




# the media lab

THINKING FOR THE NEXT GENERATION



*Using patients' experience in  
healthcare to set the pace of the  
industry's therapeutic advances*

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AND PARTNERS



## HARNESSING THE POWER OF PATIENT INSIGHTS

In recent years, there has been a meteoric shift in the healthcare ecosystem, with the rise of the empowered patient, who has transformed from a passive recipient to an active consumer. Gone are the days when healthcare was focused solely on treatment and its delivery; operating in today's increasingly connected and digital environment, where patients are the experts of their own condition, demands greater and earlier patient involvement in the drug development process.

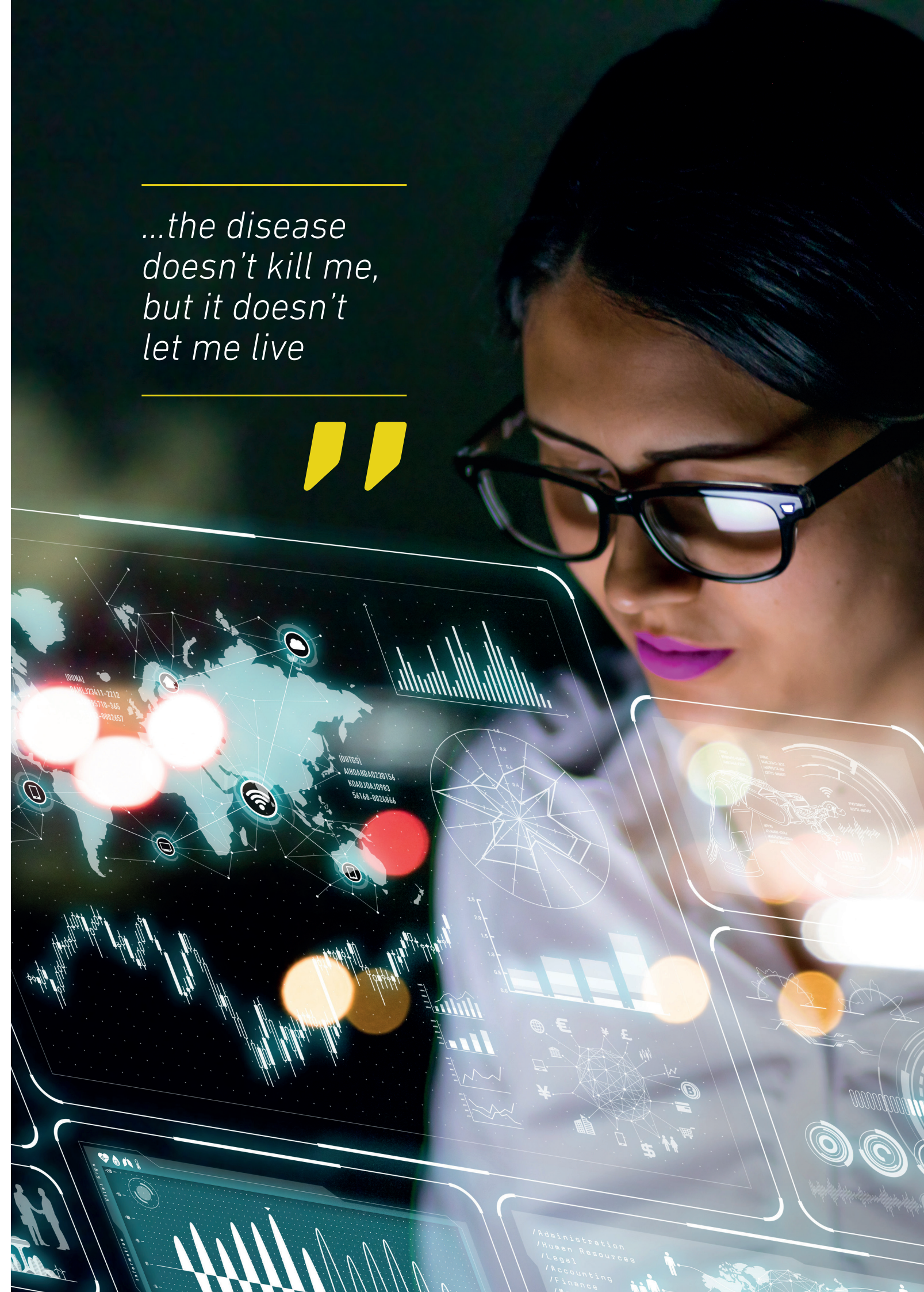
Companies can no longer afford to begin the drug development process without giving patients a 'seat at the table': there can be no more guessing, assumptions or estimations when it comes to understanding the patient's needs. For decades, provision of healthcare has been focused almost solely on the physiology of a disease and the treatments needed, with little emphasis on truly understanding of the impact interventions may have on quality of life, day-to-day.

The field of dermatology provides a pertinent example, as one patient said: "...the disease doesn't kill me, but it doesn't let me live". This powerful statement illustrates that there is a clear lack of understanding the impact a condition and treatments can have on a patient from a humanistic standpoint. With such intense focus on treating and managing the disease, the impact on the patient can fall from view. Patient insights, such as those seen in the statement above, can help drive drug development to reach the true needs of the patient – improving their journey, experience, and potentially, outcomes.

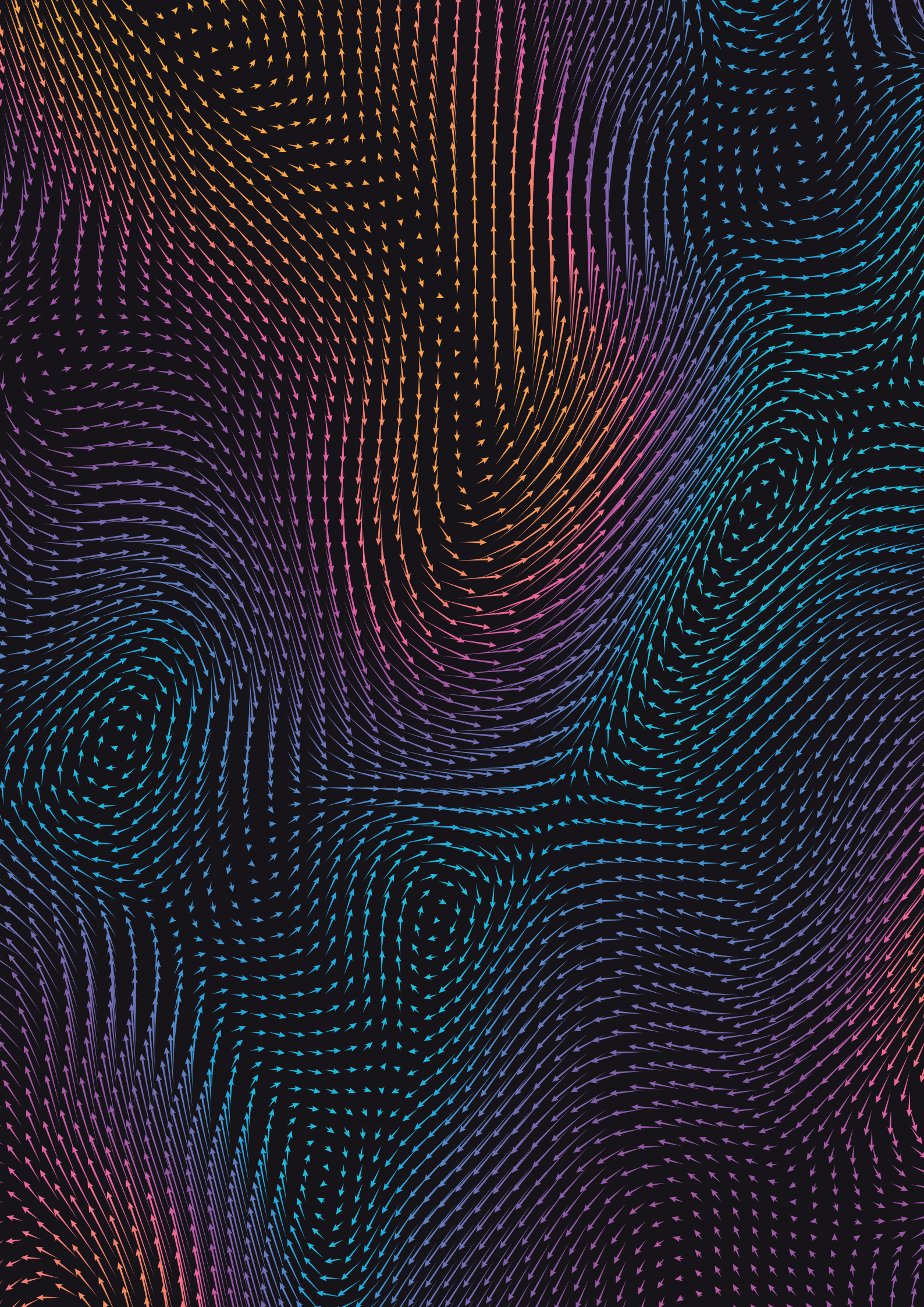
By working together and pooling resources and knowledge, the industry can begin to better understand the true patient experience. Through collaboration, better insights can be gained, and, in turn, a 'right fit' can be achieved to ensure resources are spent in the most beneficial way. When the industry listens, learns and acts upon those findings, the result is a win/win for everyone involved.

Involving patients as early in the development process as is possible, and appropriate, would also have significant implications for concordance, demands on the healthcare workforce resources and wastage, helping to relieve both care and costs burden in health systems around the world.

...the disease  
doesn't kill me,  
but it doesn't  
let me live



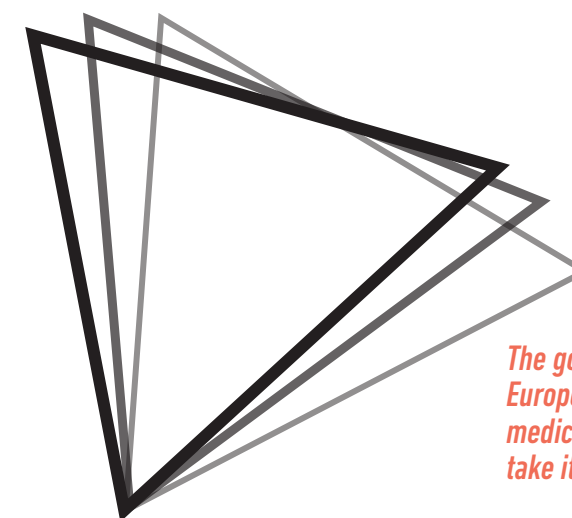




## TRIANGLE OF CONFLICTING INTERESTS

The dynamics of healthcare and the treatment of patients are anything but simple. Decision making is complex and there are multiple stakeholders with often conflicting agendas and priorities. While there are many nuances and branches of complexity, one such example of this can be seen in the triangle of conflicting interests:

*The physician chooses  
the medicine but does  
not take it or pay for it.*



*The government (in  
Europe) pays for the  
medicine but does not  
take it or choose it.*

*The patient takes the medicine  
but does not usually pay for it  
(outside prescription charges)  
or choose it.*

There is a need for all stakeholders to move the efforts, attention and education to find a common ground and ensure that the patients' interests are always driving development, as a key step of progression towards shifting the industry's approach to healthcare. This triangle of conflicting interests must be reimagined by pharma, to ensure that everyone's best interests – clinical, fiscal, political – are driven by patient insights.



## CHANGING ROLE OF THE PATIENT

Historically, patients have not always been aware of what is available to them or what they can ask for. The wealth of accessible, available information has paid to this dynamic and, as a consequence, has irreversibly altered the relationship between patients and healthcare professionals. This heightened awareness has driven demand and resulted an increase in the routes via which patients can access care. Proactive and empowered patients are changing the healthcare landscape, and organisations need to do more than just keep pace.

There are numerous examples, particularly in rare diseases, that illustrate the power of recognising, harnessing and responding to patient needs. One expert explains: "We are seeing groups of patients who have organised themselves and created big data. They can then monetise this data and sell it to pharma for the early stages of R&D. This gives power back to the patient and gives them a platform to negotiate. Patients are no longer a subject of research, but are active, powerful players. Pharma needs to see them as such." These patients are demanding that their voices are heard and their needs met, beyond physical disease outcomes. They understand how important their data are to therapeutic advances.

With vast investment and growing interest in providing medical education, rare diseases is a fast-developing area and there is ample opportunity to change the patient journey and process, because, "unlike more common diseases, it is not a 'set-in-stone journey' that impacts hundreds of thousands of patients", another panel member observes.



## CASE STUDY

*Cardiomyopathy is a notoriously difficult diagnosis that can require patients to visit a variety of specialists, across a number of years just to reach a diagnosis. Many clinicians struggle to spot cardiomyopathy and cannot connect the dots and diagnostic features because the condition has a similar presentation to other, less complex heart conditions.*

*However, an exchange of information between patients is changing the paradigm, with exercises like social listening and genetic explorations to analyse certain population groups and help clinicians to identify potential risk candidates. This group of cardiomyopathy patients are driving change and switching this particular patient journey on its head, by helping to identify at-risk patients much earlier, rather than waiting and diagnosing a patient after they show symptoms.*







## WORKING WITH PATIENT ASSOCIATIONS

Patient organisations have access to, and an understanding of, patients that pharma will never be able to achieve, due to strict regulations, which make it exceedingly difficult for pharma to communicate with patients. These regulations are in place for good reason: there is a duty to protect patients from the misuse of information and promotion. However, involving patients in development programmes “is extremely challenging, but that doesn’t mean we should not, and cannot, do it,” adds another expert.

Many patient organisations are uniquely positioned to be the bridge between pharma and patients. With the weight of an organisation behind them, patients are able to share their experiences and feel that their voices are being heard. Organisations can then work directly with pharmaceutical companies to ensure these data and insights are being used to address what is really important to patients and to drive experience-led drug development.

### IMPROVING CLINICAL TRIALS

Working with organisations can impact all stages of the development pathway, from initial research and development to clinical trials. Many companies are constantly battling against poor clinical trial recruitment and retention, and patient organisations can provide insights into how to make these more appealing for patients, who have busy lives outside of their condition.

Patient associations can help pharmaceutical companies to better understand challenging aspects, such as complex technical and legal jargon that is found on clinical trial documentation, which may seem minor, but could be a deciding factor for the patient on whether or not to participate. While it is critical to follow all of the relevant regulations, it is equally important to provide patients with the support and ability to read, digest and understand what they are getting involved in. Accessible language is a pivotal part of tailoring trials to suit and empower patients.

### CLINICAL TRIAL CONSIDERATIONS INCLUDE:

- *Transport requirements*
  - *Accessibility of trial centre*
  - *Work commitments*
  - *Family or pets who require attention*
  - *Other medical requirements*
  - *Mental health concerns*
  - *Time commitments of the trial*
  - *Legal and technical documentation*
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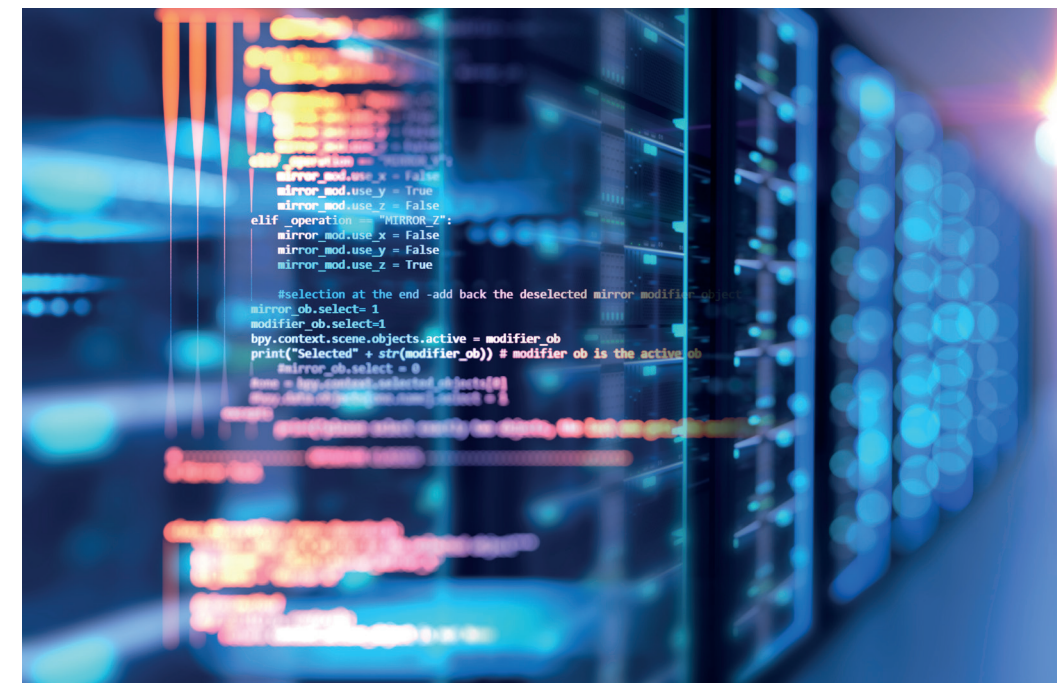


# DATA AND TECHNOLOGY INNOVATION: PREVENTION, DIAGNOSTICS AND TREATMENT

## PREVENTION

The changing role of the empowered patient is being fuelled by the rapid growth of innovative technology and proliferation of big data. Innovative technologies, such as fitness trackers and wearable UV sensors, are helping patients to monitor their own health. With improved access to personal health information, patients can become champions of their own health and prevention. As patients become more empowered with the growth of technology and big data, their demands for their voices to be heard will only increase.

In drug development, manufacturers need to be integrating this technology and matching outcomes to patients' needs, with meaningful and tangible improvements, rather than continuing to focus on standard patient-related outcomes. The industry needs to improve uptake and development, and work with technology companies to enable patients to improve their self-monitoring and prevention efforts.





## DIAGNOSTICS AND TREATMENT

With game-changing innovations and an influx of wearable devices, there is huge potential for big data collection to improve industry-wide knowledge and insights into specific diseases to impact diagnosis and treatment. After bringing patients into the drug development process, the next players that must be involved are the companies who are dealing with data and analytics, from machine learning to data management, collection and protection. It may be starting with healthcare apps and fitness watches, but to gain real benefit, it should lead to data analysis and identification of insights that can impact outcomes for huge cohorts of patients.

### REAL WORLD DATA FROM SOCIAL MEDIA

The increased relevance and usage of social media is significant and is likely to be integral in gathering insights to inform the drug development pathway. Social media data, or real-world data, offers an opportunity to gather a real-life perspective from patients and understand what is important to them in day-to-day life. By gathering this data and retrieving insights, companies can begin to use these findings to better understand patients.

As with the use of any real-world data, social media data usage does not come without internal tensions, pressures and legislation, all of which can still add complexities; but companies cannot use this as a reason not to utilise and explore this opportunity. One expert comments: *"Data is going to be exchanged and analysed by many industries; pharma can choose to go along on this journey or they risk being left behind."*

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## TRANSPARENCY AND DATA PRIVACY

A critical element to consider with increased data usage is the real and significant concerns around data privacy and the risks related to using real-world data, from many stakeholders. Alleviating these concerns is pivotal to the success of using data to gain insights and to move the data dialogue between patients, regulators and healthcare professionals forward.

Important steps to alleviating data privacy concerns include:

- Be clear about patient data privacy
- Outline reasons for data collection
- Use accessible language
- Communicate usage of data
- Provide legal consultancy and advice
- Mitigate improper data usage risks
- Ensure tangible benefits for patients.





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## SUMMARY

IN THE FUTURE, HUMAN RELATIONSHIPS AND PHYSICAL COMMUNICATION WILL BE CRAVED MORE THAN EVER, AND THE INDUSTRY MUST WORK CLOSELY WITH HEALTHCARE PROFESSIONALS, GOVERNMENTS, MEDICAL SOCIETIES, PATIENTS AND PATIENT ORGANISATIONS TO TAKE THE NECESSARY STEPS TOWARDS RESHAPING THE DRUG DEVELOPMENT PATHWAY TO BE LED BY EMPATHETIC AND TRULY HUMAN INSIGHTS. THE SHARING OF NEUTRAL INFORMATION, EDUCATION AND EXPERIENCES, ACROSS A RANGE OF PLATFORMS, WILL ALLOW COMPANIES TO GAIN THESE INSIGHTS AND ACHIEVE A STRONGER UNDERSTANDING OF THE IMPACT OF A DISEASE, BEYOND PHYSIOLOGY.

COLLABORATION ON THIS SCALE WILL REQUIRE BRAVERY FROM THE INDUSTRY TO FULLY EXPLORE THE POTENTIAL OF PATIENT INSIGHTS WITH REASONABLE FREEDOM; ONLY THEN CAN PHARMA FULFIL ITS RESPONSIBILITY TO DEVELOP, WORK AND THINK IN COHESION. DESPITE OPERATING IN A HIGHLY COMPETITIVE INDUSTRY, COMPANIES NEED TO START VIEWING ONE ANOTHER AS MEMBERS OF THE SAME TEAM, DRIVING TOWARDS ONE UNIFYING COMMON GOAL. AS ONE EXPERT CONCLUDES, "IT IS BETTER TO BE A PART OF SOMETHING BIGGER, IN AN INDUSTRY FIT FOR THE FUTURE, THAN IT IS TO GET LEFT BEHIND BECAUSE YOUR COMPANY IS STUCK IN A TRADITIONAL MODEL OF PHARMACEUTICAL PRACTICE."

STRONG PARTNERSHIPS, WITH SHARED AGENDAS, WILL BE PIVOTAL IN PUSHING THE INDUSTRY TOWARDS USING PATIENTS' EXPERIENCE TO SET THE PACE OF THE INDUSTRY'S THERAPEUTIC ADVANCES.





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