Branding Science Group

Why health inequities matter in rare disease **and how to bridge the gaps**

Health disparities currently have a huge impact on healthcare systems, and **this impact is only set to worsen over the coming decades.**

Deloitte, for instance, estimated that, in the US alone, health disparities presently cost the US healthcare system $320 billion per year and could reach a staggering $1 trillion in annual spending by 2040 if they are not actively addressed.

Key disparities within countries can stem from a variety of factors, including geographic location, access to healthcare providers and facilities, language proficiency, health and technology literacy, availability of information, socio-economic status, employment flexibility and the representation of marginalised groups in healthcare. On a broader, international scale, disparities often arise from economic conditions, political stability, climate change and educational opportunities, all of which play a significant role in exacerbating these gaps.

What's even more unfair is that, often, people concerned by health disparities tend to belong to several underserved groups. For example, someone with less fluency in the country's language will also tend to have a lower economic background, and perhaps less health literacy, therefore putting them at a multiplied risk of not accessing proper care.

...health disparities presently cost the US healthcare system **$320 billion per year...**

Why do health inequities matter **more in rare disease?**

There are four main reasons why health disparities are particularly impactful in the rare disease space:

- Health disparities can hinder patient access to treatments for rare diseases, preventing these treatments from reaching their full potential. In such cases, both pharmaceutical companies and patients/health systems are at a disadvantage.

- Without including the patients facing these disparities in research, we will not capture insights on how to tackle the barriers that stop them accessing drugs.

- Accessing diagnoses and treatments for rare diseases is often a lengthy and challenging process, with patients having to take on the role of actively managing their own healthcare journey. When faced with inequalities, patients may struggle to obtain the necessary information to navigate the steps required to consult with physicians and receive appropriate treatment. This can contribute to gaps in knowledge about the rare disease itself, such as the diagnostic process or the disease's prevalence.

- Addressing health inequities can improve the relevance of treatments for regulatory bodies, supporting faster approvals.

So, let's propose some key tips and solutions/processes to put in place in pharma, particularly during research, to be able to help improve and bridge the gap of health disparities.

Think about it from the **start of the product life cycle**

First and foremost, it is crucial to implement changes early in the product life cycle, as this will shape the mindset and enhance knowledge of both the therapy areas and the asset from the very beginning. For example, despite significant efforts, people of colour remain underrepresented in clinical trials and research, highlighting that there is still considerable progress to be made.

This means that you should start thinking about researching differences in access to care, symptoms and patient experiences for different types of underserved groups from the time you start to explore a therapy area for an asset, and also when you implement your first clinical trial:

Logically, that means you will need to implement a culture of 'thinking about it' in your organisation, and of preparing for it from the start.

For example, include criteria at recruitment to achieve this, and don't shy away from speaking about differences in interactions patients have with HCPs/ stakeholders.

Also consider reserving sections of your discussion guides for it, ensuring that the underserved populations are covered in any patient experience assessment data/insights gathered.

Since rare diseases are, by nature, rare, and adding additional layers of demand will increase the complexity of programmes, it's essential to factor in extra time for research and clinical trial setup to ensure optimal recruitment. When planning for innovation or future assets in the pipeline, this additional time should be accounted for in advance, as it will provide the necessary time to effectively establish your medical research or clinical trial programme.

As best practice, it is also invaluable to conduct an exploratory phase, based on readily available information, to uncover any hypotheses and include them in your research.

Diversify your **recruitment**

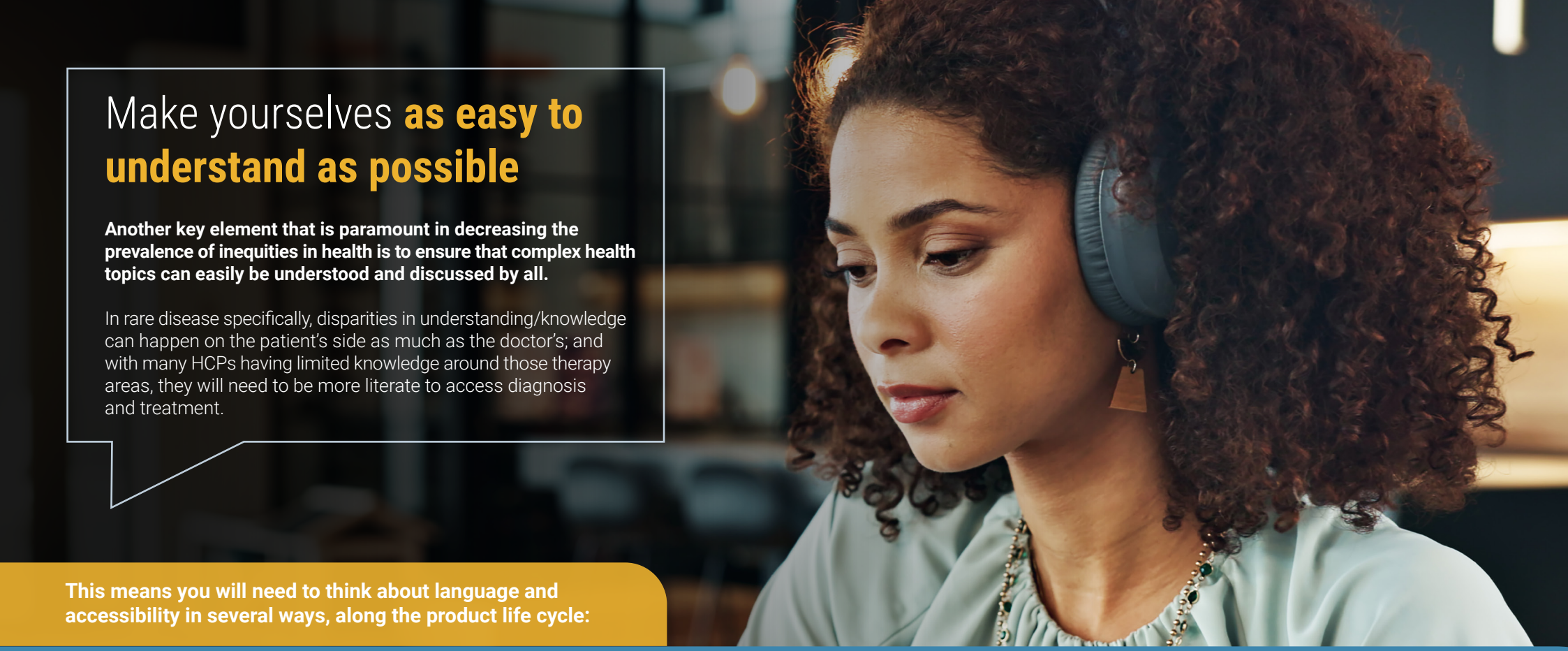
Relying on several techniques to increase your chances of thinking 'outside of the box' for recruitment is also a key driver in ensuring your work has greater chances of being representative of health disparities:

01 First, vary your recruitment partners and their recruitment methodologies, relying on experts, communities/patient advocacy groups, support groups and several techniques (online, offline) to help maximise your reach. Even use unusual access approaches, e.g. approaching the patient where they are, via churches/religious centres/ local communities (if the condition is more common in one population group or another).

02 Then, think about accessibility and location when you set up your clinical trial/research.

03 Another key consideration is increasing collaboration to enhance the knowledge you have through research, which in turn expands the pool of stakeholders you can learn from. You can do this by:

- Increasing collaboration between countries, meaning running the research in as many countries as you can. This will also increase the chance of equal adoption of your asset because, currently, even within Europe, rates of adoption and time to adoption following EU market authorisation vary considerably[4], with some countries excluded from gaining access to treatments.
- Increasing the points of view of your participants – for instance, by recruiting from other groups (i.e. nurses, patient advocacy groups, or carers) to increase your chance of finding respondents with knowledge and/or representation in your underserved groups.



Make yourselves **as easy to understand as possible**

Another key element that is paramount in decreasing the prevalence of inequities in health is to ensure that complex health topics can easily be understood and discussed by all.

In rare disease specifically, disparities in understanding/knowledge can happen on the patient's side as much as the doctor's; and with many HCPs having limited knowledge around those therapy areas, they will need to be more literate to access diagnosis and treatment.

This means you will need to think about language and accessibility in several ways, along the product life cycle:

First, focus on making complex concepts easy to understand by using plain language and making science and health more accessible. For example, enhance your research and materials with creative exercises or visual aids, such as drawings or videos, to help explain complex ideas, particularly for patients with lower health literacy. A picture paints a thousand words!

Also make sure you aren't overly reliant on technology to reach out to and speak with patients/HCPs. Large proportions of many populations are still unable to easily access tech, either due to costs or a lack of tech knowledge. Ensure you still include traditional calls or face-to-face interactions, which will help diversify the respondents you interact with.

Choose to include several languages for your materials as well, based on representing the biggest migrant communities' languages of each country, to ensure you can also gather knowledge and include feedback from those groups, as their access to and experiences with care will be vastly different.

Make sure you develop support solutions for those who are economically challenged, those who have little work or time flexibility and those who are remote or have less access to travelling:

- If someone is required to miss work to participate in your research, they should be suitably compensated for, to account for the inconvenience of participating – and make research participation an attractive option. This means fair market values should ideally be revised for finding rare recruits such as these.

- Compensation should also be provided for any travel costs.

- Adapt your research to their schedule – for instance, by running interviews at weekends or during evenings, when they are available.

Use the information you gather and **highlight differences**

Another part of bridging the gap in health inequities is simply to make health inequities a key requirement to incorporate in your analysis.

Make sure you check and utilise the data you might already have on underrepresented groups and try to understand how their experience might differ from others.

Highlight differences of sub-groups/underrepresented groups in further analysis you implement, even if it means highlighting the experience of a minority of respondents.

Dedicate part of your presentations to feeding back on the topic of inequities, to help create solutions with your teams.

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GET IN TOUCH

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