CROSS-HEALTHCARE COLLABORATION WITH PATIENT ORGANISATIONS

YOUR HANDBOOK FROM THE EARLY START

pharma.be
ASSOCIATION GÉNÉRALE DE L'INDUSTRIE DU MÉDICAMENT
ALGEMENE VERENIGING VAN DE GENEESMIDDELENINDUSTRIE

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FOREWORD

Caroline Ven
CEO

By showcasing what works —
and what does not —
we foster continuous learning and improvement.

Driven by the motto *"Patients at the Heart of Everything We Do"*, and aligned with our pharma.be mission, the innovative biopharmaceutical sector is actively collaborating and co-creating with a wide range of stakeholders across the healthcare ecosystem. Together, we aim to foster a healthier society.

To ensure that the patient perspective is systematically integrated into these initiatives — moving from working for patients to working with patients — pharma.be has developed a guidance handbook. This handbook is designed to inspire and inform through real-life examples that demonstrate how broader collaboration between healthcare stakeholders and patient organisations leads to higher quality and more sustainable outcomes.

From co-developing educational materials and establishing patient registries, to mapping patient journeys and drafting disease plans, numerous collaborative projects are underway. By showcasing what works — and what does not — we foster continuous learning and improvement. That is why this handbook will be regularly updated with new insights and success stories.

By embracing co-creation from the very beginning, we can move beyond fragmented efforts, engage patient organisations early on, and work collectively toward meaningful, real-life outcomes.

TESTIMONIALS

The true strength of a multistakholder set-up lies in its diversity: by bringing together patient organisations, healthcare professionals, policymakers and industry, we move beyond individual agendas and create meaningful and united action. Including the patient voice keeps us grounded in what really matters: creating healthier generations and saving lives.

Rik Vanhoof
General Manager, Belgian Heart League

As a Multiple Sclerose Patient Expert, I've seen the value of true multistakeholder collaboration including the patient perspective. Considering patient organisations as a trusted partner will ensure that the developed solutions have maximum impact in real life. Learning from successes and failures!

Inge Van de Velde
Patient Expert, MS-Liga Vlaanderen

As a patient advocate and member of SMA Europe, I firmly believe that meaningful cross-healthcare collaboration is only possible when patient organisations are engaged at every step — from identifying patients' real needs to shaping the care they receive. Patient organisations bring unique real-world expertise, helping to ensure that treatments and care pathways truly reflect what matters most to people living with the condition. This aligns fully with our mission at SMA Europe to embed the patient perspective in treatment development and policy, so that patient engagement translates into real impact across the entire journey.

Véronique van Assche
Patient Advocate, SMA Belgium / Europe

INTRODUCING THIS HANDBOOK

Our aim is to be an inspiration and motivation for all stakeholders to envision and pursue transformative collaborations.

This handbook is designed by the members of pharma.be together with patient organisations, to facilitate and stimulate partnerships between pharmaceutical companies, patient organisations (PO's), caregivers, policy makers, and other healthcare organisations and serves as a practical guide for leveraging collaboration across the entire patient journey.

The handbook provides a non-exhaustive list of examples, offering diverse and innovative approaches for fostering cross-healthcare collaboration.

It features:

- a definition on cross-healthcare collaboration
- a legal framework for you to operate more time and resource-efficiently
- a concrete list of projects organised into different categories, enabling stakeholders to explore a wide range of collaborative opportunities.

Additionally, the handbook includes a more general section with practical tips and tricks. Our aim is to be an inspiration and motivation for all stakeholders to envision and pursue transformative collaborations.

Please note that this handbook is meant as a living guidance document that will be adapted with learnings and action points after new interesting initiatives have been established.

WHAT IS CROSS-HEALTHCARE COLLABORATION WITH PATIENT ORGANISATIONS?

Cross-healthcare collaboration with patient organisations involves non-product-specific initiatives aimed at enhancing the context for patients and improving the quality of healthcare. It is more effective and efficient to collaborate on projects that are relevant to more stakeholders. Many projects are currently still pursued for competitive differentiation that should be approached as cross-healthcare collaboration to raise the quality and be more sustainable.

Our vision

We **envision** a future where collaborative projects improve patient care. By working together, we can address the needs of different patient groups and promote inclusivity. We are committed to engaging with patients to support solutions that enhance their experience and that of their caregivers. Collaboration helps maintain patient organisations' independence, prevents duplication of efforts, and uses resources efficiently, fulfilling our community responsibilities. Our goal is to not only innovate but also create lasting improvements in patient care beyond individual company interests.

Our mission

Our **mission** is to promote collaboration between pharmaceutical companies and healthcare partners like patient organisations, healthcare professionals, and policymakers to improve patient care. By working together, we aim to involve patients early on, ensuring their needs are better met. Our focus goes beyond medicine development, covering the entire patient's journey: prevention, awareness, diagnosis, treatment, support, and aftercare. We aim to address specific patient needs through sustainable, non-commercial solutions based on real insights from patients and caregivers. We believe multi-stakeholder initiatives create a broader, more impactful response while maintaining the independence and neutrality of all involved.

WHAT ARE THE LEGAL AND COMPLIANCE CONSIDERATIONS IN A CROSS-HEALTHCARE COLLABORATION?

Research shows that very few guidance exists on how one can step into a cross-healthcare collaboration amongst different healthcare stakeholders. All organisations (EFPIA, EUPATI, etc.) agree upon the need and added value of collaborating in a cross-healthcare setting, however, lack an actual legal framework to do so. In this section we aim to provide you with a legal and compliance framework with important considerations to consider and on the other hand with an example template of a Memorandum of Understanding (MoU).

🔗 MoU

Before starting up a cross-healthcare collaboration, one must consider the following points:

1. Data protection

The collaborative agreement may need to follow **privacy laws** like the **GDPR***, which protects personal data. It is generally OK to share **aggregated information** but consult your legal advisor if unsure.

- Biopharmaceutical companies should not access data that can identify individual patients. However, qualified individuals, such as healthcare professionals or statisticians, can access such data if they are not in a promotional role.
- The data controller, who decides how and why the data is processed, should be clearly identified in the agreement.
- When collecting data, only gather what is necessary for the specific initiative, and keep it only as long as needed to fulfil that purpose.

2. Anti-bribery and corruption

- **Care must be taken if a physician/HCO employee could benefit personally** from the project (especially when working with small HCO such as GP practices): Anti-corruption laws prohibit the offering, promising or giving of a financial or other advantage to public officials for the purpose of obtaining any improper business advantage.
- **No payment** for a service and/or material (e.g. equipment that is expected to be part of normally equipped hospital/medical practice) which the public healthcare system should be providing.

3. Anti-competition

As more than one pharmaceutical company will be involved in the project, compliance with competition law must be always kept in mind. Anticompetitive agreements, decisions or concerted practices between companies (e.g. agreeing prices or discount schemes with competitors) are illegal. **Contact your local legal counsel in case of doubt, especially when asked to share sensitive information.**

4. Transparency

It is important to ensure **transparency, including financial transparency**, throughout the project towards the outside world. Whenever output from the collaborative work is made public, it should be clearly stated who are the collaborative parties and which parties are funding the project.

* Only part of the GDPR requirements is highlighted here due to its relevance in this cross-healthcare collaboration setting, however, the full GDPR requirements remain applicable.

WHAT ARE THE LEGAL AND COMPLIANCE CONSIDERATIONS IN A CROSS-HEALTHCARE COLLABORATION?

Do's

- Establish a **written understanding of the purpose and scope of the discussions** to ensure that they remain consistent with parties' objectives.
- Provide a **written agenda** for all meetings which can be approved in advance and make sure to **verify** the meeting agenda ahead of the meeting to ensure that solely legitimate objectives are addressed and make sure to start each meeting with the **do's and don'ts** on competition law.
- **Limit participation** to appropriate personnel who are briefed about potential competition concerns and importance of keeping to the approved agenda.
- Consider whether **legal counsel** from at least one company should attend meetings and request an external lawyer to join the meeting when the meeting agenda suggests that commercially sensitive topics may be (indirectly) discussed.
- Take detailed **minutes** of all meetings, chair amongst all project participants and archive.

Don'ts

- Do not disclose or discuss confidential or commercially sensitive information or enter into agreements in the following areas:
  - **Pricing** of products or **commercial strategies** of any of the companies.
  - Individual company **cost components or structure**, or relationship between **cost and price** in the industry generally.
  - **Allocation of market or market practices**, either in relation to individual customers or geographical regions.
  - Actual or potential company-specific **customer relationships**
  - Actual or potential **bidding opportunities**, and each other's responses to such opportunities.
  - Individual company or industry **production** levels, capacities or inventories, or individual company market **shares**, or **R&D activities or results.**
  - Avoid any off-topic discussions or private meetings outside of the main meeting.
- **Object to any discussions or exchanges of commercially sensitive information** and make sure to leave if the discussions continue. Ensure that your objection and departure are noted in the meeting minutes. Notify your legal counsel immediately if this takes place.

A STEP-BY-STEP APPROACH TO FOLLOW

THE FOLLOWING 9 STEPS SHOULD BE FOLLOWED TO ESTABLISH A SUCCESSFUL AND COMPLIANT CROSS-HEALTHCARE COLLABORATION:

1. IDENTIFY THE PATIENT NEED/GAP
2. SCOPE UP THE PROJECT
3. DEVELOP THE CROSS-HEALTHCARE COLLABORATIVE PROJECT PLAN
4. GAIN STAKEHOLDER ALIGNMENT
5. DRAFT THE COLLABORATIVE/JOINT WORKING AGREEMENT
6. GAIN FORMAL APPROVAL FROM ALL ORGANISATIONS WORKING TOGETHER
7. START THE PROJECT
8. MONITOR DELIVERY OF THE PROJECT
9. FOLLOW-UP AFTER COMPLETION

1. Identify the patient need/gap

These projects are often drawn from data analysis or patients feedback which highlight an area of proven patient or clinical need. Make sure to document this specific need.

2. Scope up the project

Please consider the following questions to further scope the project centred around an identified and documented patient need:

- What is the specific unmet need and why is it an **unmet need**?
- What is the patient and the healthcare ecosystem **benefits** of addressing this need?
- What would **success** look like when addressing this need? How can you measure it? (determine key performance indicators)
- Have other healthcare stakeholders successfully tackled a similar challenge?
- Which would be the different project participants?

Discuss this amongst all project participants and agree on the objectives and outcomes. A confidentiality agreement is only needed when product specific information is shared that is not available in public space.

A STEP-BY-STEP APPROACH TO FOLLOW

3. Develop the cross-healthcare collaborative project plan

Please consider the following questions when defining the details of the project plan:

What

- How to tackle the documented objective?
- What is the plan of action?
- What are the expected benefits for all parties?

How

- Define the **roles and responsibilities** of all project participants: who oversees what (e.g. materials ownership and distribution, logo's & disclaimers, different steps of the project, etc.)
- **Way of working**: meeting organisation and frequency, shared drive, etc.
- **Which financial** resources are needed and how will they be obtained and managed?

Who

- **Which resources** (people, skills, technology) are required to be able to deliver the project?
- Who will be the **project participants**: single point of contact per party (which are the responsible roles within each company/party)?

When

- What is the overall **timeframe**? Are there different **milestones** to set?
- Assessment of how the **output** from the project can be sustained longer term

A STEP-BY-STEP APPROACH TO FOLLOW

4. Gain stakeholder alignment

Check that the project aligns with each party's objectives and compliance/legal processes.

For pharma partners: involve your legal, medical and ethics and compliance departments.

For patient organisations: make sure you understand the language and the feedback from the pharma companies. In case of uncertainties, don't hesitate to reach out to pharma.be with your questions and/or concerns. The contact details can be found at the end of this document.

- Ensure the project has been reviewed by each party's management
- Re-discuss all collected feedback amongst all project participants

5. Draft the collaborative/joint working agreement

Check that the project aligns with each party's objectives and compliance/legal processes.

6. Gain formal approval from all organizations working together

By signing the Memorandum of Understanding/Collaboration agreement

7. Start the project

8. Monitor delivery of the project

During each contact moment, at minimum the following should be done:

- Review action items previous meeting
- Document minutes of the meeting
- Verify milestones determined in Memorandum of Understanding/Collaboration Agreement (potentially create a GANTT chart to do so)

9. Follow-up after completion

Measurement and documentation of defined outcomes: reflect on KPI's set upfront
Publication of a summary of the project and lesson learned: report back to pharma.be to develop this handbook

WHAT TYPE OF CROSS-HEALTHCARE COLLABORATIONS ARE THERE?

Ideally, we form and operate from a multi-stakeholder platform to launch multiple initiatives that are sustainable and offer long-term solutions. For this purpose, one can work with a third party/consultancy agency to facilitate the logistics and administration of the initiatives. We will list an example of such a platform, however, one must consider setting up a multi-stakeholder initiative requires time and resources and does not come overnight.

We would like to share several examples of successful collaborations.

ALL.CAN LUNG CANCER WORKING GROUP

🔗 **WEBSITE**

Objective

The objective is to bring stakeholders together to work towards optimal lung cancer care by setting thematic priorities supported by each stakeholder. In this way we aim to address those areas where patient needs are the highest.

History

2020

Informal gathering of a few Patient Engagement Managers to discuss how to integrate the patient perspective in our daily work.
At this point there was no active lung cancer patient association in Belgium. Cross-healthcare collaboration was still very new and the decision was taken to first work on general lung cancer awareness, by co-creating an awareness campaign.

2021

Purpose of the collaboration and the campaign: The broad objective of this project was to coordinate and set up a multi-stakeholder collaboration aimed at co-creating a lung cancer awareness campaign that focuses on prevention. More specifically with this project, we aimed to lay the foundations for the creation of a long-term strategy to prevent lung cancer, to foster collaboration and co-creation on priority areas defined by the working group members and to build a strong patient advocacy approach and provide information and support for patients and caregivers living with lung cancer.

2022

Discussions started with All.Can integrate the coalition as a working group under All.Can. This was mainly to ensure continuity and sustainability of the project, which would not have been possible otherwise.

2023

Official integration under All.Can

The partners who actively participated in the co-creation at this stage of the project included:

- **Patient organisations** (Vaincre, ALK Positive Belgium, LuCE)
- **Healthcare professionals and academic centres** (UZ Leuven, UZ Gent, UCL – Cliniques universitaires Saint-Luc, AZ Delta, AZ Vesalius)
- **National and regional organisations** (Fondation contre le Cancer/Stichting tegen Kanker, Kom op tegen Kanker, BeRS, AFBOT, LLCG and REO)
- **Biopharmaceutical companies** (AstraZeneca, Johnson & Johnson, MSD & Roche)

ALL.CAN LUNG CANCER WORKING GROUP

🔗 **WEBSITE**

Stakeholders involved

Patient association
Prolong, ALK+, Stichting tegen kanker, Vaincre

HCP/expert associations
Individual physicians: Prof. Paul Van Schil, Prof. Ingel Demedts, Prof. Jan Van Meerbeeck, Prof. Thierry Berghmans, Dr. Cuppens

Biopharmaceutical companies
AstraZeneca, Bristol-Myers Squibb Belgium, Johnson & Johnson, MSD Belgium, Roche

Ownership

All.Can

Outcome

A long-term multi-stakeholder collaboration, which will be used as basis for different initiatives to contribute to more efficient lung cancer care i.e. awareness campaigns, organisation of symposia, policy shaping, etc.

Key milestones
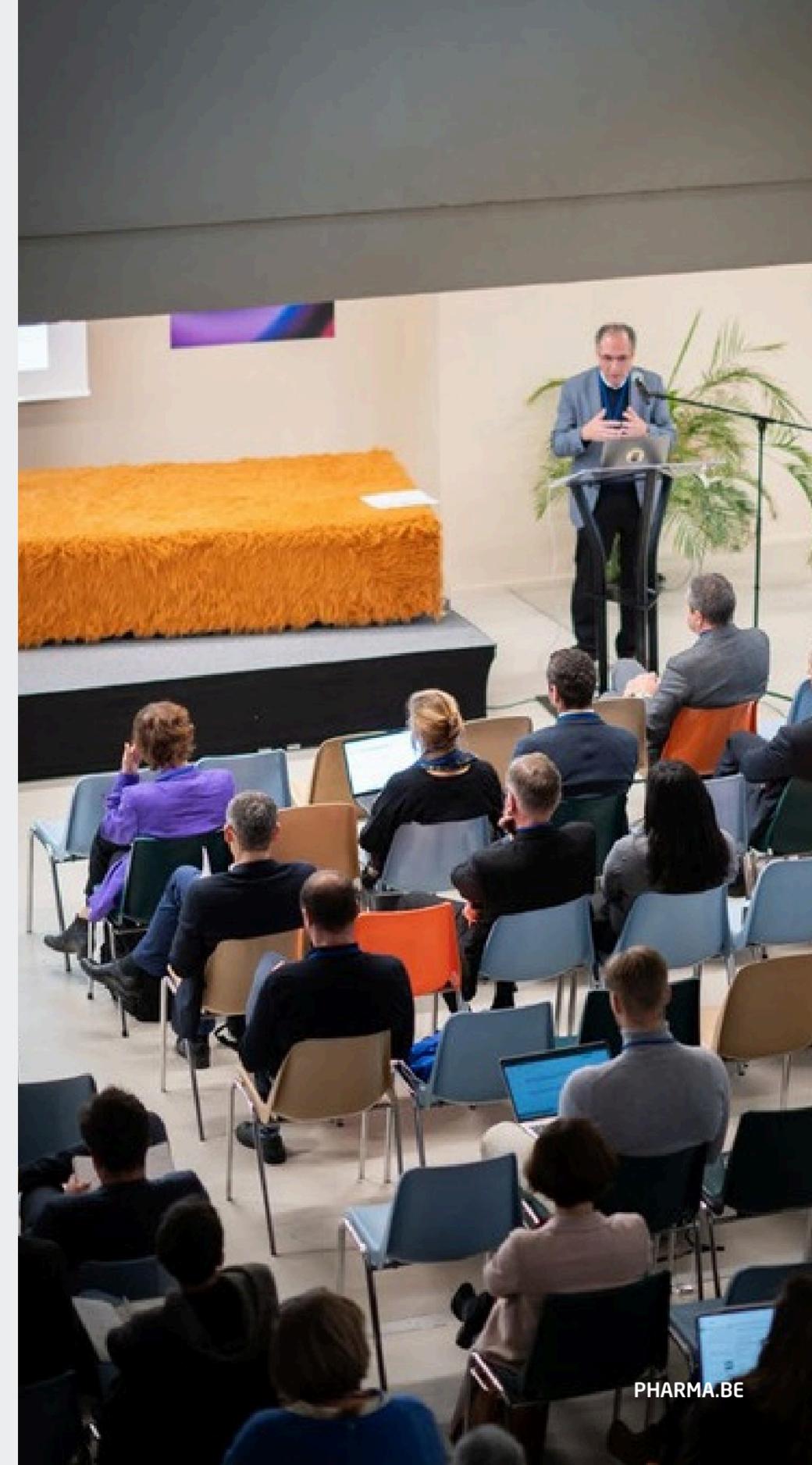
Bringing stakeholders together in a sustainable way on a frequent basis

November 2024

External event to kick-off the lung cancer working group about Lung cancer care: past, present and future together with different stakeholders

CATEGORIES
OF INITIATIVES
OF CROSS-HEALTHCARE
COLLABORATION
WITH PATIENT
ORGANISATIONS

- GOVERNANCE AND POLICY INITIATIVES
- DISEASE AWARENESS CAMPAIGNS
- HEALTH LITERACY INITIATIVES
- PATIENT JOURNEY INITIATIVES
- PATIENT MATERIALS AND SERVICES
- EDUCATIONAL AND INFORMATIVE MEETINGS
- DATA GATHERING INITIATIVES

GOVERNANCE AND POLICY INITIATIVES

Governance and policy objectives are essential for improving healthcare by structuring effective delivery, leading to better patient outcomes and quality of care.

However, implementing these objectives faces challenges like complex regulations, resistance from stakeholders, limited funds, workforce shortages, and political and economic hurdles. Overcoming these requires collaboration, stakeholder engagement, strategic resource use, and change management. Collaborative efforts might include drafting memorandums to influence policy, developing national disease plans, and engaging in parliamentary actions to support better healthcare policies. Such collaborations often involve pooling resources and expertise from patient organisations, HCP's, Universities, HCO's and biopharmaceutical companies, aiming to shape policies that prioritise the needs of patients and the healthcare community.

BELGIAN ALLIANCE FOR CARDIOVASCULAR HEALTH (BACH)

EXAMPLE

🔗 **WEBSITE**

Objective

BACH is dedicated to uniting diverse stakeholders within the Belgian cardiovascular health landscape. The collective mission of the alliance is to enhance awareness surrounding cardiovascular diseases and advocate for their prioritisation on the policy agenda. BACH calls upon policymakers to prioritise cardiovascular health by integrating health objectives into a comprehensive Belgian Cardiovascular Plan.

Stakeholders involved

Patient association
Belgian Heart League

HCP/expert associations
Belgian Society of Cardiology, Belgian Atherosclerosis Society, Belgian Stroke Council, Belgian Working group of Angiology, European Association of Preventive Cardiology, Belgian Working group of Rehabilitation and Prevention, Belgian Hypertension Committee

Biopharmaceutical companies
Amgen, AstraZeneca, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb Belgium, Daiichi Sankyo, Edwards Lifesciences, MSD Belgium, Novartis, Novo Nordisk, Sanofi, Servier Benelux
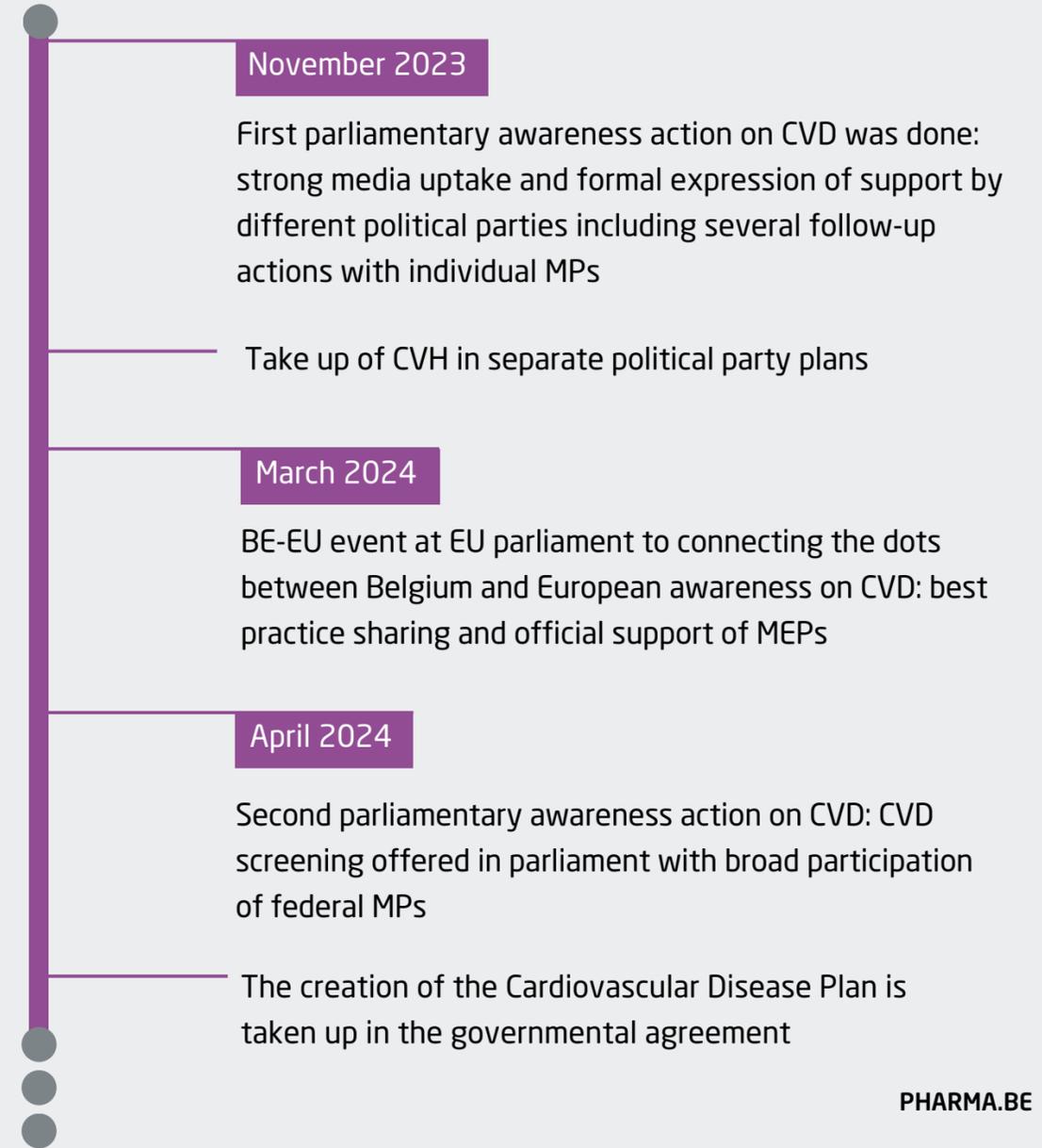
Ownership

Growth Inc neutral secretariat

Outcome

As a significant health concern, cardiovascular diseases, along with cancer, represent the primary cause of death in Belgium. These conditions impact over one million patients, resulting in nearly 30,000 fatalities and incurring an annual healthcare cost of 4.5 billion euros. The alliance is committed to addressing these challenges and fostering a healthier future by setting up parliamentary awareness campaigns, symposia, conferences, debates, writing a multi-stakeholder memorandum and laying the foundation for a Belgian CVH plan.

Key milestones

November 2023
First parliamentary awareness action on CVD was done: strong media uptake and formal expression of support by different political parties including several follow-up actions with individual MPs

Take up of CVH in separate political party plans

March 2024
BE-EU event at EU parliament to connecting the dots between Belgium and European awareness on CVD: best practice sharing and official support of MEPs

April 2024
Second parliamentary awareness action on CVD: CVD screening offered in parliament with broad participation of federal MPs

The creation of the Cardiovascular Disease Plan is taken up in the governmental agreement

RADDIAL

EXAMPLE

🔗 **WEBSITE**

Objective

The ambition of RADDIAL (Rare Disease Diagnosis Alliance) is to organise a broad dialogue between different stakeholders. Together we define several concrete and realistic policy recommendations to shorten the diagnosis pathway for rare disease patients and make them aware towards policy makers.

Stakeholders involved

Patient association
RadiOrg, BOKS, ABMM, VASCAPA

HCP/expert associations
SSMG, Domus Medica, KBS

Academic experts
UZ Leuven, UCL, UZA, Université de Mons, KUL, VUB, UZ Gent, CHU Liège, IPG Charleroi

Health insurance specialists
CM, CRM

Biopharmaceutical companies
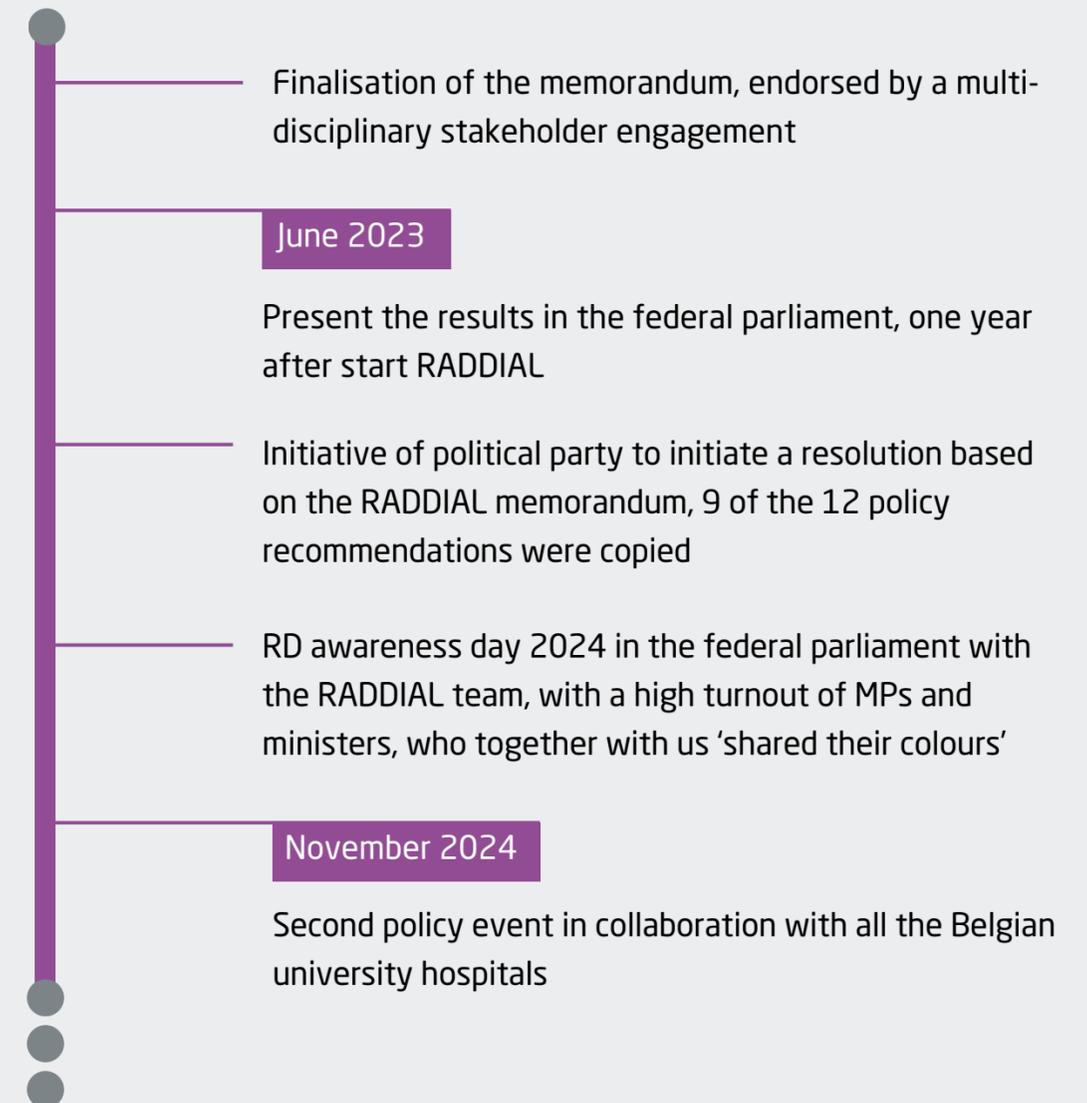Sanofi, Takeda, Chiesi, Johnson & Johnson, Alnylam

Ownership

RADDIAL members

Outcome

RADDIAL was founded in 2022. The Alliance consists of Sanofi, Takeda, Janssen, Chiesi and Alnylam, in collaboration with RaDiOrg. By mean of a series of roundtable conferences, RADDIAL brought together different stakeholders involved in the Rare Disease field for a collaborative dialogue. This resulted in the development of twelve concrete policy recommendations for a faster diagnosis of rare diseases in Belgium. The recommendations were clustered into four thematic areas and are listed in a memorandum. After presenting the memorandum in the federal parliament in June 2023, a resolution has been written and submitted by a political party in the parliament.

We continue the work of RADDIAL with highlights in 2024: Rare Disease day awareness action in the parliament and a next policy event, in collaboration with all university hospitals, RaDiOrg and RADDIAL in November 2024.

Key milestones

Finalisation of the memorandum, endorsed by a multi-disciplinary stakeholder engagement

June 2023

Present the results in the federal parliament, one year after start RADDIAL

Initiative of political party to initiate a resolution based on the RADDIAL memorandum, 9 of the 12 policy recommendations were copied

RD awareness day 2024 in the federal parliament with the RADDIAL team, with a high turnout of MPs and ministers, who together with us 'shared their colours'

November 2024

Second policy event in collaboration with all the Belgian university hospitals

DISEASE AWARENESS CAMPAIGNS

The patient journey involves many stakeholders like patients, healthcare providers, nurses, relatives, and employers. Recognising a disease and its impact is the first step in improving patient health. Each stakeholder plays a crucial role, and disease awareness campaigns help start the journey with the best information. This section focuses on raising disease awareness and educating patients and the public about the disease, diagnosis, and screening.

Objectives include:
- Educating the public about disease symptoms, diagnosis, and life impact
- Informing patients and their support network about the disease and treatments
- Highlighting patient support options

These efforts should produce independent, widely accessible disease awareness materials and events to empower patients and support organisations, without any promotional goals from pharmaceutical companies. Stakeholders ideally include patient organisations, healthcare professional associations, third-party agencies, pharmaceutical companies, and others related to the core message, like pharmacists, nurses, physiotherapists, and therapists.

WORLD AIDS DAY

EXAMPLE

Objective

Creation of a joint campaign across biopharmaceutical companies to raise awareness around HIV/AIDS and more specifically the message of U=U (Undetectable equals Untransmittable). People living with HIV/AIDS still face stigma and discrimination in Belgium as misinformation about HIV and U=U remains among the public. Also, no national awareness campaign is available.

Stakeholders involved

Biopharmaceutical companies
MSD, Gilead, ViiV: project leads

Patient organisations
Sensoa, Plateforme Prevention Sida, ex Aequo, Utopia: validation of campaign

HIV reference centres
Distribution of campaign

Third party agencies
Concept creation and social media advertising

Ownership

Created materials are owned by all participating biopharmaceutical companies, with each material including everyone's logo, the three Veeva promotional codes and company addresses.

Outcome

Shared cross-company campaign during the period of World AIDS Day and Awareness Month instead of multiple individual campaigns.

The campaign deliverables were:
- One webpage explaining the campaign message in easy and understandable language
- Posters, lightboxes and digital visuals that could be ordered (or downloaded) by the HIV reference centers and patient associations via an order module
- Shared company booth at the national congress of HIV with brochures
- Social media campaign with influencer Gustaph (a Belgian singer) towards the general public (creation, production and associated advertising)

Corporate materials for employees mail to spread the campaign message (such as signature banner).

Key milestones

For the third year in a row, this joint campaign was organised across several stakeholders

Joint-virtual meeting with HIV partners to review the campaign concept and gather feedback before campaign launch

The campaign was supported by and carried out in HIV reference centres and Patient Associations. Broad reach of campaign message thanks to collaboration and endorsement of influencer Gustaph

Positive feedback and high involvement of important HIV stakeholders

HEALTH LITERACY INITIATIVES

To empower patients to advocate for their own interests, it is crucial that they have a comprehensive understanding of the disease, available treatments and their pathways, innovations, and the healthcare environment. As a pharmaceutical industry, our societal role lies within applying a holistic approach towards patient engagement. This includes fostering an environment that encourages health literacy initiatives and/or contributing to health literacy initiatives.

This category showcases two initiatives that approach health literacy in a different way while having the exact same goal of providing tools to the population and patients to increase health literacy.

THE ABC OF CELL AND GENE THERAPY WEBINAR

EXAMPLE

🔗 **WEBSITE NL**   🔗 **WEBSITE FR**

Objective

Providing lay public with understandable information on advanced treatment medicinal products (ATMPs), also known as Cell and Gene therapies

Stakeholders involved

pharma.be
Organiser of the event through a small working group of representatives of multiple biopharmaceutical companies

PEC
Co-host of the event (to reach as many PAG members as possible)

Third Party
For logistics, studio, recordings, simultaneous translations, etc.

Speakers
Combination of HCPs, PAGs, patient testimonials, payers and industry

Ownership

pharma.be – Focus Group ATMPs

Outcome

A webinar in Dutch and French, recorded and available on-demand

Key milestones

Scientific update, regulatory framework and patient perspective were perceived

Chat function well used, also for follow-up

On demand version available on the website of pharma.be

HEALTHNEST, BRINGING HEALTH LITERACY TO LIFE

EXAMPLE

🔗 WEBSITE

Objective

HealthNest is a coalition of professionals and organisations that since 2013 is committed to addressing health literacy in Belgium. It searches, accompanies, and promotes Belgian projects in the field of health literacy, thereby increasing awareness around them and helping them realise a significant impact on the Belgian health landscape.

Stakeholders involved

HealthNest helps key actors and stakeholders pool together their experiences with health literacy and define what approaches have the most potential to improve the situation on the ground.

Stakeholders are:
- APB
- Domus Medica
- AUVB
- Belgische Cardiologische Liga
- Stichting tegen kanker
- KUL / UCL (Chairman)
- MSD
- Multipharma
- Ophaco
- Patient Empowerment vzw
- NIHDI
- Socialist mutual health insurance funds
- Zorgnet Icuro
- Reflexion Medical Network

The secretariat is managed by Growth Inc (paid service)
The congress has been set up in partnership with Deloitte (as a partner in health equity).

Ownership

HealthNest fosters an environment to encourage health literacy initiatives and aims to bring/keep health literacy on the policy agenda. It is an MSD sponsored initiative, with an independent board for decision making. No participants are paid to be a part of the initiative, and this is mainly for the neutrality of the project, and to respect the independence of participating organisations.

Outcome

Between 2013 and 2020 this was an initiative where yearly one to max three projects were elected as winners by the HealthNest board. The prize was non-monetary and existed out of coaching to further develop the initiative and give visibility to the winning projects and organisations. After 2020, HealthNest pivoted towards a platform and incubator to bring several organisations together.

Some of the recent outcomes are:
- the identification of five pillars to leverage health literacy initiatives, available in the format of a detailed report
- the first Health Literacy conference aiming to bring a wide range of stakeholders together and aiming to inspire by sharing best practices, (2023) and to be an "Inspirational Guide for Organisations and Governments" (2023)

With the guide at hand, HealthNest board members visit the political parties, with the ultimate goal to see health literacy incorporated in the policy notes.

PATIENT JOURNEY INITIATIVES

A patient journey maps the interactions and experience with the healthcare ecosystem, from the initial recognition of symptoms or need for care to the eventual outcome or resolution. It typically encompasses not only clinical interactions (such as doctor visits, tests, treatments, and surgeries) but also non-clinical aspects like emotional, social, and logistical challenges the patient may face. It focuses on understanding the holistic experience of the patient and carer.

The methods to create the journey can range from desk research, market research, and individual conversations with patients and healthcare providers to marketing advisory boards or other initiatives.

The ultimate objective is to create a better collective understanding of the patient's experience and to identify needs and gaps in the current treatment landscape.

Through this collaboration, we seek to develop innovative solutions that improve patient care and outcomes to enhance the patient pathway within the Belgian healthcare system. The patient journey built and supported by PO's aim to raise their voice towards policy makers and help move them towards solid patient-focused disease plans.

LONGKANKER NEDERLAND

EXAMPLE

🔗 WEBSITE

Objective

Via qualitative interviews with lung cancer patients (14) and carers (6) this initiative aimed to have a better view on the care of lung cancer patients in the Netherlands and more importantly, to have a view on the gaps in this care pathway.

Stakeholders involved

Patient organisations
Longkanker Nederland

Biopharmaceutical companies
- Roche
- MSD

External Company
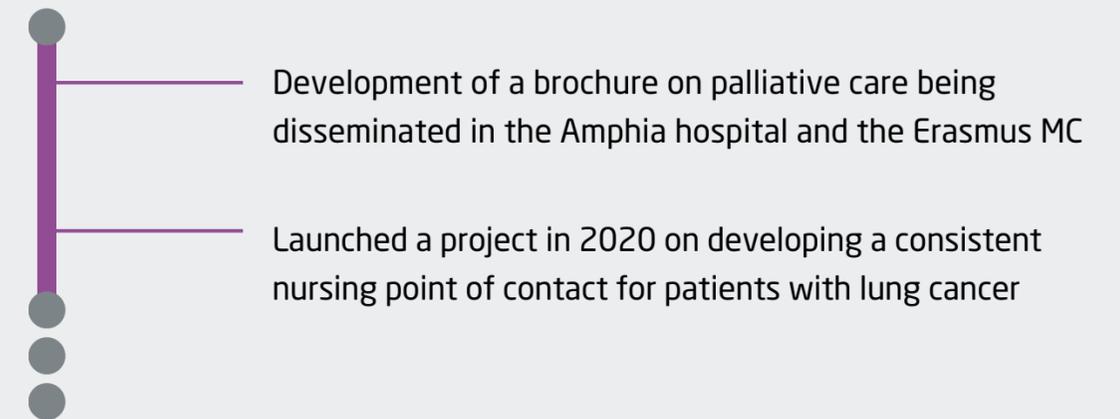Beautiful Lives

Ownership

Beautiful Lives undertook the research, Longkanker Nederland is the owner

Outcome

Identification of the needs and gaps for patients and carers, which were shared via the patient organisation, e.g.:
- More attention needed for psychological support
- Need for a single point of contact in cancer care
- Clearer information

Key milestones

Development of a brochure on palliative care being disseminated in the Amphia hospital and the Erasmus MC

Launched a project in 2020 on developing a consistent nursing point of contact for patients with lung cancer

PATIENT MATERIALS AND SERVICES

When developing tools, info brochures or services related to a therapeutic area, but not for one specific product, a patient organisation can collaborate with multiple companies on the same material rather than seeking individual support from every company.

There is a tendency to also look at digital health applications to support the treatment of and outcome of patients. Here as well, collaboration could lead to a more efficient use of resources. A dedicated focus group at pharma.be investigates the possibility of these types of collaborations. It is important to ensure a centralised distribution of material and to guarantee only one material exists (no duplication by different pharmaceutical companies). That is why ownership should ideally be with the patient organisation.

DIGITAL HEALTH APPLICATION

Objective

We are active in the domain of multiple myeloma. After a multidisciplinary advisory board, the rehabilitation of patients was highlighted as an important gap in the current patient pathway. Although we are not active in rehabilitation as such, our mission to serve patients goes beyond the prescription of our drugs. We setup a multistakeholder partnership to improve the rehabilitation of Multiple Myeloma patient's post-transplant.

Stakeholders involved

UZ Brussel

- Haematologist
- Transplant coordinator
- Physiotherapy team

MoveUp

Third party with a proven rehabilitation pathway for patients following hip and knee surgery

Amgen

Setting up and managing the VBHC, facilitating multistakeholder advisory boards and bringing different experts around the table

Ownership

The UZ Brussels team developed the rehabilitation pathway - moveUP is owner of the supporting application.

Outcome

This three-party partnership, with input from experts of other hospitals in Belgium, led to the development and implementation of the rehabilitation pathway in a pilot phase in UZ Brussel. Short presentation on the pilot study is available on **video**.

Key milestones

With the limited support of one company, we were able to execute the pilot over multiple years. Milestones payments: consider budget spread over multiple years

BELGIAN PROSTATE CANCER WORKING GROUP FOR SHARED DECISION-MAKING MATERIALS

Objective

The Belgian Prostate Cancer Working Group objective is to initiate a pilot collaboration with pre-set deliverables to facilitate Shared Decision Making (SDM) among prostate cancer patients to improve the lives and care of patients living with prostate cancer in Belgium. The parties engaging into this cross-healthcare collaboration through the Belgian Prostate Cancer Working Group are convinced that by pooling and channelling resources, expertise, and information there is the ability to coordinate and scale more impactful and unbiased solutions that help respond to the detected patient needs better than what could potentially be achieved by each individual party.

Stakeholders involved

The Belgian Prostate Cancer Working Group is an informal group that brings together multiple companies and PAGs working on prostate cancer in Belgium.

Biopharmaceutical companies
Bayer, Johnson & Johnson, Astellas, Novartis, Pfizer

Patient organisations
Wij Ook with advice/support of Think Blue

HCP/HCO (consultancy)

Ownership

To ensure co-creation and neutrality a PAG, more concrete vzw Wij Ook, will be the owner of this pilot project. With the assistance of the other working group members the PAG will coordinate the working group meetings, the creation of the material and the administration regarding invoices and contracts. All the members of the working group will equally contribute financially to the foreseen pilot outcomes.

Outcome

The deliverables of the pilot project are the following (non-exhaustive list):

- Creating and providing availability (digital and printed) of patient-focused infographic/brochure in Dutch and French to guide patients and their families through their disease journey, help patients to engage properly with their HCP, ask the correct questions during consultation and explain how they can implement SDM.
- Launch campaign for these materials, potentially consisting of launch event, multi-channel media presence, advertising in scientific magazine, presence at local congress, etc.

PHARMA.BE
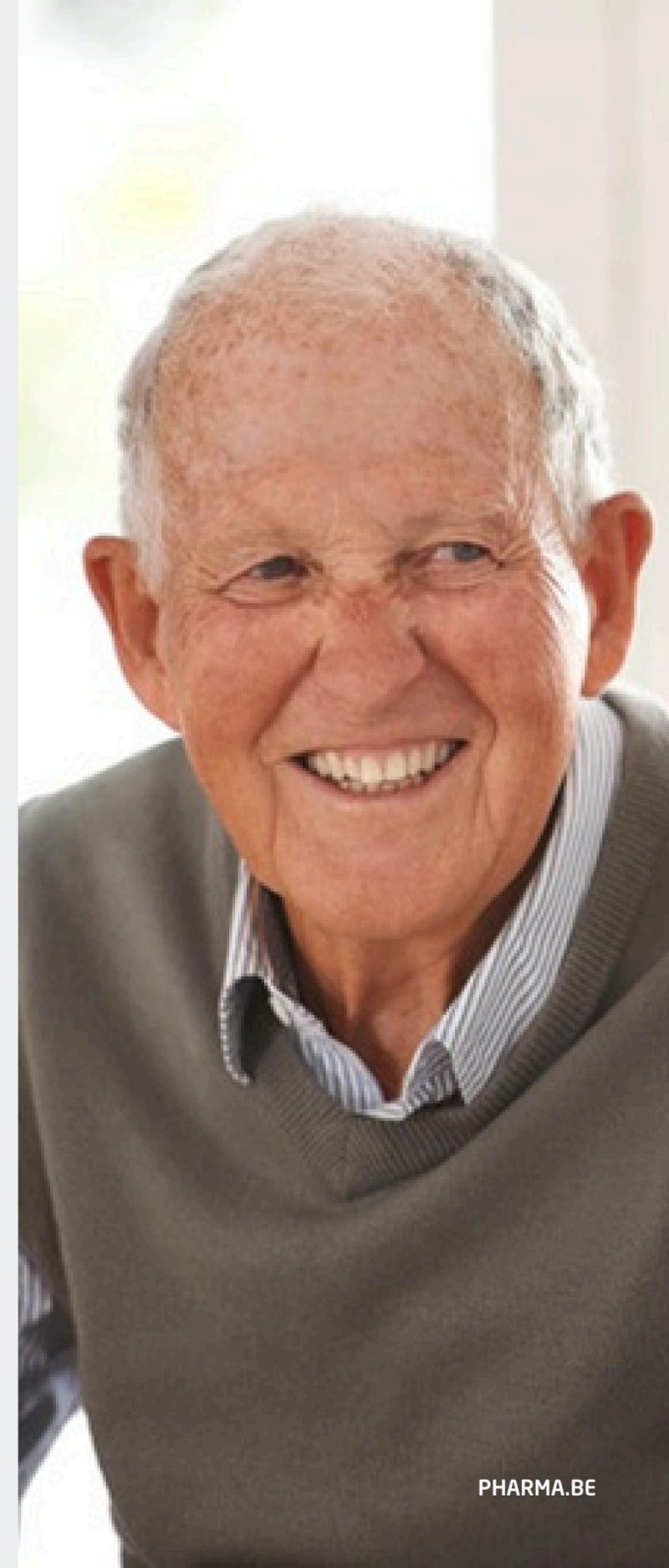
EDUCATIONAL AND INFORMATIVE MEETINGS

When a patient organisation aims to organise an educational meeting in a therapeutic area where multiple companies are active, support can be solicited from these companies in reaching out to potential speakers and assistance with logistics.

It is advised to work with an independent third party to take the organisation in charge with support of multiple companies.

MULTI-COMPANY PATIENT ADBOARD

Objective

To gather insights from patients on their experiences and journeys, we organised adboards with different patients to question their insights. As the questions were not related to specific products, but to more general multiple myeloma related experiences, Amgen and Sanofi collaborated on this.

Stakeholders involved

Amgen and Sanofi
Medical department together with patient engagement leads

UZ Leuven and Jolimont
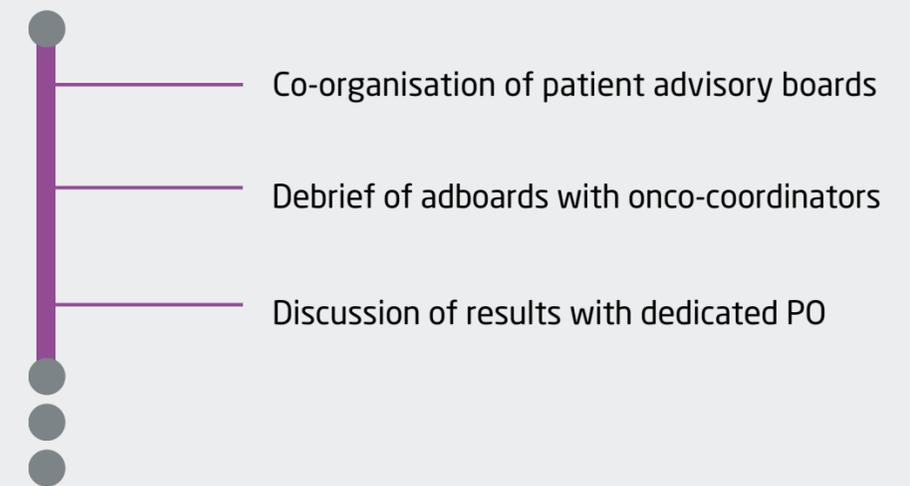Haematologist and onco-coordinator

MM patients from UZ Leuven and Jolimont in various stages of their disease

CMP & Mymu

Outcome

In each hospital, an adboard was organised with a small selection of patients, led by the onco-coordinator, to discuss gaps in the patient journey (non-treatment related) and identify potential initiatives to address these gaps. The outcome was shared with respective patient organisations.

Key milestones

Co-organisation of patient advisory boards

Debrief of adboards with onco-coordinators

Discussion of results with dedicated PO

DATA GATHERING INITIATIVES

These objectives focus on using data to benefit patients and the healthcare community. Projects may include creating registries to gather data on diseases, patient demographics, and treatment outcomes. pharma.be helps connect biopharma companies and governmental institutions (e.g. NIHDI, Sciensano, FAMHP, clinical experts) to maintain these registries.

Other initiatives involve developing patient-reported outcome and experience measures (PROMs and PREMs) to gather insights directly from patients, aiding medicine development and healthcare decisions. Collaborations also ensure secure access to patient data for research and allow the repurposing of existing data for new insights. By working in this cross-healthcare collaborative space, pharmaceutical companies, healthcare institutions, and patient organisations can use data to drive innovation and improve patient outcomes.

Involving patients in data initiatives empowers them and gives them a voice in healthcare research. Overall, these collaborations lead to impactful research and a better understanding of diseases, benefitting patients and the broader healthcare system.

DISEASE REGISTRY
EXAMPLE

Objective

Gather data on diseases, patient demographics, and treatment outcomes.

Stakeholders involved

Doctors, nurses
Sciensano
Industry (via pharma.be)

Ownership

Sciensano

Outcome

A qualitative disease registry with the minimum care dataset and datapoints important for industry that is FAIR:

- Findable
- Accessible
- Interoperable
- Re-usable

Key milestones

Contracts signed

First data registration in the registers

GENERAL TIPS AND TRICKS

Collaboration between pharmaceutical companies, and other healthcare-focused partners, such as patient organisations, healthcare professionals and/or organisations in multistakeholder initiatives is essential for advancing healthcare innovation and improving patient outcomes. However, successful collaboration requires careful navigation of diverse interests, effective communication, and mutual trust. In this chapter, we will explore practical tips and tricks to enhance collaboration between these two stakeholder groups.

- Open the initiative to all relevant companies/organisations, avoid a closed and limited group of stakeholders using a simple structured canvas
- Be transparent
- Foster open communication:
  - Transparency between different partners
  - Regular dialogue, feedback sessions and information sharing
  - Ensure all stakeholders have equal opportunities to contribute their perspectives and insights
- Define clear objectives, expectations, and deliverables to ensure alignment and accountability
  - Identify objectives of mutual interest
  - Roadmap for achieving these goals, including timelines and milestones
  - Define clear expectations (timings, budget, outcomes)
- Define clear roles and responsibilities of each stakeholder within collaboration
  - Leverage complementary expertise and resources – every partner has unique strengths, expertise and resources
  - Ensure equal voice and equal input from the different stakeholders
- Define clear governance structures and decision-making processes to facilitate effective collaboration (to ensure alignment within the same stakeholder group – it might be relevant to have sometimes separate meetings with the same stakeholders to ensure one voice per stakeholder group)

You can find hereafter an overview of the key learnings and hurdles from past and present cross-healthcare collaboration projects, as well as various tips on making the collaborations a success and on way of working gathered from these experiences.

Specific learnings

- Setting clear goals and ways of working from the beginning, even if time consuming, will result in more time gain and better collaboration afterwards
  (from All.Can Lung Cancer Working Group)

- Important to align early in the project around practical and compliance details of the collaboration in a collaboration charter but be aware of the time it takes to first establish this with the involved teams **(from World AIDS DAY)**

- Aligning as one industry voice: separate industry calls to decrease attention of industry during alliance meetings **(from BACH)**

- Third party involvement can imply high financial needs **(from BACH)**

- Establish one primary point of contact for patient associations by company (schedule all touchpoints with PAGs together with each company's Patient Engagement Lead)
  (from World AIDS Day)

- In the output generated the logo of the PAG will be represented and "funded by" followed by the member pharmaceutical companies will be mentioned, as a resemblance of equal input and equal voice within the group
  (from Belgian Prostate Cancer Working Group)

Specific hurdles

- **TIME MANAGEMENT:**
  - Alignment on a WoW and MoU with all stakeholders involved takes time and is not easy **(from BACH)**

- **LEGAL AND COMPLIANCE:**
  - Many involved companies imply many different compliance rules and legal requirements **(from BACH)**
  - Took couple of months as multiple industry partners involved with varying legal requirements **(from RADDIAL)**

- **OTHER:**
  - Equal voice and equal input: not always easy with many stakeholders involved **(from BACH)**

Success factors

- Collaboration led to identification of prioritised initiatives in group and subsequently create taskforce of members interested to participate per initiative results in more efficient collaboration
  (from All.Can Lung Cancer Working Group)

- Unification in RADDIAL led to a stronger voice, with more credibility towards policy makers and bigger achievements **(from RADDIAL)**

- Early project plan and goal alignment:
  - Setting clear common goals from early start is essential
    (from BACH, from Digital Health Application and BE Prostate Cancer Working Group)
  - Clear from the beginning for all partners, which is important to ensure its respected by all members
    (from RADDIAL)

- An independent chairman, who is also a renowned health literacy expert, is an important part of the success of the initiative **(from HealthNest)**

- The diversity of partner organisations (board members) reinforces the accessibility and credibility of the project (especially since there are no payments involved). The fact that industry is not in a leading role, is much appreciated by the partners **(from HealthNest)**

Specific ways of working

- All elements related to the Prostate Cancer Working Group will be hosted on an online shared platform, such as SharePoint, where all information is accessible to all members (i.e: meeting minutes, material design, input on materials, offers, invoices and contracts)
  (from Belgian Prostate Cancer Working Group)

- All decisions regarding the deliverables of the pilot project and taken approaches will be made by unanimous consensus
  (from Belgian Prostate Cancer Working Group)

CONTACT DETAILS

It is important to note that this is a working document, and we are still learning. This is not the golden thread, but rather a first step to inspire further development. We also need input from all external parties, so please share your own tips and tricks. Let us join forces before embarking in parallel on a patient-focused project.

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GLOSSARY

ATMP	Advanced Treatment Medicinal Products
CVH	Cardio Vascular Health
CVD	Cardio Vascular Disease
CM	Christelijke Mutualiteit (Christian Sick Fund)
CRM	Commission for Reimbursement of Medicines
EFPIA	European Federation of Pharmaceutical Industries and Associations
EUPATI	European Patients' Academy on Therapeutic Innovation
FAMHP	Federal Agency for Medicines and Health Products
GANTT	Chart named after Henry Gantt
GDPR	General Data Protection Regulation
GP	General Practitioner
HCP	Health Care Professionals
HCO	Health Care Organisation
HIV	Human Immunodeficiency Virus

GLOSSARY

KPI	Key Performance Indicator
MoU	Memorandum Of Understanding
MM	Multiple Myeloma
NIHDI	National Institute for Health and Disability
PAG	Patient Advocacy Group
PO	Patient Organisation
PEC	Patient Expert Center
PROM	Patient Reported Outcome Measures
PREM	Patient Reported Experience Measures
RD	Rare Disease
R&D	Research & Development
SDM	Shared Decision Making
VBHC	Value Based Health Care
WoW	Way of Working

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ALGEMENE VERENIGING VAN DE GENEESMIDDELENINDUSTRIE