FROM PATIENT CENTRICITY TO PATIENT LEADERSHIP

A GLOBAL ANALYSIS

OVID

Driving positive engagement
between the pharmaceutical industry
and public in the digital social age

1 / FOREWORD

We commissioned this world-first global report because we cannot ignore the fact that the environment today is almost unrecognisable in comparison to that of 20, or even 10 years ago. In the age of the smart phone and social media, patients are both better informed about their healthcare, and much closer to the companies which shape the healthcare sector. So, what patients and those who represent them are saying online matters, and our industry must respond to this.

From the very inception of OVID Health in 2018, patients have been at the heart of all we do. Of course it is easy to say this, but looking back at the diverse range of projects we have delivered, the golden thread of using communications and advocacy to deliver change which benefits patients has been our 'raison d'etre'.

This focus couldn't have come at a better moment. Like "environmental, social and governance" before it, "patient centricity" is increasingly seen as a key pillar of corporate social responsibility for the life sciences sector, and I am deeply proud to have worked with many of the pharma companies at the forefront of this movement. But despite progress, there remains much to do. I worry that, in some quarters, patient centricity is an overused buzz word which makes little difference to company strategies, let alone to the lived experience of patients (which must always remain our sector's guiding light).

This was why, five years ago, OVID set up the *Patient Partnership Index* to showcase the best examples of meaningful collaboration between pharma and patient groups. And it is why we have now undertaken this new research to explore how pharma companies communicate with patients and the broader public. As with our *Patient Partnership Index*, we want to highlight what works, and what opportunities there are to drive deeper, more impactful conversations between patients and the public on one hand, and pharma and life science companies on the other.

This report offers insights that will spark discussions as to how our sector can reach patients, allowing us to translate the rhetoric of patient centricity into reality. This is about moving from *patient centricity to patient leadership* – and this report will help us all to do this with confidence.

Jenny Ousbey
CEO and Founder, OVID Health

WHY READ THIS REPORT?

From Patient Centricity to Patient Leadership provides valuable insights as to what campaigns most effectively spark engagement among patients and the broader public including what themes and therapy areas currently lead the conversation, as well as which pharma companies are most effective at engaging the public.

Overall, our report provides valuable insights as to what campaigns most effectively spark engagement among patients and the broader public. This includes what themes and therapy areas currently lead the conversation, as well as which pharma companies are most effective at engaging the public.

It also provides recommendations for how any campaign can be made more effective, through the use of language and co-creation through partnerships. In combination with our insights and experience with the PPI programme, we hope patient partnership index, we hope to inspire conversations and critical appraisals of how pharma companies can more effectively use digital communications channels such as X (formally Twitter) to reach the patient communities they are looking to serve.

REPORT CONTENTS

2 EXECUTIVE SUMMARY & RECOMMENDATIONS

This report definitively shows the increasing efforts of the life sciences sector to prioritise patient engagement. This is a welcome shift, which enables a better understanding of the healthcare needs and priorities of patient communities. Digital communications, primarily through social media, have been a key pillar of engagement strategies. Yet, social media communications have evolved organically across the sector, leading to significant variation in approaches and outcomes.

This world-first report analyses a substantial body of social media campaigns from pharma companies, exploring what makes for successful campaigns. This world-first report analyses a substantial body of social media campaigns from pharma companies, exploring what constitutes success. Our aim is to support the sector to more effectively engage patient communities through campaigns which are relevant and engaging.

This report is not the last word on the topic of effective social communication, but we hope it will spark debate and discussion, and ultimately foster deeper conversations between patients, the public and the life sciences sector.

RECOMMENDATIONS

1

To secure positive engagement on social media, companies should ensure campaigns are relevant to the lived experience of patients.

2

Patient engagement campaigns should be clear as to how they bring benefits to patients, particularly where they have a ‘call to action’ for patients.

3

Disease awareness campaigns should seek to maximise “shareability”. This might require a more informal, conversational approach, the use of humour or other approaches drawn from broader social media strategy.

4

When seeking to engage minority groups, co-creation with communities is essential to ensure campaigns are authentic and not “tokenistic”.

5

Social media engagement strategies should be clear on the objectives, target audiences and success measures – a campaign seeking to reach investors may have different success measures to a mass disease awareness campaign.

6

Companies seeking to utilise social media to drive patient engagement should invest in developing the skills and expertise to make the most of the platform, learning from best practice within the life science sector and beyond.

7

Companies should recognise the importance of the social elements of social media platforms and should consider whether these platforms are appropriate to drive the kinds of engagement they are seeking.

8

Companies should prioritise activity rooted in priority therapy areas, where they can speak with expertise and authenticity.

9

Pharma companies must ensure campaigns use language that is accessible to, and aligned with, patient groups, co-creating campaigns to ensure authenticity.

10

Where possible, pharma companies should seek genuine partnerships with patient groups, which help create more authentic campaigns, better results and engagement and in the longer term – improved access to treatment.

3 / INTRODUCTION

In order to deliver the best outcomes, it is essential life sciences companies work with patients to understand their priorities, needs and concerns. This requires deep, meaningful engagement between life sciences companies and patient groups, which can provide insights and deliver truly co-created outcomes.

This research strengthens the evidence base around digital communications between patients and life science companies. It explores how pharma companies can lead meaningful, two-way conversations about what matters to patients, utilising the digital channels which have democratised and decentralised engagement, to secure better ethical, commercial and patient outcomes.

In undertaking this research, OVID builds on our expertise in patient engagement, including our two industry-leading standalone initiatives aimed at strengthening partnerships between life science companies and patient organisations.

Our *pro bono Patient Partnership Index* (PPI) showcases best practice collaborative projects between pharma and patient groups, while our *Patient Advocacy and Centricity Tracker* (PACT) enables companies to capture cross-organisational insights into the efficacy of their patient engagement. We hope the findings of this new data will substantiate and complement these initiatives even further.

PPI & PACT: LEADING CHANGE IN PATIENT ADVOCACY

First launched in 2020, the **Patient Partnership Index (PPI)** is OVID Health's flagship *pro bono* initiative, offering pharmaceutical and biotech companies an opportunity to showcase, benchmark and evaluate the quality of their communications and partnerships with patient advocacy groups. The aim is to celebrate as many partnerships that meet the mark as possible so we can continue to raise the bar across the industry.

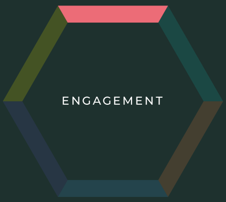
The 2024 Index saw four projects awarded the highest GOLD standard, demonstrating excellence across the six PPI metrics of engagement, co-creation, empowerment, transparency, innovation and impact.

While the best PPI projects typically go beyond social media activity, we have included some best practice case studies from 2024 and previous years throughout this report, to inspire deeper consideration of what effective patient engagement can achieve.

The OVID Health **Patient Advocacy and Centricity Tracker (PACT)** is a proprietary measurement tool developed by OVID to enable companies to assess, track and demonstrate the quality of their patient centricity and engagement, putting patient engagement on the same footing as ESG activities.

Through the PACT process, OVID audits company policies, materials and processes, and speaks with key decision makers to create a cohesive picture of the company's patient engagement. Participating companies are provided with insights and recommendations for improvement, alongside a Patient Advocacy and Centricity (PACe) Score, which can be used to benchmark performance against industry standards and monitor improvement over time. PACT can also be used in internal and external corporate reporting.

To use the tool contact:
PACT@ovidhealth.com

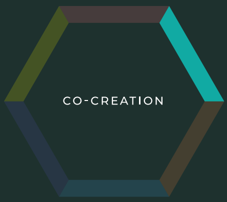


Engagement

Embed your patient partnership across the company, from CEO or MD level down, and regularly ask how the needs of your patients are being met.

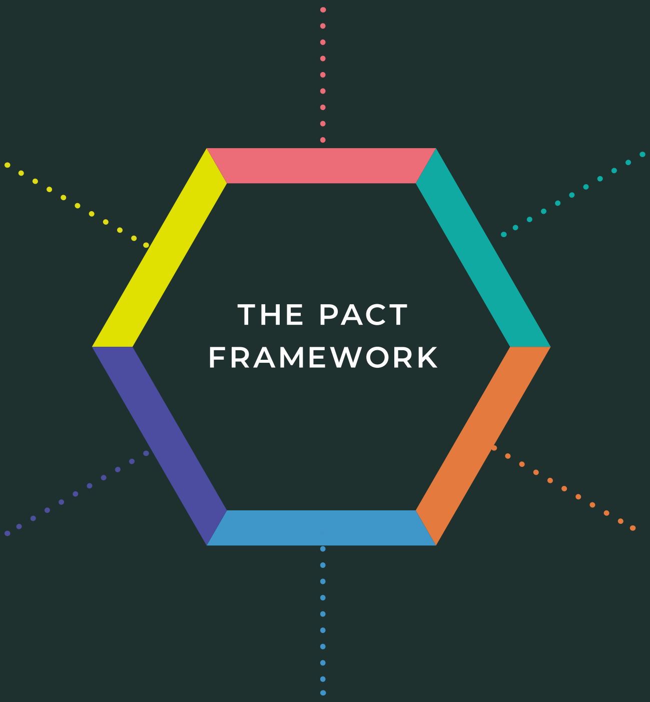
Impact

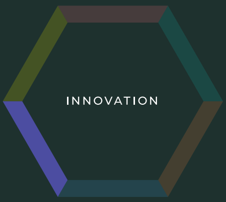
Measure the impact of your patient organisation activities regularly and make sure they are evidenced clearly.



Co-creation

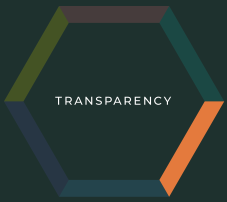
Fully co-create collaborations with PAOs, from concept to delivery, and share knowledge relevant to the PAG you're working with.





Innovation

Always be innovating in your partnerships to increase impact for the intended audience.

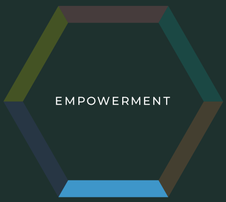


Transparency

Be transparent and set the parameters of your ways of working to be compliant and responsive to PAO needs.

Empowerment

Show genuine commitment to supporting your patient organisation partners to grow and thrive to serve their community.



4 REPORT SCOPE & METHODS

4.1 Report objectives

Our report shines a light on communications between patients and life science companies in the digital and social media sphere. It provides a robust evidence base to underpin strategies for patient engagement in the age of social media, helping pharma companies to enhance their engagement with patients and patient groups.

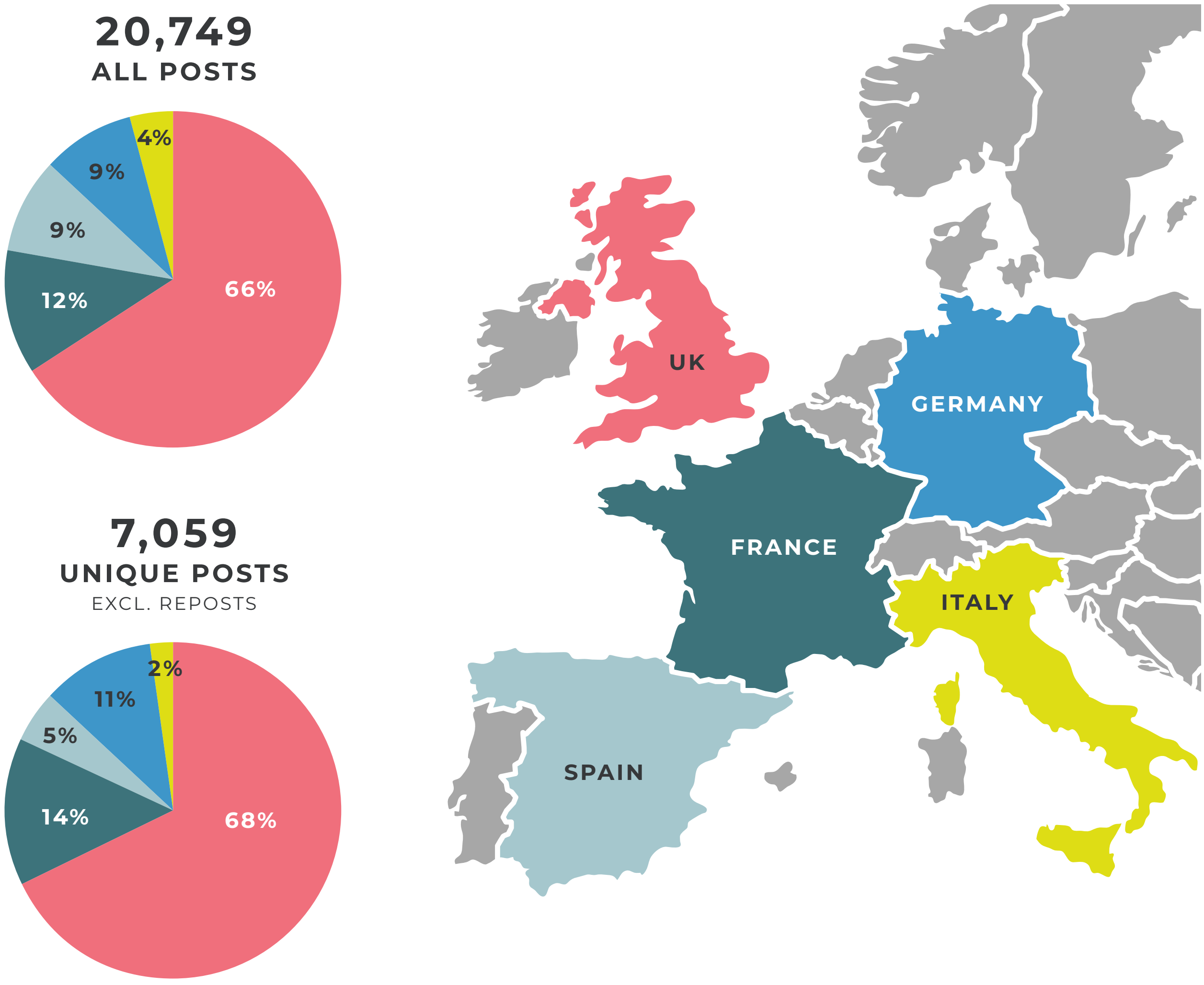
This report is framed against the following initial research questions:

1. What are the key themes, topics and trends within pharma-led online conversations? What do patients respond to?
2. Do patients and pharma "speak the same language"? If not, how can pharma companies engage in public conversations in a way which makes sense for their patient audiences?
3. What do patients value in their engagement with pharma companies?
4. What role do patient groups play in online conversations?
5. Which pharma companies are leading online conversations?

4.2 Data analysed

To address these questions, OVID Health partnered with White Swan, a charity which draws on insights from digital conversations, to map, model and understand the conversations happening between pharma companies and patient communities. Using White Swan's "Million Minds" platform, we captured and analysed English language social media conversations, from five key European markets in 2022 and 2023. Data was filtered to include only communications from or mentioning specific pharma companies, with irrelevant data and misinformation filtered out. The following data was included for analysis:

X (formerly Twitter) posts – April 2022 to May 2023



KEY TERMS

Analysis in this report is conducted mainly through the lens of "campaigns". In this context, a campaign is an individual post or sets of posts shared by a pharmaceutical company which describes multiple similar topics and types of experiences, within a close timeframe. Campaigns were manually identified from within the data set. A single post can be identified as a campaign in this data set, if no other posts can be grouped within it in this way.

The primary metric used to assess the success of the campaigns in this report is engagement, which here considers the ratio of reshares to original posts within a campaign – a higher number of reshares indicating a higher level of engagement. This does not reflect additional engagement through comments, clicks etc.

In order to effectively analyse the data, we created a “landscape taxonomy”, dividing data by themes, with three categories and seven sub-categories, based on their immediate relevance to the experiences of patients. Within each theme, some example topics are highlighted.

Experiences of care

1 **Life with disease**
e.g., daily life and symptom support, diagnosis, mental health, families and carers

2 **Patient engagement**
e.g., surveys, healthcare professional (HCP) conversations, petitions and webinars

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Accessing care and the need for care

3 **Awareness and prevention**
e.g., early diagnosis, education, public disease awareness, health literacy and tackling misinformation

4 **Health equity**
e.g., diversity, empowerment, ethnicity and poverty

Management and R&D

5 **Health systems and outcomes**
e.g., workforce, the NHS system, training, care pathways and drug reimbursement

6 **Research and development (R&D)**
clinical trials, drug approvals, innovation, generic drugs, digital technology, genetics and patient safety

7 **Sustainability**
e.g., packaging and waste, climate change, and energy use

WHAT CAN THE DATA TELL US?

The findings of this research should not necessarily be interpreted as universal, particularly when addressing specific issues such as what language is effective, or how impactful a given company has been in their communications. The findings of this research do not seek to be universal but rather provide a snapshot of activity on a particular platform at a particular time. It remains the case that “the medium is the message”, and effective communications should be tailored by platform and audience.

5

WHAT MAKES A GREAT PATIENT ENGAGEMENT CAMPAIGN?

This report highlights what perhaps many of us know but can often be overlooked – that any good campaign starts with an awareness of the target audience. This in turn supports the development of a campaign which speaks to that audience in a way that is relevant and engaging. The campaigns which we viewed as most successful in engaging patients were those that provided relevant content in a relatable style. We explore what works through this section.

Given the large number of companies competing for market share and engagement, focussing on themes or topics which have shown high engagement rates, against relatively small numbers of campaigns is the most effective route for pharma. In addition, these engagements must feel genuinely relevant to the company and their audience, so what is suitable for one company may not work for another. Similarly, there are some audiences which are not well engaged by the campaigns captured in this research such as people from Asian ethnic groups. To some extent, this reflects the limitations of considering only English language campaigns.

Nonetheless the report clearly shows engagement with, for example, British Asian communities, is poor. Companies should consider how their campaigns can reach these communities (without being tokenistic). Developing relatable, authentic campaigns will require deep engagement and co-creation with these communities.

Furthermore, with health equity as an increasingly important consideration for pharma companies – this data shows there is a long way to go for successful engagement with disenfranchised or minority communities.

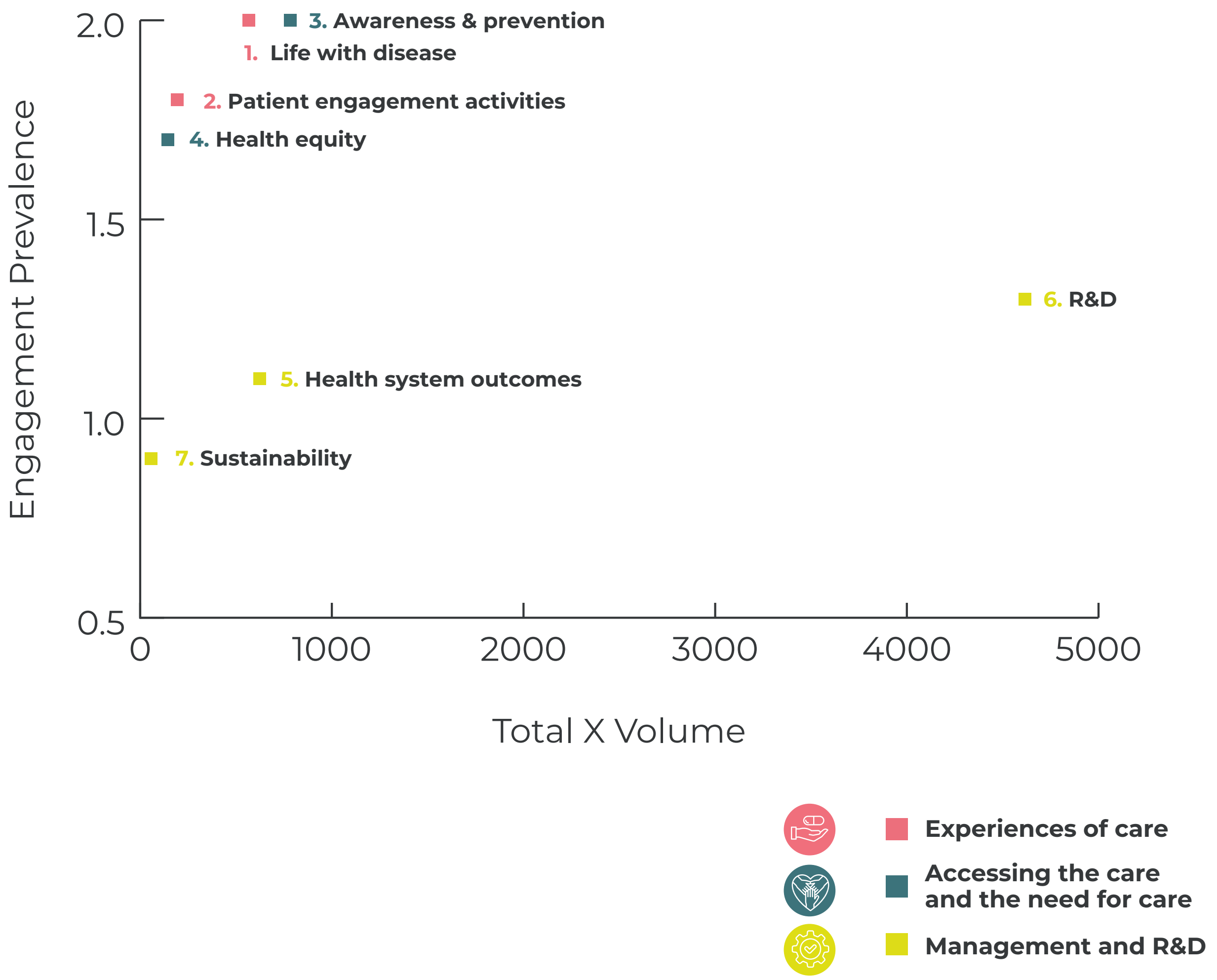
5.1 Thematic engagement

As outlined above, to enable analysis of the data we developed a unique “language taxonomy”, which broke down the online conversation into seven key themes. Each campaign in the data set was assigned to one of these themes, and engagement prevalence was measured and compared to the average topic engagement rate of 1.5. It is important to note from the outset that the engagement being measured here is among users of X (with a bias towards those users who choose to follow pharma company pages).

5.1.1 Life with disease

We can see campaigns focusing on the lived experiences of patients performed best. Campaigns about life with disease secured an engagement prevalence of 2.0, against 567 items (compared to the average of 1.5). In particular, campaigns which fostered open discussions about the impact of disease or treatments on patients’ symptoms and bodies were well received, as were discussions of diagnosis and symptom support. Posts with clear calls to action, such as tips for things patients could do to manage the impact of a disease on their daily life, were well received.

Campaigns by theme



Areas with lower rates of engagement included mental health and stigma and discrimination.

This clearly offers opportunities for deeper engagement, for example by engaging with patients' emotional response to mental distress. Themes of friendship and loneliness appear to be almost entirely absent from the conversation and may therefore offer new opportunities to engage patient communities on what matters to them or affects their day-to-day lives most acutely.

Lower engagement across these themes may be reflective of an over-emphasis in campaigns on positive messaging, hope and treatment innovation, which leaves limited space for realistic conversations about the sometimes-harsh realities of living with illness.

For example, at OVID, we have heard from young cancer survivors who feel campaigns too often focus on celebrating "beating cancer" or "battling cancer", while glossing over negative experiences of survivors, such as experiences of chemotherapy, long-term drug toxicity, disability, or infertility. Furthermore, being diagnosed with cancer is not a fair fight or a battle that anyone chooses.

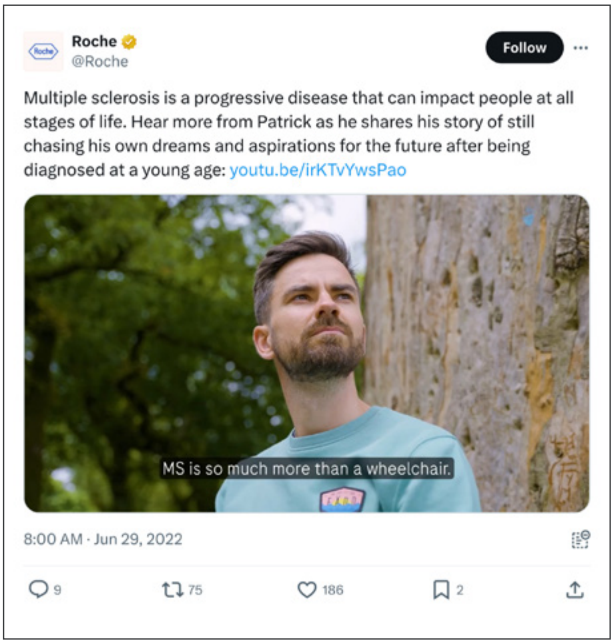
RECOMMENDATION

To secure positive engagement on social media, companies should ensure campaigns are relevant to the lived experience of patients.

These life with disease campaigns, from Sanofi and Roche, help patients and the public better understand the impact of health conditions, and crucially, explore what can be done to minimise these impacts.

Roche: https://x.com/Roche/status/1542040173722181632

Sanofi: https://x.com/EDEN_Leicester/status/1600121130005700610



Roche
@Roche

Multiple sclerosis is a progressive disease that can impact people at all stages of life. Hear more from Patrick as he shares his story of still chasing his own dreams and aspirations for the future after being diagnosed at a young age: youtu.be/irKTvYwsPao

MS is so much more than a wheelchair.

8:00 AM · Jun 29, 2022

EDEN Diabetes Training
@EDEN_Leicester

Our Highly Commended (#QiCDiabetes2022), #Sanofi Cares 🤗 virtual programme is available for #free! Aiming to educate & improve knowledge & confidence to effectively manage people living with #diabetes in #carehomes & community care. Register: diabetesmatters.co.uk/sanoficares

SANOFI CARES
1. INTRODUCTION VIDEO
2. THREE eLEARNING MODULES
3. MENTORING SUPPORT
#SANOFI #TEAMEDEN

1:33 PM · Dec 6, 2022

BEST PRACTICE PATIENT PARTNERSHIPS

Recordati Rare Diseases

Q bag for children with high-risk neuroblastoma

GOLD

patient partnership index 2024

Recordati Rare Diseases' partnership with both the Healthcare professional patient community at Princess Maxima Paediatric Oncology Center, The Netherlands and the Dutch Childhood Cancer Association (VKKN) achieved some outstanding real-world results. This partnership began informally as a result of children and their families reporting their experiences undergoing continuous IV immunotherapy for high-risk neuroblastoma (HRNB). Infusion pumps are normally attached to an IV-poll or carried in a shoulder bag. However, both options can be restrictive for children. Inspired by one parent of a child undergoing continuous IV immunotherapy, Recordati Rare Diseases worked with Princess Maxima Hospital and a specialist design agency to develop a safe and robust backpack for IV pumps, the Q-bag.

Throughout development, children and families were continuously consulted, to ensure the bags were both user-friendly and appealing to the children for whom they were designed, with user feedback prompting multiple revisions.
All children with HNRB in the Netherlands now receive a Q-bag for immunotherapy, which has numerous bespoke safety features and personalised design options, and Recordati Rare Diseases is in discussion with other stakeholders to roll out the Q-bag globally.

5.1.2 Patient engagement

Data showed patient engagement campaigns had a slightly lower (though still above average) engagement rate of 1.8, against a smaller total volume of activity (194 campaigns). This does not necessarily indicate this activity is less "successful". Rather, it may reflect how pharma companies are more targeted in this activity. For example, if a pharma company is looking to promote a patient survey, a public X feed may not be the most effective way to reach a relevant patient cohort, and the company may not see reshares as their primary success metric – instead, the call to action may be to register for a webinar or complete a survey. It should be noted, however, that surveys and petitions tended to have lower engagement rates than webinars or patient voice opportunities, we suspect because these topics bring less direct benefits to the audience – campaigns should therefore emphasise how a survey or petition will benefit the patient community.

Another area where there is potential to strengthen campaigns is around engagement with HCPs. In this area, patients and the public tend to use different language to pharma companies, reducing the relatability of the campaigns. Addressing this issue and providing tangible advice on how patients and HCPs can more effectively communicate with one another, could help boost engagement with this topic.

This Ipsen campaign, promoting a patient engagement webinar series, made it clear to patients what benefit they would get from participation.

https://x.com/PCR_News status/1526836170222538752

ProstateCancerResearch
@PCR_News

What to Expect: A Guide to Prostate Cancer - every Wednesday at 6-7pm from June 8th - July 27th, Prostate Cancer Research and Ipsen are bringing you eight useful, interactive webinars for anyone affected by prostate cancer. Learn more and register at pcr.org.uk/what-to-expect

9:04 AM · May 18, 2022

RECOMMENDATION

Patient engagement campaigns should be clear as to how they bring benefits to patients, particularly where they have a 'call to action' for patients.

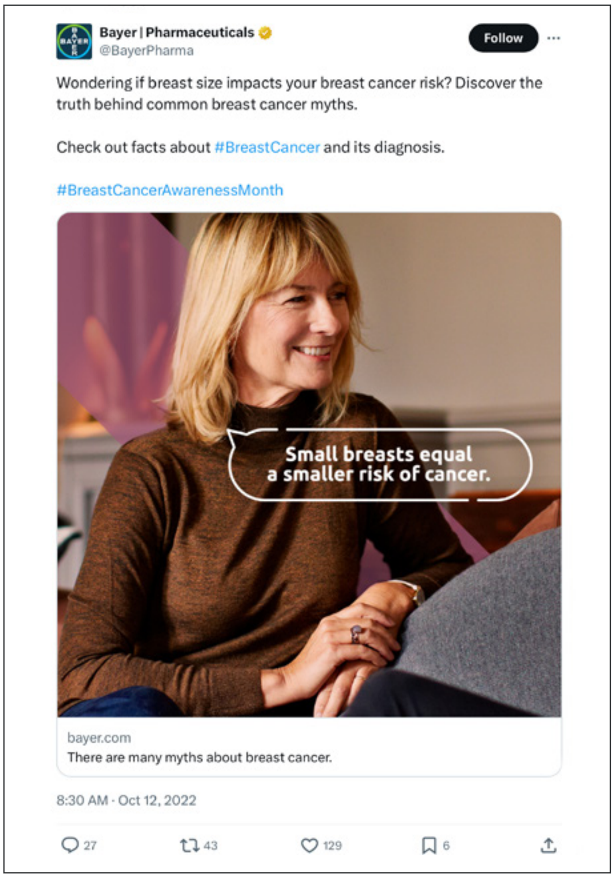
5.1.3 Awareness and prevention

The idea of prevention vs cure is an interesting paradox in our industry as often we are supporting treatment innovations within a given area, and if all diseases were effectively ‘prevented’ there would be a radically different-looking pharmaceutical industry.

Our report showed campaigns related to awareness and prevention did secure a high engagement rate of 2.0, across 782 campaigns. That these campaigns obtained relatively high levels of engagement should not be surprising; when seeking to raise awareness of a condition, engagement is itself the desired outcome, and these campaigns will have been designed with general relevance and “shareability” front of mind.

This Bayer campaign uses a breast cancer myth as a hook for further engagement.

https://x.com/BayerPharma/status/1580098445053874176



Bayer | Pharmaceuticals
@BayerPharma

Wondering if breast size impacts your breast cancer risk? Discover the truth behind common breast cancer myths.

Check out facts about #BreastCancer and its diagnosis.

#BreastCancerAwarenessMonth

Small breasts equal a smaller risk of cancer.

bayer.com
There are many myths about breast cancer.

8:30 AM · Oct 12, 2022

Within this theme, the topics of raising public awareness, education, and detection and earlier diagnosis were all fairly common and performed well. Campaigns relating to misinformation, saving and protecting lives, and time to act and change all performed well, on significantly smaller volumes of activity, and may be areas where there is scope to expand patient engagement campaigns. Activity focused on educating patients, whether directly answering patient questions, or supporting broader educational activity such as webinars, tended to be particularly well received, reflecting the desire among the public for a two-way conversation.

Perhaps surprisingly, prevention and health threats performed less well as topics, securing an engagement rate of only 1.5, in line with the overall average. This may point to a fatigue from the general public post-pandemic to alarmist health topics. Health literacy was almost entirely absent as a topic of conversation in the data set.

RECOMMENDATION

Disease awareness campaigns should seek to maximise “shareability”. This might require a more informal, conversational approach, the use of humour or other approaches drawn from broader social media strategy.

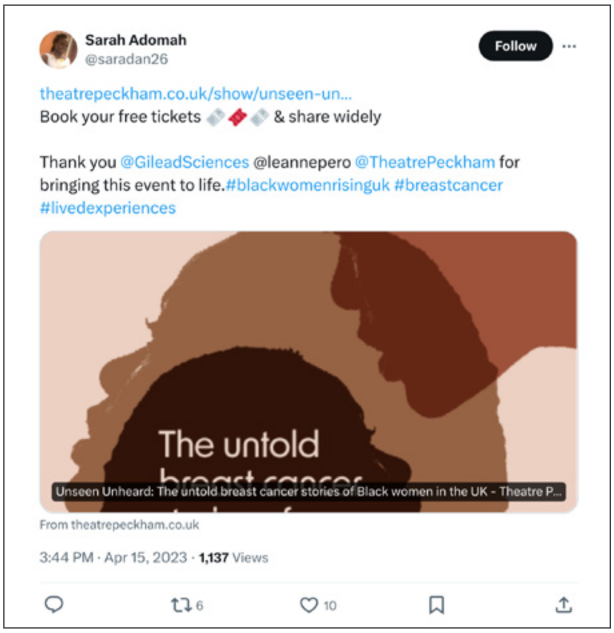
5.1.4 Health equity

Campaigns within the health equity theme were low in volume at 145 campaigns, with an engagement rate of 1.7. Within this theme, the most successful content focused on the topics of ethnicity, equity particularly in black communities. In contrast, content exploring Asian or Hispanic equity and prevalence perform poorly, with engagement rates of 0.6 and 0.7 respectively, (though the latter is likely to have limited context outside of the US, with this content drawn from major European markets). This may reflect a lack of deep engagement with these communities, which results in content that is tokenistic or only superficially relevant.

Richer co-creation is likely to result in more relevant and relatable campaigns, which engage the target audiences more effectively. The broader topics of “people of colour” and “minority ethnic” did not resonate. This may be because these campaigns inherently present diverse groups as monolithic, failing to deeply understand and engage with the many communities which fall within these groups.

Gilead’s work with Theatre Peckham represents a distinctive approach to addressing health inequalities, which garnered positive engagement.

https://x.com/saradan26/status/1647249495510466560



Sarah Adomah
@saradan26

theatrepeckham.co.uk/show/unseen-un...
Book your free tickets 🎟️🎟️🎟️ & share widely

Thank you @GileadSciences @leannepero @TheatrePeckham for bringing this event to life.#blackwomenrisinguk #breastcancer #livedexperiences

Unseen Unheard: The untold breast cancer stories of Black women in the UK - Theatre P...
From theatrepeckham.co.uk

3:44 PM · Apr 15, 2023 · **1,137** Views

RECOMMENDATION

When seeking to engage minority groups, co-creation with communities is essential to ensure campaigns are authentic and not “tokenistic”.

BEST PRACTICE PATIENT PARTNERSHIPS

Gilead

RADIAN

GOLD

patient partnership index 2024

To address the rising HIV epidemic in Eastern Europe and Centra Asia (EECA), Gilead partnered with the Elton John AIDS Foundation to establish RADIAN, an initiative aimed at reducing HIV rates, AIDS-related deaths, and HIV-related stigma. Over the past five years, RADIAN has directly reached around 247,000 people with HIV services, trained around 13,000 frontline workers in stigma reduction, facilitated treatment for 25,000 people living with HIV, and provided about 95,000 HIV tests.

The initiative funds grassroots organisations through two programs: Model Cities, which supports innovative HIV efforts in high-prevalence cities, and the Unmet Need Fund, which provides grants for prevention, care, education, and community leadership. Additionally, RADIAN supports key populations in Ukraine, funding 70 NGOs that provide essential services to over 40,400 people. With a renewed investment of $50 million, RADIAN 2.0 will expand its community-led initiatives to more EECA countries, aiming to build sustainable health systems and address structural barriers to HIV care.

5.1.5 Sustainability

At the other end of the spectrum, several themes were less directly relevant to patients and tended to secure low levels of engagement. Sustainability had an engagement rate of just 0.9, against just 58 X campaigns. While this topic is increasingly a priority for the industry, investors and broader society, our report shows it is less relevant to patient communities, and therefore secures lower engagement. Companies may well want to retain a focus on sustainability within broader ESG reporting, while deprioritising it on social media.

5.1.6 Health system outcomes

Health system outcomes secured a lower engagement rate of 1.1, against 623 X posts. While these topics may be directly relevant to patient experiences, it is perhaps not a surprise the issues addressed are too technical or require a greater level of specific policy knowledge than most patients would have.

5.1.7 R&D

Research and development of new treatments and therapeutics clearly has the potential to significantly affect patient experiences and outcomes and is at the core what the life sciences industry does. The research identified 4,617 X campaigns on the topic, almost two thirds of the total data sample. The vast majority of this activity was driven by pharma companies, yet the engagement rate for these campaigns was just 1.3, below the average, and far short of the most engaging content.

One explanation for this is companies feel it is intrinsically important that the majority of their social media activity reflects their core commercial activity. It may also be the case that sharing such content is seen as commercially essential, but that patient engagement is not seen as the key metric for the success of this activity. Instead, the aim is to inform investors and shareholders, to encourage further investment.

Campaigns focused on R&D, while important to both patients and investors, did not tend to secure as much engagement as other campaigns.

https://x.com/CRISPRTX/status/1619000746149810176

CRISPR Therapeutics
@CRISPRTX

CRISPR Therapeutics and Vertex are pleased to share that the European Medicines Agency (EMA) and the Medicines and Healthcare products Regulatory Agency (MHRA) have validated the regulatory submissions of our potential treatment for sickle cell disease and beta thalassemia.

CRISPR Therapeutics and Vertex Announce EMA and MHRA Marketing Authorization Application (MAA) Validation of exa-cel

3:53 PM · Jan 27, 2023 · **17.6K** Views

RECOMMENDATION

Social media engagement strategies should be clear on the objectives, target audiences and success measures – a campaign seeking to reach investors may have different success measures to a mass disease awareness campaign.

BEST PRACTICE PATIENT PARTNERSHIPS

Medicines Discovery Catapult

Cystic Fibrosis Antimicrobial Resistance (CF AMR) Syndicate

GOLD

patient partnership index 2024

Cystic fibrosis (CF) affects over 11,000 people in the UK, and antimicrobial resistance (AMR) poses a significant challenge to the CF population. To address this, Medicines Discovery Catapult partnered with Cystic Fibrosis Trust and LifeArc to form the CF AMR Syndicate, aiming to accelerate the development of new antimicrobials and diagnostics to the clinic. The Syndicate engages with people living with CF as strategic partners, alongside leading experts from industry, academia and the clinic, to ensure that innovations meet their needs and priorities.

Key initiatives included developing patient-focused target product profiles (TPPs) for antimicrobial therapeutics and diagnostics. Shaping a £3 million antimicrobial funding call, that attracted 36 applicants, aimed at identifying projects with potential to fulfil the needs outlined in the TPPs, and operating the UK CF Infection Biorepository to provide researchers with high-quality CF samples and data to advance their early-stage antimicrobial and diagnostic programmes. This collaborative effort has engaged the CF/AMR community across the sector, advancing projects and programmes to focus efforts where they are most needed to benefit people with CF.

5.2 Company engagement and conversations

Pharmaceutical companies ‘do’ social media and online engagement in myriad ways. There was a significant variation in engagement levels amongst different pharma companies. Some companies were minimally active, particularly on X, while other companies ran several social media campaigns through the period of data analysis. However, even among the most active companies, some were far more successful than others, indicating the importance of good content, delivered well.

The companies identified as having the highest engagement rates for their campaigns on X were Takeda, Ipsen, Boehringer Ingelheim and Roche.

However, Takeda and Ipsen deliver a comparatively small number of campaigns. Roche and Boehringer Ingelheim should therefore be seen as leaders in consistently delivering engaging campaigns.

RECOMMENDATION

Companies seeking to utilise social media to drive patient engagement should invest in developing the skills and expertise to make the most of the platform, learning from best practice within the life science sector and beyond.

It’s called “social” media for a reason

Boehringer Ingelheim was among the pharma companies with the consistently highest engagement across campaigns. One key element of Boehringer’s use of X, which drove increased engagement, was active comment response management. This leans into the social elements of the platform, moving away from one-sided distribution of information, towards conversations which foster deep engagement with patient communities and the public.

Of course, some companies may have limited capacity or appetite to engage in these conversations, particularly given the risks associated with compliance and promoting medicines. However, Boehringer demonstrates that such engagement can be undertaken compliantly. In the future, one imagines that patient and public feedback received in this way will perhaps go on to represent validated real-world data or a living breathing advisory loop, but in the meantime there is value in pharma being braver and more authentic in a two-way discourse.

RECOMMENDATION

Companies should recognise the importance of the social elements of social media platforms and should consider whether these platforms are appropriate to drive the kinds of engagement they are seeking.

Boehringer Ingelheim’s willingness to engage in conversations helped drive positive engagement.

https://x.com/Boehringer/status/1579426519394443265

Boehringer Ingelheim @Boehringer

It is important to look after your kidneys. If they are damaged, this can lead to #ChronicKidneyDisease. Did you know that reducing the consumption of potassium-rich foods such as raisins can be beneficial for people living with #CKD?

From organs-talk.com

12:00 PM · Oct 10, 2022

Shambhavee Mishra @ShambhaveeMish3 · Oct 12, 2022
Very Good Post.... But will limiting the K+ raise Na+?...

Boehringer Ingelheim @Boehringer · Oct 17, 2022
In people with chronic kidney disease, high potassium levels might lead to more serious acute complications than milder alterations in sodium could. It's recommended to discuss changes in potassium consumption with a physician or dietitian, based on individual laboratory levels.

Judith Sherry @JudithSherry1 · Oct 13, 2022
What about bananas.

Boehringer Ingelheim @Boehringer · Oct 14, 2022
Dear Judith, Thanks for your question. Bananas are high in potassium as well and reducing the consumption of such foods can help contribute towards relieving symptoms of chronic kidney disease. Kind regards, Helen

5.3 Therapy area engagement

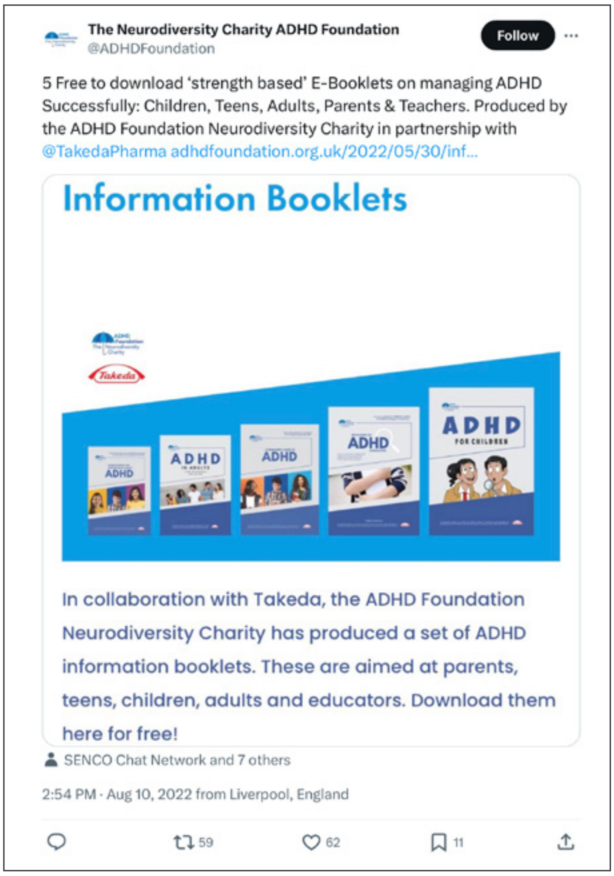
From *Patient Centricity to Patient Leadership* revealed a significant variation in average engagement rates seen between campaigns in different therapy areas. The highest engagement rates were seen with campaigns across pulmonary disease, neurodevelopmental conditions, neurodegenerative conditions and non-immune dermatology. This may indicate that further campaigns in these areas could drive similar positive engagement. However, only a small number of campaigns were identified across these four therapy areas, so it is impossible to tell if they are exceptional outliers, or consistently drive high engagement.

Several therapy areas were identified which combined both a large number of campaigns and high engagement rates, with oncology, autoimmune, infectious disease and cardiovascular campaigns standing out in particular.

With the COVID-19 pandemic (infectious disease) and global prevalence rates of cancer and heart disease this observation is not a surprise, and companies should continue to focus on those therapy areas which are most relevant to their pipeline – areas where they are likely to either have existing credibility or will want to establish that credibility. An engaging, authentic, high-quality and appropriate campaign will perform well with its target audience and should be the priority for pharma led campaigns.

Takeda's collaboration with the ADHD Foundation achieved the highest engagement levels of any 'living with disease category' campaign, tapping into an increasing interest in neurodiversity by meeting the informational needs of patients and the public.

https://x.com/ADHDFoundation/status/1557364730058121216



The Neurodiversity Charity ADHD Foundation
@ADHDFoundation

5 Free to download 'strength based' E-Booklets on managing ADHD Successfully: Children, Teens, Adults, Parents & Teachers. Produced by the ADHD Foundation Neurodiversity Charity in partnership with @TakedaPharma adhdfoundation.org.uk/2022/05/30/inf...

In collaboration with Takeda, the ADHD Foundation Neurodiversity Charity has produced a set of ADHD information booklets. These are aimed at parents, teens, children, adults and educators. Download them here for free!

SENCO Chat Network and 7 others

2:54 PM · Aug 10, 2022 from Liverpool, England

59 62 11

RECOMMENDATION

Companies should prioritise activity rooted in priority therapy areas, where they can speak with expertise and authenticity.

BEST PRACTICE PATIENT PARTNERSHIPS

RareCan

RareCan Brain Tumour Trial Access Partnership

GOLD

patient partnership index 2024

RareCan formed a partnership with the charities Braintrust, OurBrainBank, and the US biotech Fore Biotherapeutics. The partnership aimed to improve access to clinical trials for patients with rare brain tumours, while improving equality, diversity and inclusion.

The partnership, which was fully co-created from the outset, provided patients with a clinical trial matching service through a secure portal. The portal includes information on clinical trials, while the involvement of Fore Biotherapeutics enabled managed referral to their clinical trial activity, helping patients make informed choices about which trials might suit them. This coordination between charity and pharma partners streamlined what can otherwise be a burdensome process.

The partnership's approach to transparency towards patients was well thought through. They provided clear metrics for the service's growth and outlined learnings from the project so far, while positive patient feedback measures and testimonials from both partners and participating patients effectively showcased the strengths of the partnership and its work.

5.4 Language matters

Alongside relevance to patient experiences, effective patient engagement needs to be accessible and engaging to the community. At the most basic level, this means communicating in the native language of the patient group you are trying to reach. But going further, it also means the tone used towards patients is vitally important.

Our report showed in some cases, there appeared to be a disconnect between the terminology of pharma companies and the language used by patient communities in their organic conversations, even when pharma companies were using accessible language. Some examples are given below.

Divided by a common language

Some common differences between how patients and pharma companies speak about the same issues

PHARMA TERMINOLOGY	PATIENT LANGUAGE
Quality of life	My life, my body, my treatment
Mental health, mental challenges, low mood	Mind, upset, distress, irritation, stress
Signs and symptoms, symptom management	My symptoms, my experiences, coping strategies
Loved ones, families, caregivers	Father, mother, dad, mum, brother, sister, daughter, son, carers
Deprivation	Poverty, low income
Minority ethnic	Black, Asian, my community

As we can see, health and diseases are very personal to the patient, they want to talk in specifics not generalised terms. Earlier we noted how the term ‘health literacy’ is not cited in any discussions monitored online involving patients but is a well-used pharmaceutical term so perhaps closer attention could be paid to speaking in the patient’s own terms and what matters to them which is what is happening to their bodies, how they feel about that, how they are coping, what they need for better coping and the impact on those they love. Nor is it possible to generalise about patients as a single monolithic group.

Like all communities, different patient communities will have their own shared languages, which effective campaigns should be sensitive to. This need to “code-switch” creates challenges for pharma comms professionals, which can be most easily addressed by ensuring that campaigns are co-created with the relevant patient community and deeper social listening exercises, particularly on PAG forums or even platforms such as Reddit, would inform campaign language much better.

RECOMMENDATION

Pharma companies must ensure campaigns use language that is accessible to, and aligned with, patient groups, co-creating campaigns to ensure authenticity.

Talking about misinformation

Recent years have seen an increase in healthcare related misinformation (particularly concerning vaccination in general). This rise has been accelerated by the COVID-19 pandemic.

Patient communities are concerned about misinformation and content which counters this is often well received. However, the public may talk about misinformation in broader terms than pharma companies.

Common terms include lies, speculation, false, misleading, disinformation, myths, rumours, and fake news. In contrast, a term such as “health literacy” may not be well understood by lay audiences, reducing engagement.

Pharma companies are understandably risk-averse in their use of social media. However openly engaging with misinformation, using a wider range of terms which patients will understand may help companies engage with broader audiences.

5.5 Partnerships and collaboration

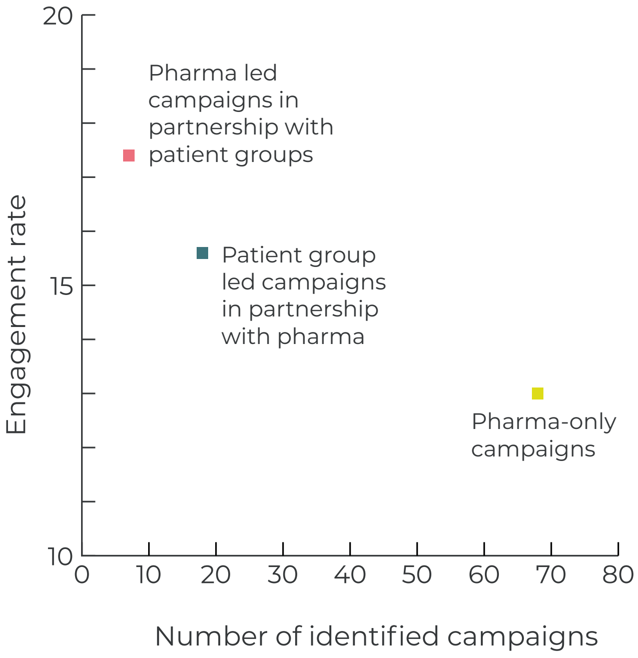
At OVID, we consistently advise our clients that campaigns delivered in partnership are stronger than the sum of their parts, and we work with pharma companies to develop meaningful collaborations with patient groups, to support activity across communications, public affairs and patient engagement. We do this because we believe that, by bringing together different perspectives and insights, we can build campaigns which are better rooted in the needs of patients and deliver better outcomes.

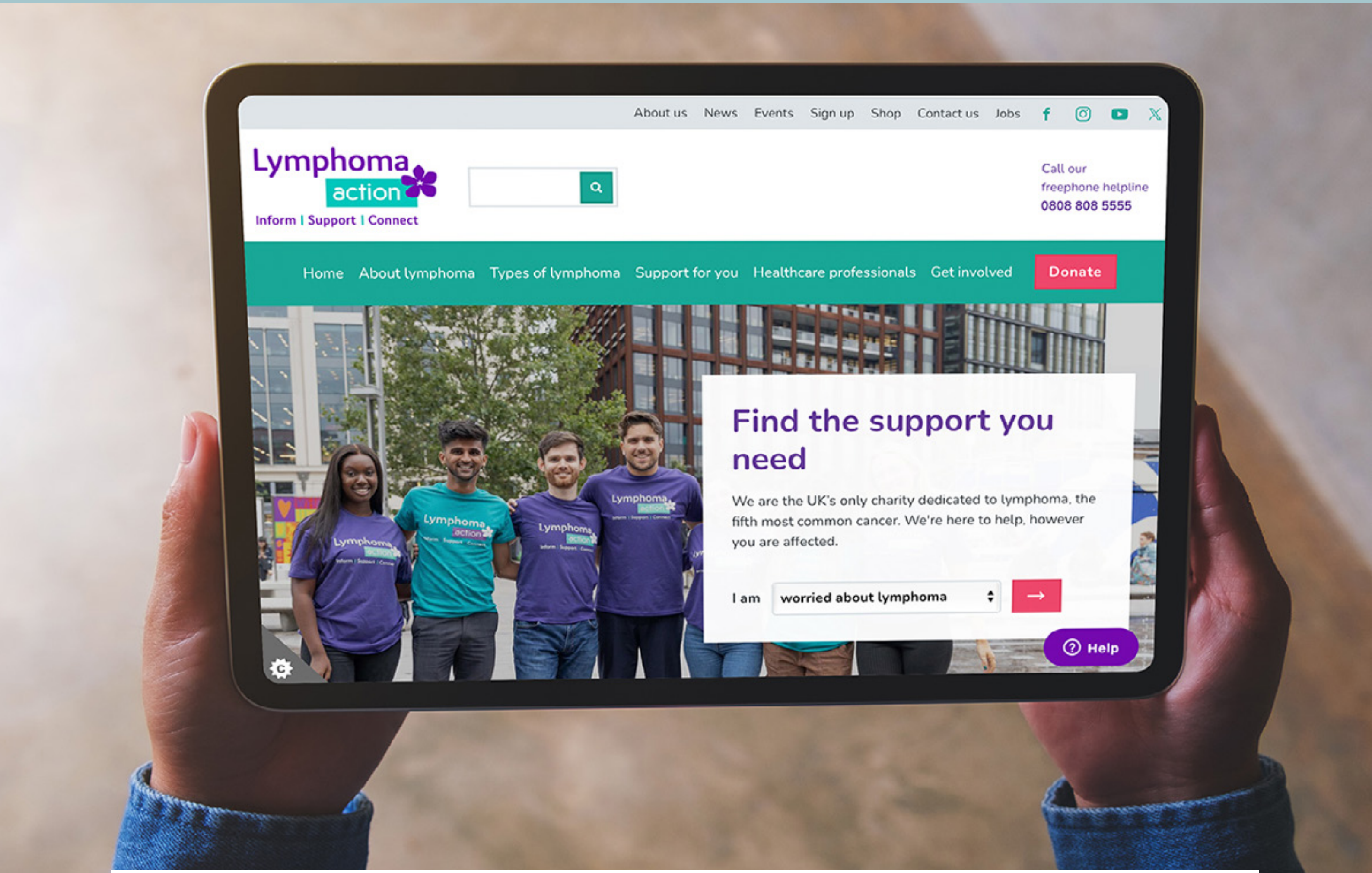
This research backs up our unique approach, demonstrating that joint campaigns consistently outperforming campaigns delivered by pharma companies alone. For example, the average post engagement on X for joint campaigns was 18.9, compared to just 13.0 for campaigns delivered by pharma companies alone. Therefore, campaigns delivered in partnerships with patient groups are more engaging and one would argue more credible.

There are several possible reasons for the higher engagement rates of joint campaigns. Perhaps the most obvious explanation is that campaigns which arise from collaboration are inherently better – more relevant in content and more relatable in style – due to being informed by people with a more direct understanding of patients' needs and experiences. We believe this is a factor, and would encourage companies struggling to engage key communities to work with third party advocates to strengthen their campaigns.

In addition, the endorsement of a trusted patient group can give greater legitimacy to campaigns from pharma companies, ensuring patients see them as trustworthy and focused on patient benefit, not just on profit or commerce.

Our proprietary tools such as PACT and PPI have been created to not only benchmark patient advocacy success and best practice but educate industry that advocacy work and disease awareness can align to commercial goals. Conversations as part of patient advocacy and patient engagement programmes ensure health systems are improved, and over time, patients are more likely to access the treatment or strategy that works for them.





Find the support you need

We are the UK's only charity dedicated to lymphoma, the fifth most common cancer. We're here to help, however you are affected.

BEST PRACTICE PATIENT PARTNERSHIPS

Kyowa Kirin

Kyowa Kirin & Lymphoma Action

GOLD patient partnership index 2023

People living with rare diseases face many challenges, not least accessing appropriate expert care and support. For a condition such as cutaneous T-cell lymphoma (CTCL), many healthcare professionals may not even know where to look to find the expert support and guidance their patients need.

To help meet the information needs of the CTCL community, Kyowa Kirin worked with Lymphoma Action to develop an interactive digital map of specialist centres and the services they offer.

Working in partnership has ensured that this project is as widely accessible as possible, making best use of the respective strengths of the partners involved.

Despite the benefits of such partnership working, however, joint campaigns made up just 27% of all campaigns in the data set. This is likely reflective of the additional compliance challenges associated with developing partnerships. Nonetheless, this additional effort clearly brings returns in terms of greater credibility and engagement.

Interestingly, the best performing joint campaigns are those fronted by pharma companies (securing engagement prevalence of 27.4, compared to 15.6 for those joint campaigns fronted by patient groups). This indicates that, while the involvement of patient groups helps to validate campaigns, the scale and reach of pharma companies (as well as the financial capacity to boost campaigns) plays a greater role in boosting campaign reach and engagement. This also challenges a prevailing school of thought (amongst some in the industry) that the life sciences sector should shy away from 'fronting' advocacy themselves.

One area we were not able to evaluate from the data was the impact of additional engagement by patient groups on pharma-led campaigns. In future, it would be helpful to explore how much impact comments or reposts from patient groups have on broader engagement with a campaign.

RECOMMENDATION

Where possible, pharma companies should seek genuine partnerships with patient groups, which help create more authentic campaigns, better results and engagement and in the longer term – improved access to treatment.

6 CONCLUSION

Social media engagement is one tool of many in the life sciences' toolbox that enables the industry to reach patient communities. So, we end this report by going back to the beginning. Our insights show we are moving from patient-centricity to a new sort of type of patient power aided in no small way by social media.

We have come far as an industry to embrace social media but compared to other sectors such as banking, retail and even charities and advocacy groups, we haven't gone far enough. Of course, ethics and medico-legal constraints have historically slowed progress and increased risk-aversion, but our global analysis shows that social media as an omni-channel solution is not going anywhere. It is growing in prominence and therefore effective healthcare communications campaign should embrace this openly, positively, authentically and creatively.

Social media engagement is one technique among many used by pharma companies to reach patient communities. Yet the ubiquity and relative low cost of social media means that it is seen as an essential pillar in almost any patient engagement strategy or campaign plan. And with ever increasing pressures on budgets, it is essential patient engagement/advocacy and communications teams are able to secure the greatest value from all their activity, including social media communications. That means ensuring campaigns (earned or paid) are relevant and accessible to their target communities.

The recommendations within this report can help companies meet these twin goals. They are, of course only one part of a more complex picture, and the social media landscape is constantly evolving, with new techniques and platforms gaining prominence. Ultimately, the best communicators will be able to adapt to these changing circumstances, learning from the communities they serve, to foster meaningful conversations which deliver a better understanding of the healthcare needs and priorities of patients.

APPENDIX 1: DATA LIMITATIONS

While this report is built on a substantial body of data, there are a number of limitations which should be acknowledged.

UK and global presence

Content was included in the data set if and only if it came from or mentioned a pharma company. Only English language data was included. This means content encompasses a mixture of UK and regional/global pharma company accounts. Given the regulatory requirements for the UK market, which may not fall on global companies in the same way, accounts for global entities may be more open in their communications than those of UK entities. In addition, the activity analysed is in English language only. Communications targeting non-English speakers may vary in focus, tone or style. Additionally, the focus on English language may obscure efforts to address health equity challenges among specific minority groups using native languages.

Avoiding misinformation

In order to avoid capturing misinformation and false reports which could crowd out genuine engagement with pharma companies, conversations relating to Coronavirus were excluded from the data set (along with other identified vaccine misinformation). This had the effect of significantly reducing the volumes of activity from some companies, notably BioNTech and Moderna, as well as (to a lesser extent) Pfizer and AstraZeneca. It is therefore hard to accurately assess the efficacy of communications campaigns originating from those companies for whom a COVID vaccine has been the primary item in their portfolios.

Quality and quantity

Another factor to consider is the variable representation of different companies within the data set, as some feature far more prominently than others. For example, within the X data set were nearly 1300 unique posts from or mentioning AstraZeneca, over 700 from or mentioning Roche and GSK, and over 600 from or mentioning Eisai and BioMarin.

In contrast Biogen, Daiichi Sankyo, Ipsen, Viatris, BioNTech and Moderna were each represented in fewer than 100 unique posts. While analysis of engagement rates can mitigate variation in activity volume, for less active companies, the volume of data may be too small to draw meaningful conclusions. Similarly, larger, more active companies may have greater capacity to test and refine messaging.

Platform limitation

Finally, it should be noted that analysis was limited to X (Twitter) as this information is readily available, with the primary focus on X. Other social platforms, including forums, Facebook, LinkedIn and TikTok were not captured within the data set. It is likely that conversations on different platforms may look substantially different. For example, users may speak in different terms, or themes, in a closed Facebook group for people with lived experience of a particular condition, than they might on their public X feed. This is particularly relevant for more sensitive health issues or those associated with greater levels of stigma.

Additionally, it is not possible to extract demographic data for X users. However, we would expect that people actively engaging with content on X are not representative of the wider public, or of those engaging with content on other platforms. Equally, while this report aims to focus on patient and public engagement, there is no guarantee the individuals engaging with content are in fact relevant patient communities.

Finally, the data extract shows a marked decline in activity on X in the second half of 2022, following the platform's takeover by Elon Musk. This may reflect changes to the algorithm, or changes to the appetite of individuals and pharma companies to engage on the platform.

About OVID Health

OVID Health is a healthcare consultancy that executes campaigns powered by partnerships, communications and policy to improve the well-being of people and nations worldwide.

We believe change cannot happen unless you work in partnership with all levels of stakeholders, from policymakers to politicians through to patients and HCPs, in one coherent and connected campaign.

We specialise in blending the best of communications, patient advocacy and public affairs to make this a reality.

Our patient engagement services at a glance

Patient organisation landscape mapping and analysis	Collaborative disease awareness campaign development and implementation	Patient activation campaigns
Patient insights and analysis (e.g. patient experience assessments, gap analysis, and AI/social listening)	Patient stories (e.g. experience films, podcasts and written case studies, etc)	Patient organisation petitions
Patient (and caregiver) advisory board/focus group convening and report development	Patient content development (e.g. patient educational information, social media content, etc)	Patient awards and grants
Patient surveys	Patient organisation profile / reputation / thought leadership raising	Value narrative and messaging (e.g. for new innovation based on PROs and patient unmet needs)
Coalition building (e.g. patient advocate networks)	Patient engagement events delivery (e.g. summits, roundtables, panels, invention sessions, etc)	Patient support programmes
Strategic programming for patient engagement across the lifecycle	Patient organisation upskilling (e.g. HTA skills, digital/social skills, media skills, storytelling workshop, etc)	Lobbying
Patient journey mapping	Patient engagement toolkits (e.g. for affiliates)	Measurement and reporting

OVID

We are Health Change Makers.
www.ovidhealth.co.uk

To learn more about our patient engagement, advocacy, public affairs and communications offer, contact:

Jenny Ousbey (CEO)
jenny@ovidhealth.com

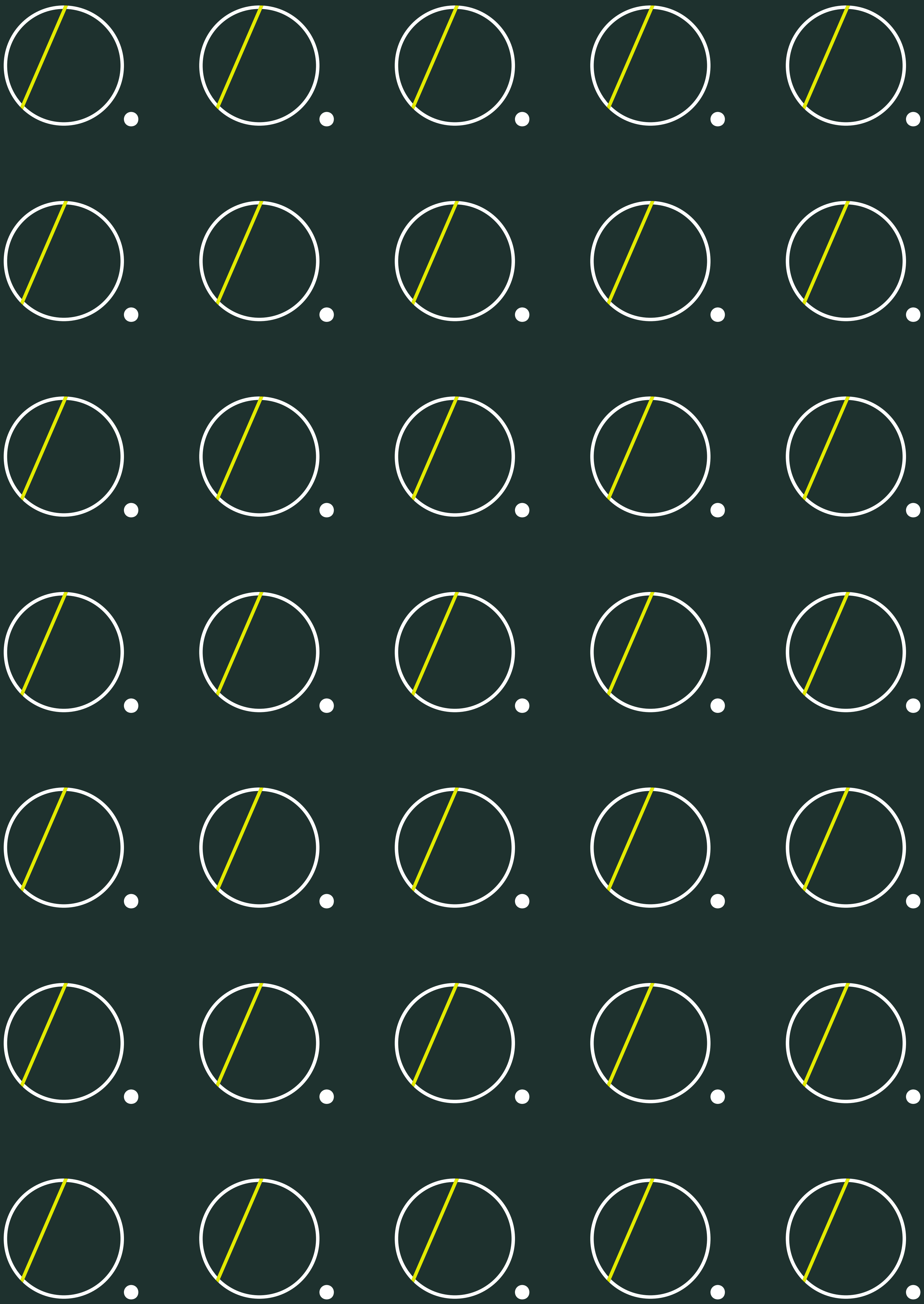
WHITE SWAN

About our research partner

White Swan is a registered charity, which uses technology and analytics to unlock the power of the patient's voice and improve the health of society.

By leveraging the proprietary health social insights platform, Million Minds, White Swan unlocks the power of the patient's voice, helping clinicians, researchers, charities and healthcare organisations accelerate diagnosis, develop more effective treatments, deliver better patient care and support prevention across a wide variety of health conditions worldwide.

www.whiteswan.org.uk



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