

Future of Advocacy Partnerships



This project has been initiated and funded by Sanofi. Sanofi hosted a roundtable discussion with patient groups in July 2020 and commissioned M&F Health to develop this report, which has been informed by the roundtable discussions and input from the patient group organisations that attended.

Contents

1	Foreword by Henry Featherstone	3
2	Setting the scene	4
3	The value of collaboration	7
4	Case study: Missing Pieces campaign – the value of collaboration from the outset	9
5	Establishing key principles for partnership	10
6	A vision for the future	12
7	Vision for 2030	13
8	Calls to action	15

Foreword by Henry Featherstone, Head of UK Public Affairs, Sanofi



"We recognise the importance of working collaboratively with patient organisations and strive to ensure that the patient voice is at the heart of all that Sanofi do."

Collaborative advocacy between the pharmaceutical industry and patient advocacy groups lies at the heart of pursuing better health outcomes. This has been evident in recent years with successful partnerships and sharing of expertise leading to improvements in clinical trials and better patient engagement and communication through the life cycle of medicines. This provides research insights for the development of more personalised medicines, and ultimately better outcomes for patients.¹

Advocacy remains a complex process. It involves a diverse ecosystem of stakeholders: pharmaceutical companies, research bodies, policymakers, clinicians, and patient advocacy groups are all operating in the same space, either working independently or in partnership towards common goals. However, the environment is such that sometimes patient advocacy groups are unable to participate as equals in a partnership, or the decision-making process, when they should be at the heart of it. It is not enough to state an intention to make the patient voice central to the advocacy work; this can only be achieved through genuine equity in partnership working.

What are the barriers to full participation and equity? They are many and varied, but for some groups problems lurk in the increasing administrative burden that comes with working with industry. Others may be sceptical of the nature of partnership and afraid their involvement is a tick-box exercise. Others may be afraid of backlash from their community, or the media.

As a health journey partner, Sanofi is committed to putting patients first and to amplifying patient

voices. We recognise the challenges that patient groups face and want to help overcome them so that we can work together effectively and deliver the best outcomes for patients as part of our advocacy work.

Our aim is to celebrate working collaboratively. We are keen to look at the ways we can extend and increase the benefits of such partnerships under the increased transparency and reporting to which all organisations need to adhere. This report is borne out of a workshop that brought together representative voices from a number of different patient advocacy organisations. Our intention was to provide a space for this group to discuss the current state of play of patient group-industry partnerships and to identify key challenges and potential solutions. Drawing on our findings, we aim to create a blueprint for the next generation of industry representatives and patient advocates, to help drive collaboration that will lead to improved outcomes for patients, patient organisations and industry.

In the following pages, we examine some of the obstacles to partnership working and provide thoughts on solutions we hope will inspire positive change. While it's just a starting point, it's important. We are in challenging times, as COVID-19 and upcoming changes to the NHS demand we become more adaptable and imaginative, flexible and interconnected. The solutions we find together must fit with our changing environment.

As one of many crucial conversations to come, we invite you to read on and weigh in on the future of advocacy.

Setting the scene

In order to create change in the dynamics of partnerships and collaborations, to deliver better outcomes for patients, it is critical to understand where we are now.

Advocacy partnership activity is highly diverse in nature and includes work on disease awareness, access to medicines and medical devices, shaping health policy, improving diagnostic pathways and patient journeys. Pharmaceutical companies and patient groups do important work, separately and together, that brings them into regular contact with stakeholders: the NHS of course, but also the National Institute for Health and Care Excellence (NICE), and the Medicines and Healthcare products Regulatory Agency (MHRA) (organisations which are involved at different stages of medication approval, licensing and availability), the Association of the British Pharmaceutical Industry (ABPI) (representing industry), and then a host of other organisational and individual stakeholders, policy-makers and media representatives, which wield influence. These different groups will all play a key role in shaping the new NHS and, in the midst of the COVID-19 pandemic, are keen to define key principles to guide successful future working.

Without the full participation of all stakeholders, holistic health pathways and solutions that best meet patients' needs cannot be achieved.



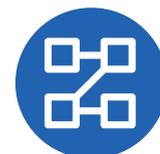
Disease awareness



Access to medicines and medical devices



Shaping health policy



Improving diagnostic pathways and patient journeys





Reflections on partnership working from Steve Clark, living with stage IV bowel cancer and Founder of Strive for Five

I've had a long career in the pharmaceutical industry and I spent many years working in marketing focusing on campaigns and projects that I delivered in partnership with patient groups. I always found this part of my work the most rewarding, and I look back with pride on some of the advocacy 'wins' I helped to deliver for patients alongside fantastic, hard-working charities.

It never really occurred to me that there was a chance that I myself might become 'a patient', but a few years ago I was diagnosed with Stage IV bowel cancer, still in my forties and to all outward appearances fighting fit and well. It was a huge shock, and a life-changing moment. I've therefore experienced first-hand the value and support that patient groups can offer.

I became involved in patient advocacy very quickly, working closely with a prominent patient group and even setting up a campaign to help give hope to fellow Stage IV cancer patients, and I think I now have a fairly unusual level of insight – I am often witness to how patients and their representatives view the pharmaceutical industry, and I still wear my industry hat occasionally too!

Of course, every patient community has a different perspective. In cancer, I think it is fair to say that there can be a degree of scepticism

about pharmaceutical involvement in patient facing activities. Yet, the media, which often paints a 'big, bad pharma' picture, usually celebrates clinical trials by crediting the scientific institutions while not acknowledging industry involvement (other than the current vaccine situation). Different contexts give different perspectives. I think some patients fear that pharmaceutical companies only get involved with patient groups for commercial gain, and it would be nice to see that view change. Open and honest communication is needed, and change will take time. Pharmaceutical companies can help by being clear and transparent about the development process for new and innovative treatments to help clarify misunderstandings. Patient advocates and groups can help by talking about positive work done together.

I honestly believe that there are interesting stories to be told about ways in which industry and patient groups are coming together to create positive change. If we can tell some of these stories, we can change hearts and minds, and adjust the environment for collaboration. Only then, will we be able to remove many of the barriers to effective partnerships, and deliver genuinely improved outcomes for individuals and the NHS.

KEY MILESTONES OF SUCCESSFUL ADVOCACY



HIV and Pre-exposure prophylaxis (PrEP)

Things have come a long way since the 'Don't Die of Ignorance' campaign in the 1980s. Today, public awareness of HIV and access to care and treatment has increased and cases of HIV infection continue to drop – the most recent HIV report from Public Health England indicates new diagnosis rates were down 29% between 2014 and 2018 in the UK.² Thanks to collective and sustained advocacy, governments have recognised HIV in policy and legislation, culminating in treatment being made universally available on the NHS. Advocacy also led to a High Court ruling to make the life-changing preventative intervention, pre-exposure prophylaxis (PrEP) – a once daily pill which prevents people without HIV from getting HIV if they are high risk – available to those who need it and meet the eligible criteria.³



Hepatitis C

Current levels of awareness of hepatitis C have inarguably been achieved through continued collaborative advocacy and campaigning. In England, there has been substantial progress towards the World Health Organization's ambition to reduce infections and mortality by 2030, with NHS England recently announcing its hepatitis C 'elimination deal' that guarantees access to treatment for anyone who's been diagnosed.⁴



Meningitis Vaccines

By ensuring access to care and treatments, advocacy activity can be life-changing for patients. Equally, it can ensure the protection of public health in wider society. The hugely successful 'Beat it Now' campaign by Meningitis Now recently led to the incorporation of a free meningitis B vaccine into the NHS immunisation programme. This breakthrough makes the UK the first country in the world to offer new-born babies protection against the infection via a national health service, demonstrating the value of advocacy to improving and protecting public health.⁵

HOW HAS COVID-19 SHAPED PARTNERSHIP WORKING?

The COVID-19 pandemic shone a spotlight on the importance of working together. The need within specific communities has been urgent, and solutions have had to be found fast. It has shown how, by breaking down traditional boundaries between private companies, patient groups, government, NHS England, regulators and NICE, work can be faster, more innovative and effective, achieving more than the sum of its parts and delivering a better result for patients. The MHRA has worked with industry

to provide rapid scientific advice, reviews and approvals on potential treatments and vaccines for COVID-19 to help ensure that breakthroughs are not held back by regulatory hurdles. NICE has in turn worked collaboratively with the MHRA to provide rapid evidence summaries for treatments. It has also worked with stakeholders across the clinical and policy community to provide rapid guidelines in protocols adapted specifically to support accelerated timelines in the pandemic.

The value of collaboration

Industry and patient groups have identified a myriad of benefits of working collaboratively.



> **Sharing skills and resources**

Both patient groups and industry value the expertise, resource and insights the other can bring to advocacy activity. For a pharmaceutical company, collaboration brings valuable insights on patient experience and needs, that help to orient research, shape future treatment development and clinical trials and inform patient support activities. Patient organisations value the data and medical insights on treatment that industry is able to provide, alongside their perspectives and insights on policy issues, from their experience of working with the medical communities, the NHS and regulatory bodies. Working in partnership can achieve more than the sum of its parts individually creating greater impact for campaigns and change.



> **Articulating the patient voice**

Patient insights are instrumental in shaping patient pathways, helping to design programmes that support patient experience and their interface with healthcare professionals or informing policymakers of the perceived value of an intervention. In a digital age, patient groups can connect with their membership and identify these insights more readily than ever before. Pharmaceutical companies and patient groups share common priorities and can build very successful partnerships, for instance to raise disease awareness and help ensure patients can access the diagnosis and care they need. Through working collaboratively, they can reach a bigger audience leveraging their own channels, networks and sharing resources.



> **Complementing rather than conflicting**

For both industry and patient organisations, collaboration is an important way to ensure they are not duplicating efforts or creating conflicting or confusing messages for advocacy audiences. By working together, they can ensure efforts to shape policy and public perception of an issue are attuned. Through regular engagement between parties, one's work could more often be a platform to build on.

Rob Dawson, Director of Communications, Advocacy and Support, Meningitis Research Foundation – The Benefits of Early Collaboration

I've worked in several disease areas over the years and while there has always been collaboration, the biggest problem is that quite often that collaboration happens at a late stage, by which point it is difficult to make the most of the expertise of different partner organisations. I have reflected on a number of occasions that had all views been included at the beginning of a new campaign or project, it would have changed the direction of the project and been richer for it.

We've seen this recently with a great, well-intentioned campaign aimed at encouraging university students to get vaccinated against meningitis. We know from our work that students are more likely to get vaccinated if their mother gives them some gentle encouragement! Because we came a bit late to the campaign we weren't able to make this point and the campaign went ahead targeting students directly. It was really well executed but just because it was missing this insight we didn't quite see the desired uptake in vaccinations. When we later ran a campaign that was targeted at Mums, it made all the difference. It's a really basic insight but it went untapped.

It goes without saying that we learn a huge amount from speaking to patients on a daily basis, and this can be hugely helpful in setting the tone of a campaign or project in the developmental stages, where partners may not have the same level of knowledge or familiarity.

We've found that the best way to work is for a basic idea to be put on the table in the early stages, and for partners then to work together to develop a plan on how to meet shared objectives. This co-design approach requires greater collaboration and engagement from partners, but really delivers in terms of a campaign designed to meet everybody's objectives. Then, with greater collaboration and co-production throughout, the outputs live up to expectations for the involved parties too.

I think people think that the time involved may be prohibitive, but in my experience if you're open about the time you have available in the beginning, working in collaboration can actually reduce the time spent on projects because you have more resources available and it can help partners to focus on the projects with the biggest impact for patients.

Dany Bell, Strategic Advisor for Treatment, Medicines and Genomics, Macmillan Cancer Support – Our journey to working collaboratively

We take pride at Macmillan in ensuring that evidence underpins all of the work we do, which is why we have recently established a new Innovation Board which has commissioned a piece of insight to explore how we can most effectively work in collaboration with industry to achieve our shared ambitions in cancer.

The Board are reviewing the market and gaining insight to identify the challenges and opportunities into where working collaboratively might be beneficial in supporting Macmillan's overarching aim to address the unmet needs of patients.

It's taken us a while to get to this point, but as the pharmaceutical industry and its approach have evolved over the past ten years, so has our policy towards collaboration, as new opportunities emerge to create valuable partnerships for the benefit of cancer patients.

We've already started to take part in collaborative projects over recent years which we have found

valuable, including through our Business Team who have been working with industry on our professional events.

We know that there are many opportunities that come from collaborating with industry and look forward to being pro-active as these emerge to align on projects and work together to achieve a greater impact for the future of all those affected by cancer.

"We know that there are many opportunities that come from collaborating with industry."

Case Study

Missing Pieces campaign – the value of collaboration from the outset

The Missing Pieces campaign was a collaborative project initiated by Sanofi UK in 2018 after listening to people with multiple sclerosis (MS) on the main challenges they believed still existed for the MS community. The discrepancies in service provision and lack of awareness amongst people around what care they should expect were raised as key issues.

Although the initial patient survey and report, which were executed by Sanofi with input from The MS Trust, were successful, in reflecting on the activity, the team at Sanofi felt there was a piece missing. It was apparent on their reflection that there would have been increased value if the MS Trust had been involved at an earlier stage and a more truly strategic partnership approach could have been taken.

Learning from this, Sanofi re-engaged the MS Trust to discuss what further steps could be taken and both agreed that a call for better implementation of the service specifications

in MS was needed and met mutual objectives for both organisations. The MS Trust and Sanofi then co-hosted a parliamentary event in December 2018 to present recommendations from the report to policymakers, highlighting the importance of implementation and what this will mean for the MS community.

In this example, early industry-PAG collaborative working resulted in public awareness raising around the need to transform MS care and improve the quality of life of people who are affected by this complex condition. The Missing Pieces campaign aligned with the nine consensus statements in the MS Trust's MS Forward View report,⁶ which set out the ambition for the future of MS Services in England and presented a shared view about the priority actions needed to make MS care fair across the UK.⁷

Establishing key principles for partnership

Workshop participants agreed the following key principles to effective and equitable partnership working:



Patient first: Projects should put the patient first, ensuring it is built around patients' needs from the start and involving them or reflecting their views at every stage of the journey. Partners should also be courageous and overcome possible challenges when developing the project to achieve what is right for patients.



Establishing and respecting expertise: Patient groups and industry should aim to co-create projects and ensure that both parties are able to meaningfully engage and contribute their respective expertise. Sometimes patient groups are presented with a near-complete idea at the end of the programme, which does not respect their independence. The importance of their expertise should be recognised, and industry should engage them early on in the project lifecycle to support the co-creation of advocacy programmes.



Support each partners' practical requirements: Industry and patient groups should work together to understand the practical requirements for initiating and running collaborative projects, with industry providing the support required to ensure that patient groups feel empowered and sufficiently resourced to meaningfully engage. Small and medium-sized patient groups may face unique challenges due to limited infrastructure or legal expertise compared to larger organisations.



Profile the benefits of collaboration: Industry and patient groups should profile examples of collaboration in a balanced way and talk about the benefits, to ensure the value is effectively communicated to patients and stakeholders, helping to shift perceptions and demonstrate the need for this type of work.



Embedding the principles of each partner: Every organisation works with their own set of values and principles. When entering the collaboration, partners should bring them into the discussions, and these should be taken into account at the start of engagement.

Ultimately, by identifying key challenges and supporting improvements in these areas, industry and patient groups can together deliver meaningful change.

Rachel Power, Chief Executive, Patients Association – Transforming our interactions with industry

When I joined the Patients Association a few years ago our interactions with industry tended to be quite transactional. However, over the past few years we've been working towards more of a partnership model of collaboration, within which our pharma colleagues have become part of our journey.

When we were developing our partnership model our aim was to ensure that pharmaceutical companies are aware and supportive of our core aims and objectives. Then, when more specific collaborative opportunities emerge we already have a forum in place to share ideas and identify opportunities to work together, often with more than one industry partner. While sometimes having multiple partners can seem complicated at the outset, in our experience the benefits outweigh the challenges.

The partnership model gives us a level of consistency and continuity in our relationships with industry colleagues. We are now in discussion with a core group of partners on an ongoing basis as opposed to once or twice a year when individual projects or collaborative opportunities crop-up. It has helped us move beyond a focus

on funding. The partnership model creates the right environment to think about peer-to-peer support, and where applicable, logistical support throughout the year. I believe our model could work for other patient advocacy groups, and that it would be particularly beneficial for smaller charities that may require more resource and logistical support or who are new to working in partnership with industry and are perhaps nervous about taking the first step.

I think one of the barriers to collaboration is concern about public perception. But it's important that the public are made aware of the benefits of charities working closely with industry. Collaboration helps us to cover our core costs and provides real opportunities to maximise resources and effort. Working with industry has never influenced our direction or decision-making; our pharma colleagues are genuinely looking to support the Patients Association and the work that we're doing, and we have been able to deliver real benefits to patients as a result whilst allowing us to maintain our complete independence.

"The partnership model gives us a level of consistency and continuity in our relationships with industry colleagues."

**Rachel Power,
Chief Executive, Patients Association**



A vision for the future

It is time to take stock and recalibrate. The pharmaceutical industry has made great strides in changing its way of working, moving to a model where patient needs are considered at every stage and more patient-facing roles have been created, but how can industry do even better? How do pharmaceutical companies become even more collaborative? What more can be achieved for patients?

In the wake of the shock of COVID-19, industry has had to step up. We have seen encouraging examples of companies nimbly providing support to patient communities in need through various means, such as the swift deployment of clever digital campaigns to raise awareness, or the redesign of clinical trials to be more remote and flexible. Confidence in industry is on the rise – and now it must harness the rising tide of goodwill and demonstrate that working collaboratively is vital and here to stay.

By reinventing our approach to partnership, what can we achieve?

> More impactful projects.

By working together, patient groups and industry can lift up advocacy campaigns to another level. Campaigns run by industry without the patient voice at their heart may have breadth, but ultimately may miss their target because they lack genuine first-hand experience, or they tackle an issue from the wrong direction. Empowering patient groups to become equitable co-designers with industry ensures projects are based on genuine insights, more tailored, and make a greater impact on patients' lives.

> More opportunities for partnerships and more ambitious projects.

Pharmaceutical companies should think bigger, bolder and better and be less risk averse when it comes to partnership activities in order to make a real difference to patient's lives. With a bolder blueprint in mind, parties can work together to act as 'disruptors', to overhaul patient experience and think in a fresh way.

> Patients' needs targeted and addressed better than ever before.

This should be the start, middle and end, of any future project that is being shaped through partnership. Is the patient at the heart of all projects and decisions impacting them? Are their needs being addressed, is their quality of life being improved, are they being treated with honesty and integrity? If so, projects should be developed with confidence, if not, organisations' approach must change. All partners should feel comfortable to ask these questions at every stage of collaboration.

Vision for 2030

“There needs to be an equal playing field where charities are respected for the value they bring, and to simplify to processes along the way as well.”

Bob Stevens, Group Chief Executive, MPS Society

“Partnerships with patient organisations need to be mainstreamed at every point along the pharma development pathway, so they’re not just brought in at the end.”

Shelagh McKinlay, Head of Patient Advocacy, Myeloma UK

“All interested parties are involved from the outset, and there’s absolute clarity around the impact and benefit that it will have for patients. It’s about patient organisations and pharma genuinely working together and respecting the roles that both parties bring, as the sum of the whole is greater than the parts.”

Marc Stowell, Executive Director of Communications and Income Generation, Kidney Research UK

“Be early and be proud, we need to celebrate collaborations rather than excuse them.”

Joel Rose, Chief Executive, Cardiomyopathy UK

Joel Rose, Chief Executive, Cardiomyopathy UK

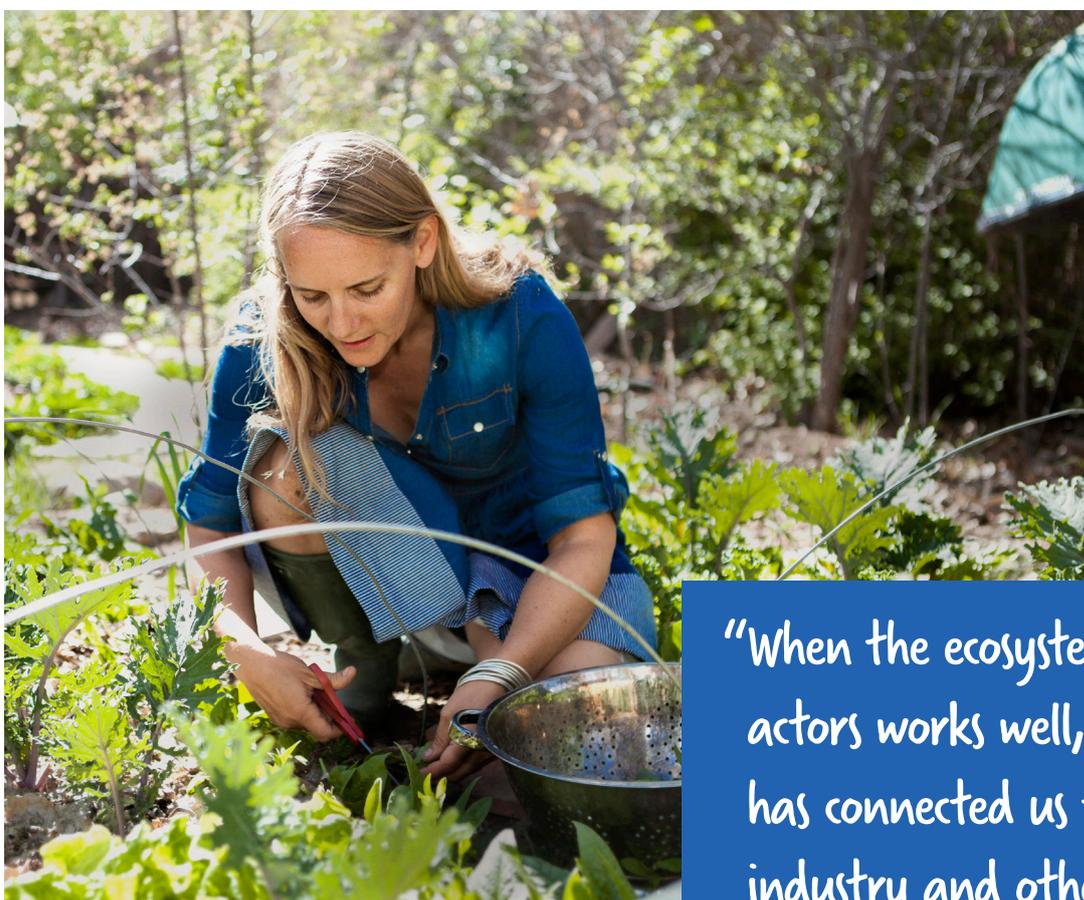
Moving forward, it would be great to see a cultural shift toward being proud of our collaborative working and putting more effort into profiling the benefits of this to the public. We need to move away from the perception that patient organisations receive funding from industry because they have to, and recognise that in reality, collaboration includes more than just funding and forms an important element of the range of work we do to support patients.

For us there is huge value in working collaboratively with industry, namely in creating an environment that is beneficial for research and development, particularly because of the lack of treatments available to patients with cardiomyopathy. If we have a good relationship with industry and support efforts to identify and raise awareness of patients and connect with clinicians, we can help to attract funding for research and encourage companies to bring their treatments to the UK, which is only becoming more important as the UK leaves the EU.

When the ecosystem of actors works well, it has connected us to industry and other patient groups, for example, through our clinical stakeholders, affording us valuable opportunities to secure early engagement and identify areas for collaboration. For example, by working with other patient organisations across Europe we're able to pool expertise and attract industry investment by highlighting cardiomyopathy as an area with a strong patient voice.

To support both industry and patient groups in the future it would be beneficial to see guidance for both parties on how best to collaborate and work together, particularly for smaller groups that may have limited previous experience of this.

While there are actions that we can take to support improvements at an organisational level, good collaboration comes down to the individuals involved and human relationships built through early and maintained engagement. Ultimately, this is what helps us to continue our work in genuinely supporting patients.



“When the ecosystem of actors works well, it has connected us to industry and other patient groups.”

CALLS TO ACTION

Taking the learnings from this report, we have identified actions that all involved in advocacy collaborations can adopt to improve impact, ways of working and perception of these projects, and the outcomes for patients.

1

All collaborative projects should be designed by partners in the best interests of patients. Both industry and patient groups should consider how they authentically serve the patient through these activities.

2

Patient groups and industry should recognise each other as key stakeholders and ensure the respective expertise of each partner is recognised within the relationship. This can help ensure the design and execution of collaborative advocacy projects are meaningful and there is purpose for the partnership.

3

Industry should ensure they provide clarity to patient groups about their processes for contracting and applying for funding and the measures in place to protect the independence of each organisation. Bureaucracy should be reduced where possible and consideration should be given to how the company can further support groups who do not have the resources to access legal advice.

4

Both partners should listen and be ready to discuss and adapt as they undertake partnerships, both in terms of maintaining an open dialogue through a project and reviewing and evaluating at the end. Learnings should then be applied, based on experience, to ensure continued improvements to collaborations and ongoing optimal ways of working. Industry may for instance ensure they adapt their processes and SOPs to reflect these learnings.

5

Industry and patient groups should always be transparent about their collaboration and consider opportunities within projects to profile the benefits of working collaboratively through different media to their audiences, including healthcare professionals, the general public, policymakers and of course the patient community.

References

1. European Federation of Pharmaceutical Industries and Associations. Working together with patient groups. September 2017. Available: <https://www.efpia.eu/media/288492/working-together-with-patient-groups-23102017.pdf>. Last accessed March 2021
2. Public Health England. HIV in the United Kingdom: Towards Zero HIV Transmission by 2019. 2019 report. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/858559/HIV_in_the_UK_2019_towards_zero_HIV_transmissions_by_2030.pdf. Last accessed March 2021
3. Keith Alcorn, AidsMap. High Court rules NHS England is responsible for funding PrEP. August 2016. Available: <https://www.aidsmap.com/news/aug-2016/high-court-rules-nhs-england-responsible-funding-prep>. Last accessed March 2021
4. NHS England. NHS England strikes world leading deal to help eliminate hepatitis C. April 2019. Available: <https://www.england.nhs.uk/2019/04/nhs-england-strikes-world-leading-deal-to-help-eliminate-hepatitis-c/>. Last accessed March 2021
5. NHS England. MenB vaccine overview. June 2018. Available: <https://www.nhs.uk/conditions/vaccinations/meningitis-b-vaccine/>. Last accessed March 2021
6. Advances in Clinical Neuroscience and Rehabilitation. The Missing Pieces: Identifying the gaps in care and conversations in MS. Report available from http://www.acnr.co.uk/wp-content/uploads/2017/07/1724-Missing-Pieces-Report_FINAL.pdf. Last accessed March 2021
7. The MS Trust. MS Forward View. Available at: <https://mstrust.org.uk/health-professionals/programmes/ms-forward-view>. Last accessed March 2021

 @SanofiUK

 [Sanofi.co.uk](https://www.sanofi.co.uk)



SANOFI

This project has been initiated
and funded by Sanofi.

Job bag no: MAT-GB-2005181 (v1.0)
Date of Prep: March 2021