.harmony-alliance.eu/en/work-packages

7 Disease Groups

www.harmony-alliance.eu/en/hematologic-malignancies

HARMONY Research Projects
by public-private-teams:
7 and more to follow

More activities related to patient access, outcomes, privacy, legal Issues, ethics, and governance

Internal audiences

HARMONY Community:
53 Partners and
32 Associated Members
=
about 300 official contacts

HARMONY

External Audiences

Hematology networks

Multi-stakeholders

Broader audiences

In Europe and beyond

Academic institutions, national clinical disease networks, European organizations, patient advocacy groups, clinicians, and pharmaceutical companies, regulatory agencies, experts in economics and ethics, and information and technology specialists, funders, media.

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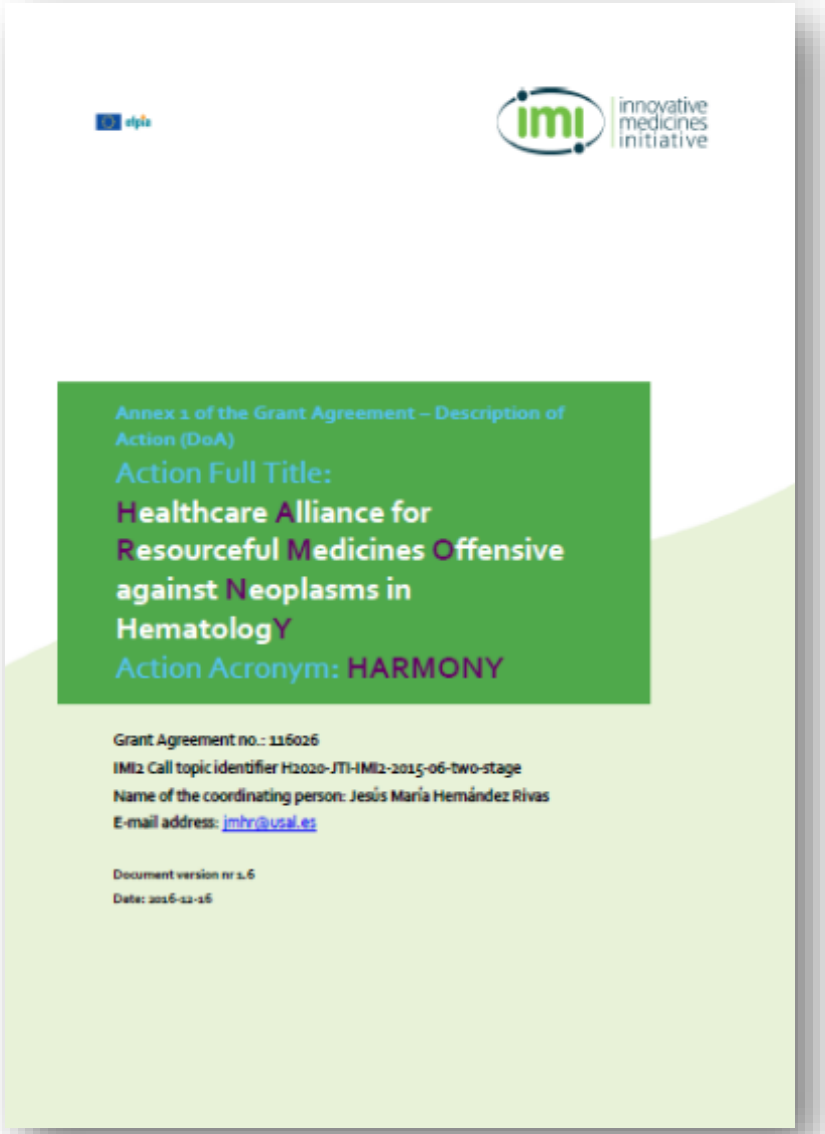
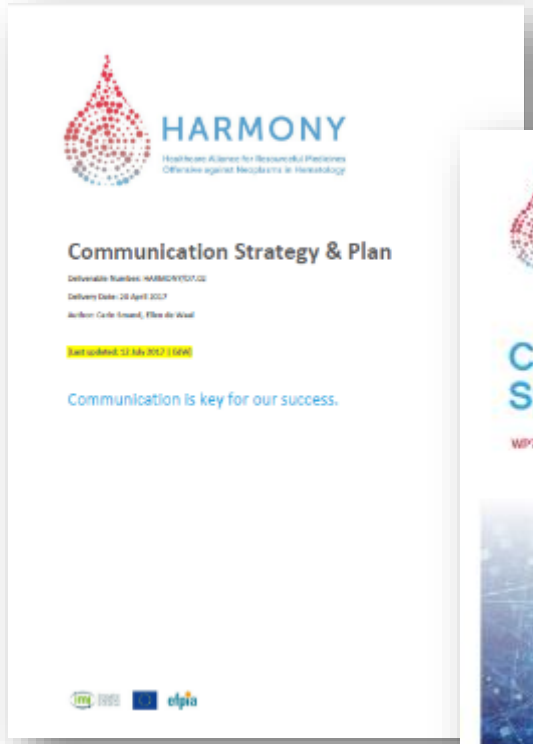
Communications Dissemination

Where to start….


Annex 1 of the Grant Agreement – Description of Action (DoA)
Action Full Title:
Healthcare Alliance for Resourceful Medicines Offensive against Neoplasms in HematologY
Action Acronym: HARMONY
Grant Agreement no.: 116026
IMI2 Call topic identifier H2020-JTI-IMI2-2015-06-two-stage
Name of the coordinating person: Jesús María Hernández Rivas
E-mail address: jmhr@usal.es
Document version nr 1.6
Date: 2016-12-16


HARMONY
Communication Strategy & Plan
Communication is key for our success.

HARMONY
Communication Strategy & Plan 2018
WP7 I 25 January 2018

HARMONY
100.000
Datasets
Reasons for HARMONY
Hits against Hematological Cancers
Communication Strategy 2019 & 2020
WP7 | 11 12 2018
efpia

Where to start .. some tips

- Understand the IMI Agreement (and tasks/roles in particular)
- Know budget possibilities and restraints
- Draft that communication plan but realize it will evolve
- Start identifying potential ‘friends’ within the partnership to provide input and/or to act as sounding boards and reach out
- Get a feel for issues that will always need special attention
- Start communicating – small scale - right from the start (web presence, basic text kit, basic house style – present vision, objectives, approach, Partners)
- Connect and stay connected with IMI, EFPIA, Horizon2020

- *Realize there are too many things in too little time … but just go for it and start shaping and building.*

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Communications Dissemination

The Objectives

- Raise awareness, inspire, inform, connect, engage and align.
- Nurture collaborations and relations.

We can only make a difference:

by communicating about real and effective developments and achievements, not by plans and intentions.

in finding the right people to connect and finding the right information to catch their interest.

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Communications Dissemination

The Strategy

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2017: year 1: **Awareness & Introduction**

2018: year 2: **Clarifying & Connecting**

2019: year 3: **Growth & Benefits**

2020: year 4: **Education & Strength**

2021: year 5: **Results & Embedding**

HARMONY 2019 & 2020 Communication strategic imperatives:

Focus on **growing database**, submit **more HARMONY Research Projects** and attract **more 'Data Providers'**

	Key objectives	Expected outcome
1.	**'Towards 100,000 datasets'** campaign to reach out and enhance awareness	**Sustain and increase momentum among multistakeholders**
2.	**Boost community of data providers** and projects proposals	**Maximise clinical and societal value of database to all**
3.	**Engage patients, nurses** and their organisations	**Expand HARMONY footprint**

		Reasons	Messages
1. ‘Towards 100.000 datasets campaign	All stakeholders	• Support achieving the overall HARMONY goals • Attract interest leading to new Associated Members • Attract interest leading to new external relations	**100,000 reasons why HARMONY matters** • Need to accelerate HM/blood cancer research to improve patient outcomes • Impact of Big Data analytics • Progress: achievements and future plans • Subsidy/investment well spent
2. Boost community of data providers	Clinicians Researchers Patient Cluster Specialist media	• Expand community of potential data providers • Expand number of Associated Members • Stimulate project proposals • Support quest for more data	**HARMONY needs you** • What is in it for you? • What has the Alliance achieved? • How can you join? • Who else has joined?
3. Engage patients	Patient, nurses and parent organisations	• Expand HARMONY footprint • Increase awareness of what Big Data can do for patients • Fuel engagement • Support educational activities among organizations	**Your benefit from HARMONY** • What is HARMONY doing for you? • How can the Alliance’s achievements help you advocate your cause?

		Tactics		Channels
1. ‘Towards 100.000 datasets campaign	All stakeholders	• Dedicated articles and posts spotlighting projects (and organization and people) • Presentations and/or sessions and/or booths by HARMONY Ambassadors at international conferences • FAQ • Consistent and strong branding (less is more), consistent tone of voice	Q1 . Q2 . Q3 . Q4	• Community Platform • www.harmony-alliance.eu • Social Media • Websites-newsletters-internal-presentations Partners/Ass.Members • Funders websites-newsletters-events • Selected conferences
2. Boost community of data providers	Clinicians Researchers Patient Cluster Specialist media	• Dedicated campaign landing pages • Recruitment kit for personalized and targeted approach • Onboarding kit (upgrade current materials) • List of prospects (together with WP-leads/KOLs and patient cluster)	Q2 . Q4	• Match-Making event • EHA Hemasphere • Editorial in other journals • Hospital associations • Annual events/websites/newsletters special interest groups • Community Platform • www.harmony-alliance.eu
3. Engage patients	Patient, nurses and parent organisations	• Dedicated landing page with a wide ranges of info/educational bites in layman language such as: articles, videos, animations (base to be created by HARMONY, added with selection of existing materials) • Mini-info-kits	Q1 . Q2	• Annual events/websites /newsletters of patient/nurses /parent organizations • Masterclass(es) • Subscription to HARMONY alerts (new content on landing page) • Community Platform • www.harmony-alliance.eu

Solid answers on how to become involved!

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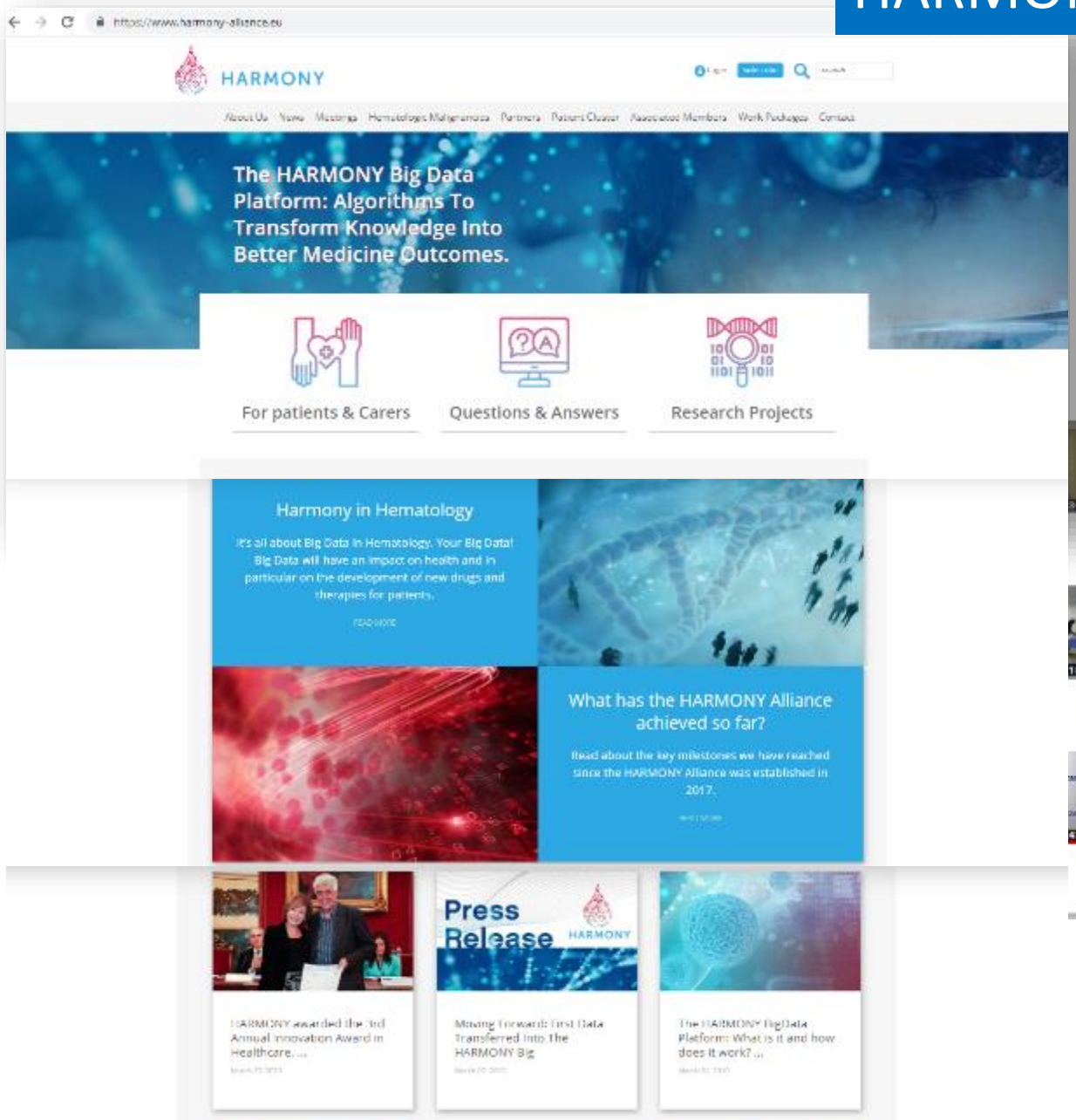
The Channels and Toolkit

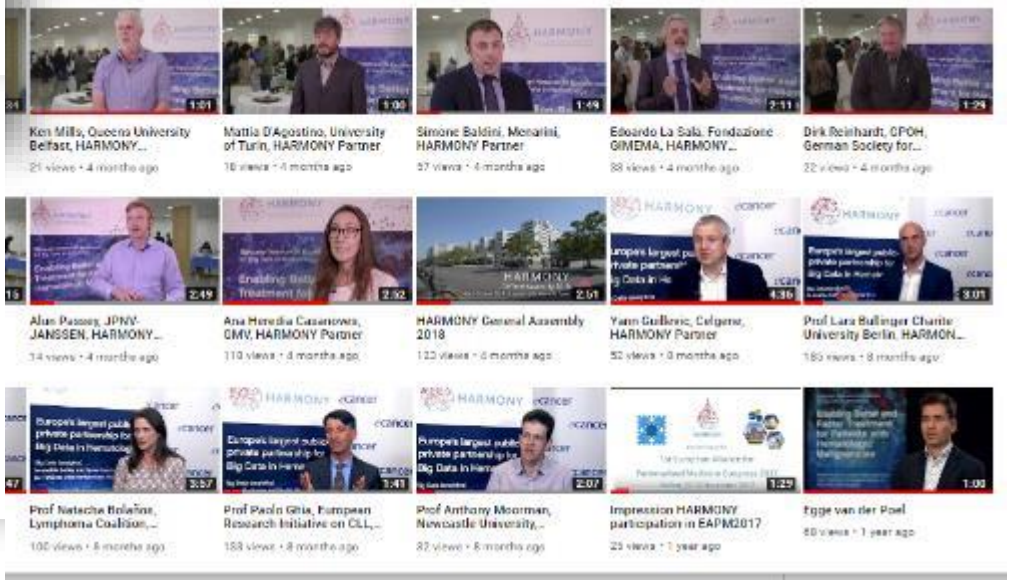
The Content

HARMONY Website



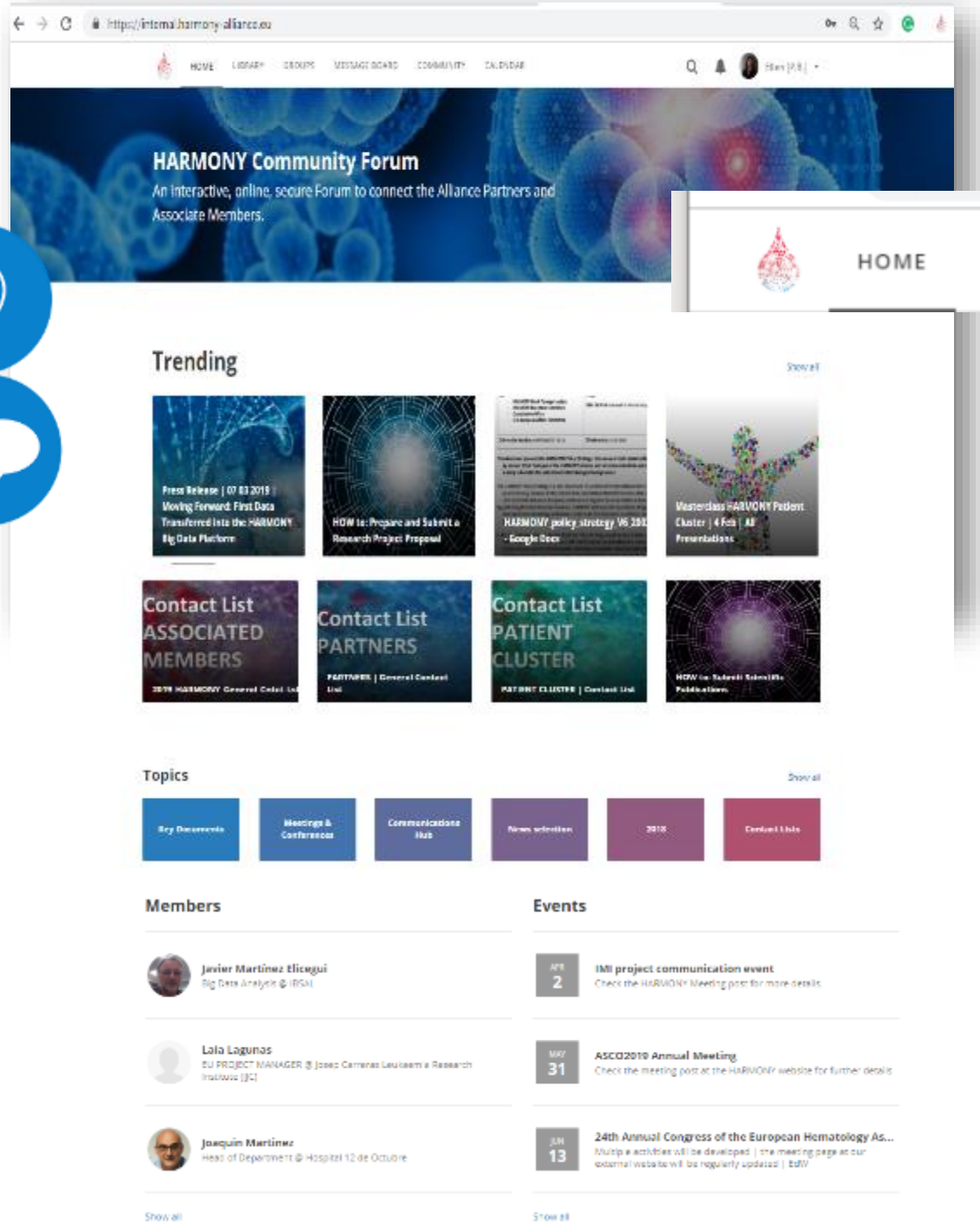
https://www.harmony-alliance.eu/

- **From web presence to mini website to full force website.**



- Video messages by HARMONY Partners and Associated Member explaining their views.

HARMONY Community Platform



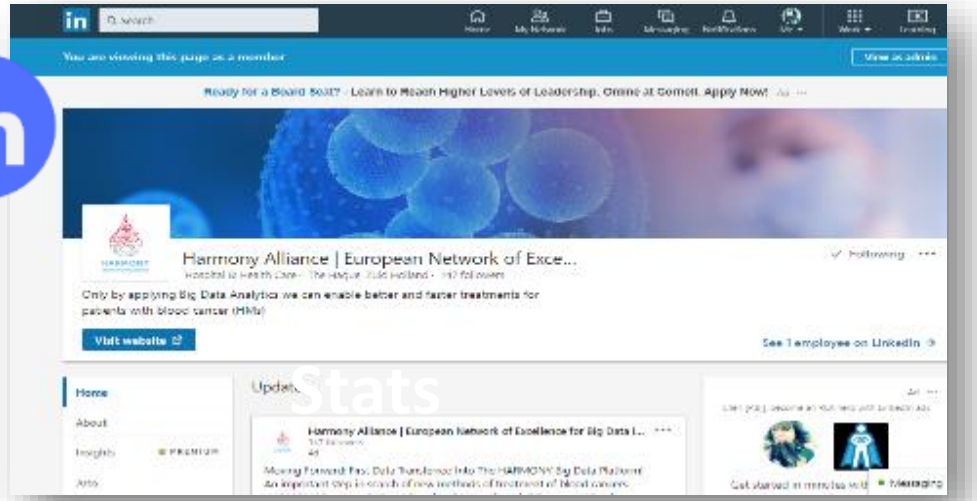
An interactive, online, secure platform to connect the Alliance Partners and Associate Members.

- Home: landing page with trending topics
- Library: for files, videos, share docs
- Groups: closed online work spaces (also with sub calendar, members)
- Message Board: for community posts
- Community: to view all member profiles
- Calendar: for selected events

- Only for official HARMONY contacts, access approval needed.

- *Note: interested in a demo?*
- *Mail to e.dewaal@ehaweb.org*

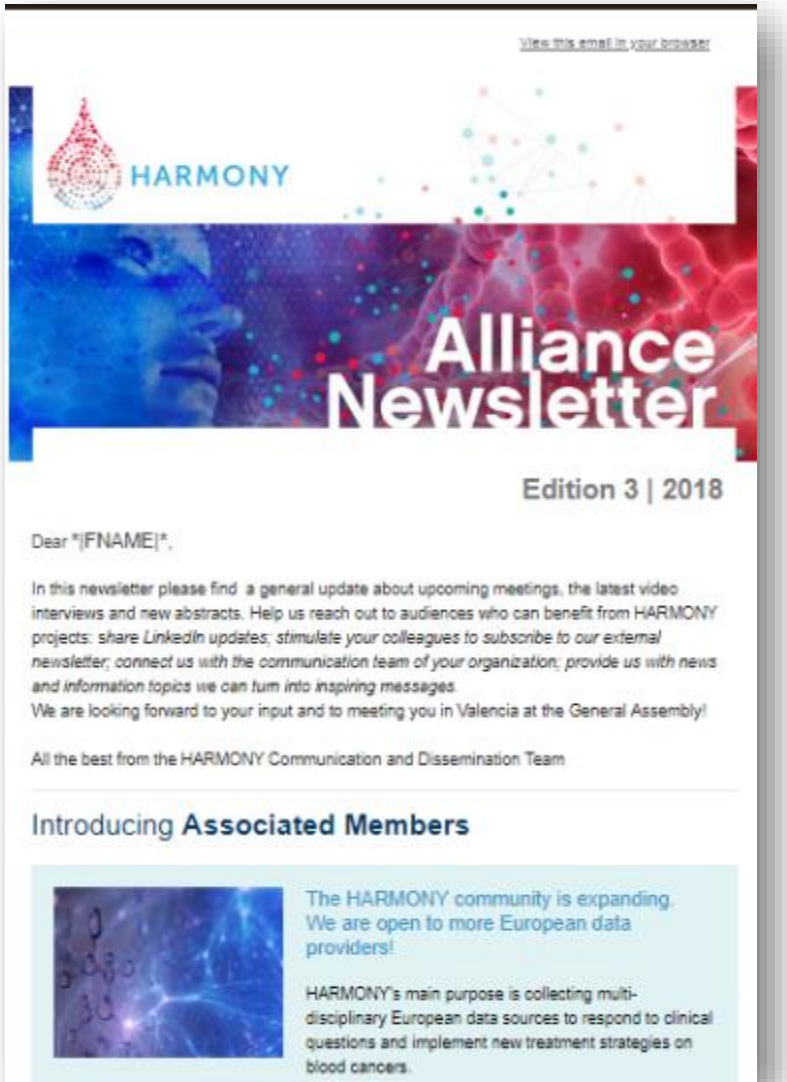
https://internal.harmony-alliance.eu/

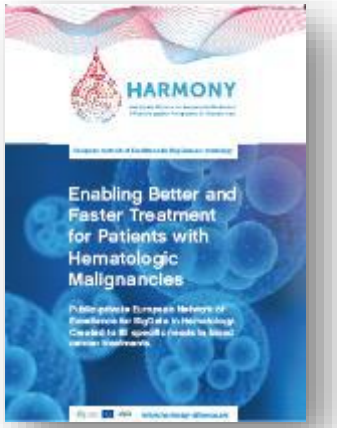


https://www.linkedin.com/company/harmony-alliance

https://twitter.com/HarmonynetEU

More items in the toolkit are: HARMONY Banners | PPT decks | Folders
Press release | Editorials

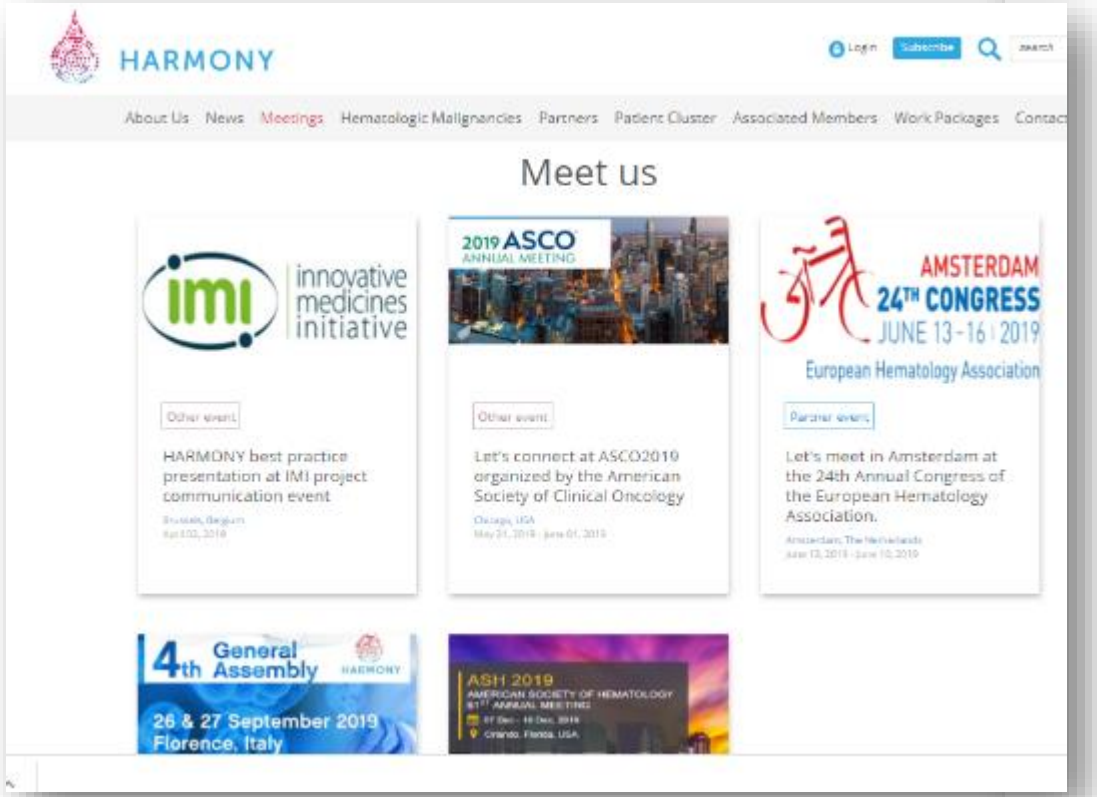


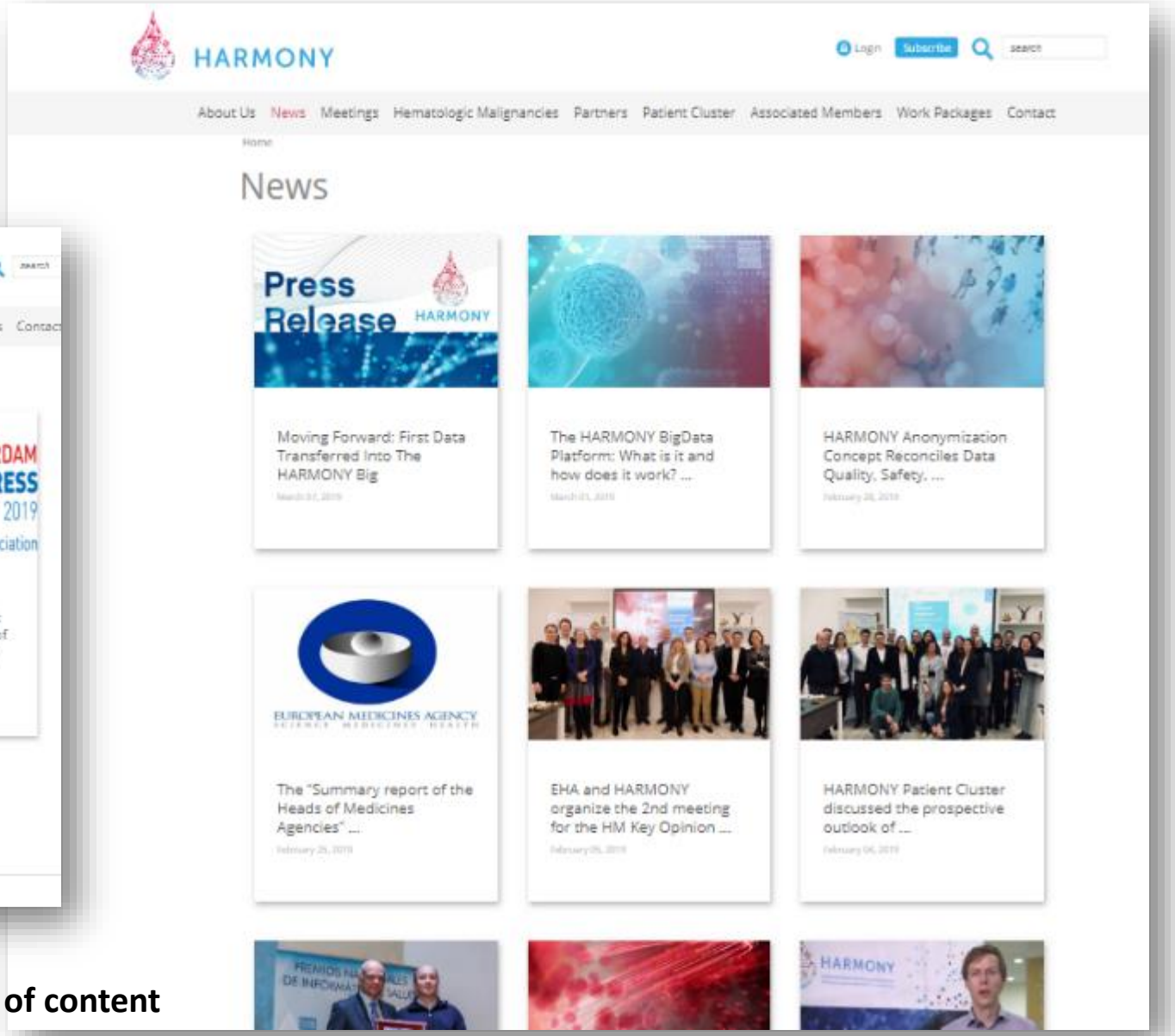


Include communication channels of Partners, Associated Members and funders in your outreach.

HARMONY participates in a selection of European and international conferences

- In addition we organize sessions
- And each year all Partners and Associated Members attend the General Assembly





- **Examples of content**

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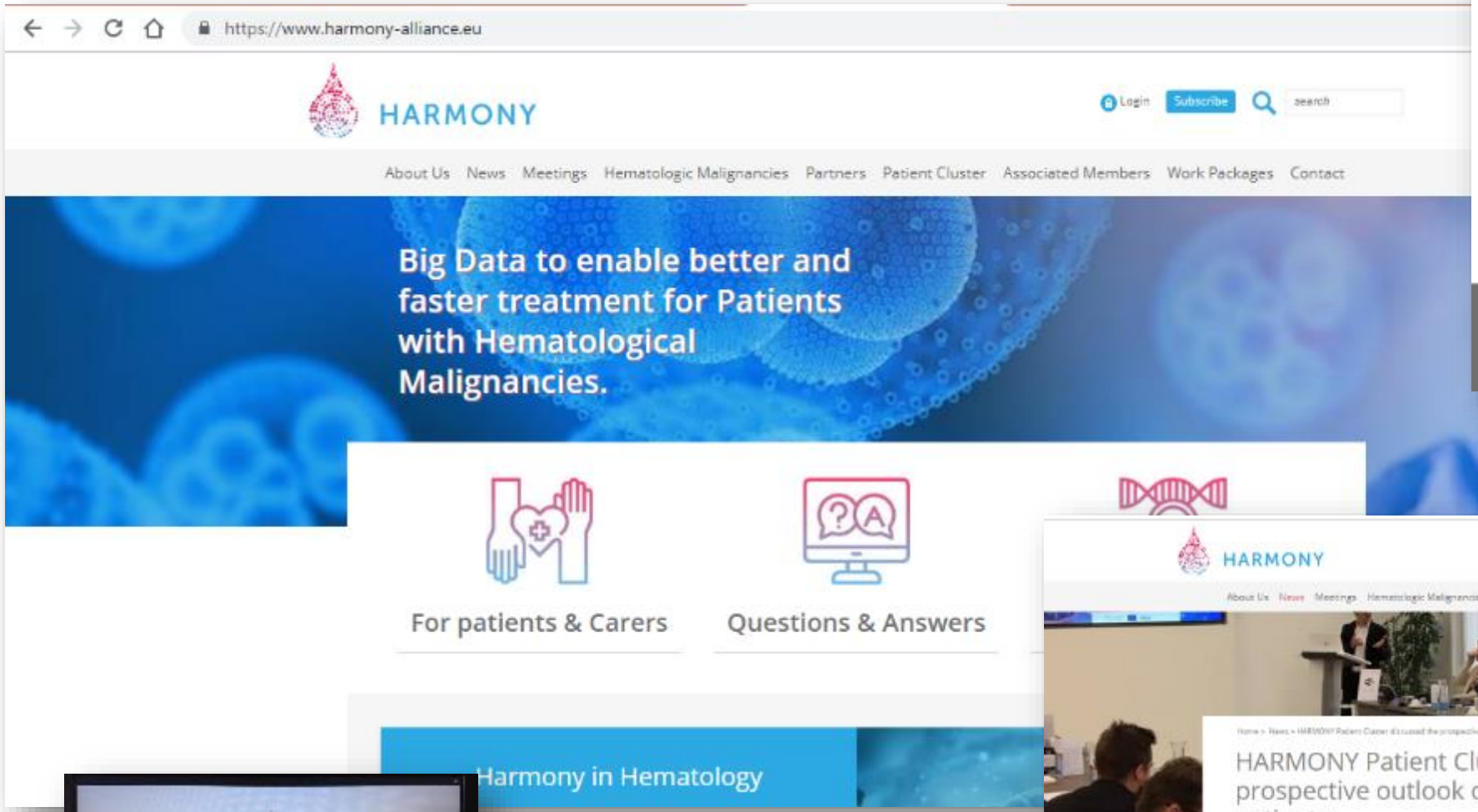
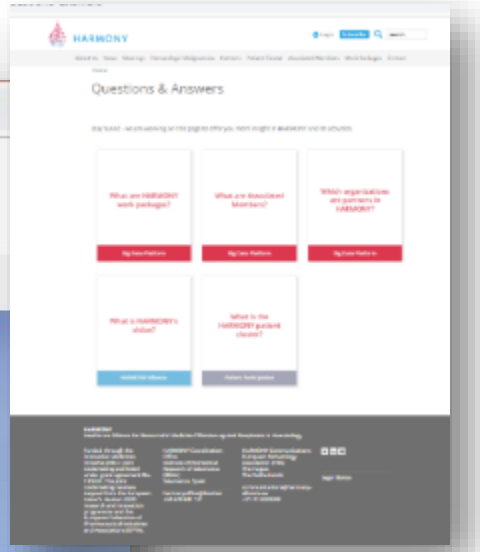
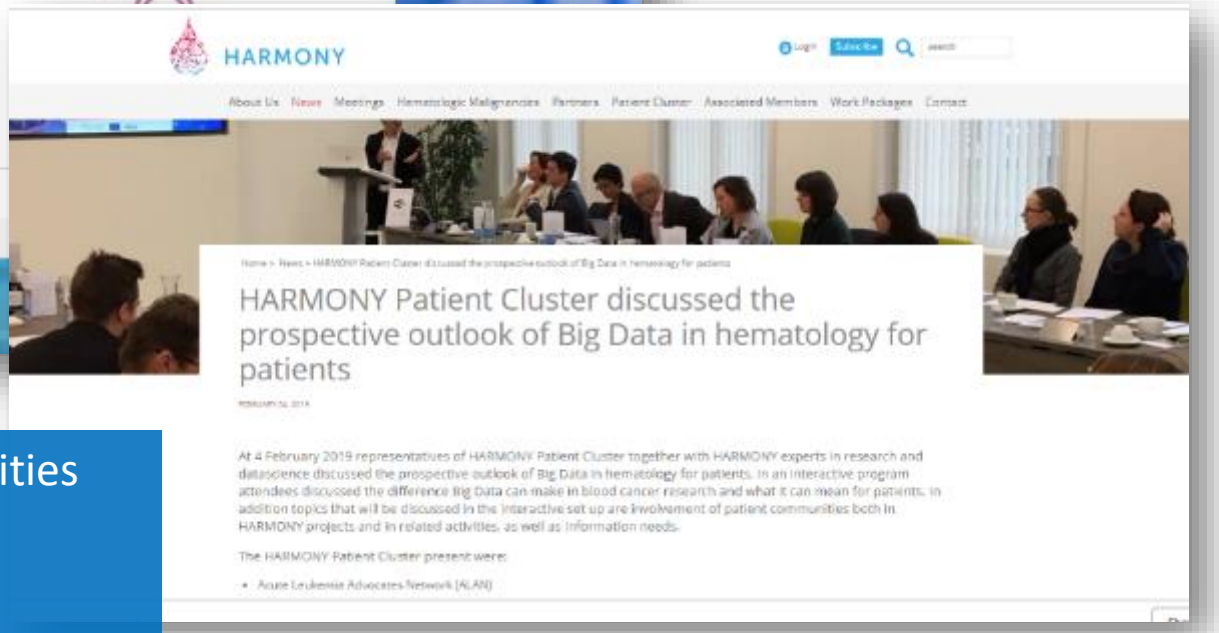
Patient Involvement







Dedicated communication activities developed together with the HARMONY **Patient Cluster** and dedicated to a **broader audience**

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Communications Dissemination

What went well

What could go better

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Wrap up

What did we – the communication team -achieve

- A solid identity
- Visibility (a full functioning and effective unique virtual organization)
- Awareness about the critical importance of Big Data in relation to Hematology
- Delivering HARMONY's "message" (through a wide range of external communication tools and materials), our view, our people, our work and how we can contribute to patients with Hematologic Malignancies
- Internal Community
- External Network

2017 | 2018 | 2019 | 2020 | 2021

Thank You

Contact: Ellen de Waal
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www.harmony-alliance.eu

@harmonyNet

HARMONY Alliance | European Network of Excellence for Big Data in Hematology

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- Read more at: www.imi.europa.eu

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