GUEST EDITORIAL

Person-Centred Healthcare *versus* Patient Centricity - what is the difference and how are pharmaceutical companies aiming to secure internal representation of the patient voice?

Ankita Batla MBBS MBA^a, Justin Soon BPharm MSc^b and Rick Morton PhD^c

- a Chief Medical Office Lead, Patient Insights, WPP Health Practice, London UK
- b Management Consultant, Medical Affairs & HEOR, WPP Health Practice, London UK
- c Chief Medical Affairs Officer & Global Head of WG Access, WPP Health Practice, London UK

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Correspondence address

Dr. Ankita Batla, Chief Medical Office Lead, Patient Insights, WPP Health Practice, Alphabeta Building, 14-18 Finsbury Square, London EC2A 1AH, UK. E-mail: ankita.batla@wpphealth.com

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Introduction

The Sixth Annual Conference and Awards Ceremony of the European Society for Person Centered Healthcare (ESPCH6), dynamically co-created by the ESPCH and WPP Health Practice, was delivered earlier this year at the University of West London on 27 & 28 February 2020 [1]. The purpose of ESPCH6 was to debate how the reintroduction of the historic tenets of humanistic medicine/healthcare could take place within a data-driven modern context, with a laser-sharp focus on the pragmatic imperative of higher quality care at sustainable or lowered cost.

The conference brought together a wide range of distinguished clinical and academic speakers, chairpersons, and key opinion leaders from across the globe, including the USA, Canada, Australia, Germany, Switzerland, Denmark, and, in the UK, colleagues from the University of Oxford, University of West London, Manchester Metropolitan University, Kingston University, St. George's University of London, the University of Hull, and the University of Gloucester UK.

Over ESPCH6's two intensive days, 33 detailed presentations were delivered across 11 academic sessions, spanning a wide range of study areas of immediate relevance to the development and implementation of person-centred approaches within health and social care systems [1]. Notably, and as a direct function of ESPCH's partnership with WPP Health Practice, a key characteristic of ESPCH6 was the inclusion, as speakers, of a wide range of expert patients and patient advocacy organisations,

alongside a range of senior colleagues as speakers from the pharmaceutical and healthcare technology industries.

In this *Guest Editorial*, we report and discuss the results of our recent interviews with senior members of the pharmaceutical industry, principally those who presented at ESPCH6, but also others. We demonstrate how pharmaceutical companies are stepping up to the personcentered care (PCC) agenda, and how their individual and collective approaches are adding value and momentum to the global PCC movement.

What is patient-centricity?

"Patient Centricity" has been a topic of interest in healthcare and the pharmaceutical industry over the past decade. However, it is only in more recent years that companies have been able to move away from citing patient-centricity as an aspirational but hypothetical concept [2,3], to representing the patient voice internally through organisational and cultural change, redefining roles and rules of engagement, and developing frameworks to define and measure success [4-6].

There have been some interesting company-wide initiatives by pharmaceutical companies to truly internalise the concept of 'patient centricity', rather than see it remain as a 'feel good' approach that fails to translate into action in everyday working. Bayer's 'Patients Like Us' initiative is a good example of the drive to incorporate a patient-centric culture/mindset across the organisation, that helps each employee across the Company to connect to a true

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sense of purpose. The campaign focuses on the healthcare stories of Bayer employees and uses the power of empathy to help embed an appreciation of the challenges faced by patients. It helps shift the traditional pharma-focussed 'product' and 'HCP' mentality, to one that embraces patients as a critical stakeholder within the healthcare ecosystem.

Another unique approach for collaborative working is AstraZeneca's Patient Partnership Program (PPP). The PPP was created in conjunction with a team of patients across a variety of therapeutic areas to ensure a compliant, open line of communication between AstraZeneca and patients from around the world who are knowledgeable about their condition, and who are influencers or advocates in their community. This allows for the co-creation of patient-centric products and services, thus maximizing their usefulness and impact for all patients and their families.

Similarly, at MSD, decision-makers engage in a continuous dialogue with patients. Patients are invited to the company offices and to 'town halls' where they speak to MSD teams in groups, but more importantly get protected time to share insights with key decision-makers.

A further example is provided by Norgine's 'all inclusive' approach to patient engagement led by a cross-functional community of enthusiasts rather than one department. This ensures that all teams have a constant focus on the patient, no matter which part of the business they are involved.

The shift to 'person-centered healthcare'

In recent years there has been a gradual evolution of the concept of 'patient centricity', which is a disease and product-focussed agenda of patient engagement in the drug development process, to the concept of 'person-centered healthcare' that extends beyond just the disease and its treatment to recognise the patient as a whole person and to take into account his/her perspectives, narratives, values, preferences, psychology and emotionality, spirituality, existential concerns, cultural context, fears, worries, hopes, goals and ambitions, in addition to the physical needs attributable to a disease [7-11]. It is a wide-ranging and sweeping change that is re-defining not just drug development, but also the delivery of healthcare services. Most pharma companies are welcoming this transition as the hidden value of the societal impact of person-centred care is being discovered [12-20].

As a concept, 'person-centred healthcare' goes beyond just the disease or the treatment, to explore the implications of the disease or treatment on the overall life of the person [13,14]. The broadening of patient support programs, as well as patient engagement initiatives to include preventive approaches, lifestyle measures, mental health and dedicated carer support, all constitute evidence pointing towards an evolution of the need to understand how multidisciplinary clinical and also pharma approaches should seek to impact the life of *the whole person*, rather than just *the patient* [8-10,12-16,19,20].

Dr Paul Robinson, European Lead for Patient Innovation at MSD, observes that pharma companies are making a journey from being focussed on the doctor (as prescriber) 30 years ago, to being focussed on the payer (as provider) 15 years ago, to now being focussed on the needs and wants of the patient (as consumer). Malar Subramaniam, Patient Engagement Manager at Bayer Pharmaceuticals, has observed in addition that healthcare systems are increasingly faced with issues of inefficient healthcare delivery, budget constraints, and lack of resources for timely introduction of new innovations. With this specific context in mind, there is a pertinent need for pharma to think of the societal and healthcare system impacts of their products, beyond a singular consideration of clinical benefit and safety to the individual patient.

Taking these factors into account, Michele Teufel, Site and Patient Engagement Lead at AstraZeneca, adds that by focusing on the entire patient experience, support can be provided to the whole person, rather than just their medical condition, through both therapeutic and non-therapeutic means. She is clear that "... the patient experience begins with prevention and awareness - understanding lifestyle and preventative measures and how to best support people before and at the first signs of illness and diagnosis. It goes beyond a linear, product-centric perspective and takes in all of the factors (mental, physical, economic and social) that influence a person as they live their lives and deal with disease". Teufel additionally emphasises that, on the Research and Development (R&D) side, simple initiatives such as supporting patients with educational materials to increase their understanding about their disease, or the study they plan to participate in, or providing transportation and reimbursement options, can improve their emotional and psychological wellbeing and can also potentially lessen the impact on caregivers. It is worthy of note that the term burden is often disliked by both patients and caregivers and yet it is a standard terminology used by many in the healthcare system and the pharmaceutical industry.

Further insights into the thinking and activities of pharma are provided by Lasse Funch Jacobsen, Senior Lead of Patient Research and Alliances at LEO Pharma, Dr. Myles Furnace, Global Digital Health Partnerships Lead at Ipsen, and Dr. Liz Clark, Vice President, Medical Affairs, Norgine.

Jacobsen has described how, within Leo Pharma, patient involvement has been institutionalised across the value chain in a way that enables every stakeholder to look at the 'total health solution' rather than just the drug in development. He has cited an example where Leo partnered with pharmacies, local municipalities and patients, to define what 'good' looks like for a patient. This approach has helped to streamline the information flow for patients and in designing products and services that patients actually want and need.

Furnace has observed that in this era of digital transformation, patients and carers are becoming increasingly sophisticated in their use of technology, empowering them to take greater control of their own health and healthcare, and make greater demands for access to new innovative therapies. This personalisation of healthcare delivery means that an understanding of the

patient as a *whole person* is critical for pharmaceutical companies to accurately represent the voices of patients internally, to shape strategy, and improve patient outcomes.

With reference to the above, Clark believes that these concepts no longer need validation through business cases justifying the ROI (return on investment) of such initiatives. On the contrary, the whole person approach is slowly but surely becoming an intuitive way of working for pharmaceutical companies. She is clear that this constitutes a 'triple win'; it not only benefits patients, but also healthcare systems and pharmaceutical companies themselves [21].

But is it an easy road to travel?

While the pharmaceutical industry has been making steady progress in the manner outlined above, some constraints remain especially attributable to compliance with strict industry regulations as well as internal processes. The industry regulations have been put in place to encourage quality patient care and protect against high misinformation, but are often cited as reasons for the pharmaceutical industry's relative inertia with regards to direct patient engagement. In this context, Teufel considers how to tackle internal processes challenges to patient engagement, arguing that leadership support and a clear process to support teams on when and how to conduct patient engagement activities is critical. Robinson agrees and is clear that "... companies have different cultures, different compliance interpretations and processes, and different hierarchies of decision-making, so there isn't a one-size-fits-all" [cf.21].

Robinson describes how patient-reported endpoints should be the ones that matter to patients, considering factors such as length of stay in hospital, return to work, independence in daily life, and the impact of pain, etc. However, incorporating these specific outcomes into a broad strategy would require all players - Regulators, HTA bodies and Industry - to understand and value the perspective of the patient. It's also valid that much of these benefits should be captured within established patient reported outcomes tools, specifically those that are disease specific. But very often this is not the case. An example of joint working to try to address some of these challenges is the ABPI's Patient Organisation Forum Steering Committee, which is composed of both pharmaceutical companies and patient groups. This forum demonstrates a collaborative approach to the shared challenges of incorporating patient voices [cf.21].

One area where the industry is looking to work more actively with patients as partners is in research and development, with most companies now incorporating some patient-reported outcomes into clinical study designs. Whether or not the name changes from 'patient centricity' to 'person-centred healthcare', there has been an evident shift to the latter, and for the better. Robinson is optimistic and believes that, in 5 years' time, it will be the normal way of business The three things that will drive the

mindset change are that it is the right thing to do, it makes commercial sense, and the regulators will expect it.

Some exemplars of activity within the new era of pharma-delivered person-centred healthcare

AstraZeneca

AZ's 'Fixing Dad' project engages patients with their disease, to optimise their care and lifestyle choices not simply to control their disease, but also to reverse it. In the UK, AstraZeneca collaborated with a patient, his loved ones and clinicians, to launch Fixing Dad. Fixing Dad is a documentary which follows the journey of Geoff, a man living with Type 2 diabetes, and his two sons' determination to support him to engage with his disease and live a healthier lifestyle. Geoff's journey culminates in him reversing his disease and being able to discontinue his diabetes medication. Geoff's story was aired on the BBC and inspired other people living with Type 2 diabetes to engage with their disease. AstraZeneca collaborated again with the Fixing Dad production company - who are Geoff's sons - to produce a docuseries following three further Type 2 diabetes patients' journeys to successfully reverse their diabetes.

Bayer

Patient Support Programs by Bayer for patients with wet age-related macular degeneration (wAMD) provide holistic support to patients that includes diet and nutritional support (which plays an important role in slowing down the progression of the disease), emotional and psychosocial support, managing co-morbidities and practical tips on how to manage loss of vision.

MSD

In HIV, MSD has been partnering with patients in a variety of ways, ranging from a single patient addressing the company about why he chose not to take his medicines regularly, through to engaging with Community Advisory Boards on study design and choice of comparators, visits to clinics to speak with patients about their preferences, and partnerships with advocates to address policy barriers. Each of these projects contributes to a collective and thus bigger picture of the patient-related ambitions of the company, as well as the Industry as a whole.

Discussion

In this *Guest Editorial*, we have aimed to demonstrate how patient centricity has constituted a prominent concern of the pharmaceutical industry for most of the past decade. Early interest was expressed largely in hypothetical terms,

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but often manifest by how companies attempted to organise themselves to demonstrate a more patient centric approach. In recent years there has been a notable shift away from this internal focus to that of engaging and implementing in a less disease and product centric way. Further, in recent years there has been a transition away from simple aspiration in the direction of the development of far more operational models geared towards representing the patient voice internally through organisational and cultural change, redefining roles and rules of engagement, and developing frameworks to define and measure success [2-6]. An increasing number of examples may now be cited which illustrate the determination of pharmaceutical companies to functionally implement the concept of 'patient centricity', and to drive the creation of a patient centric culture and mindset across their organisations, directly enabling each individual employee to experience a real sense of patient-centric purpose. We have documented a small selection of these exemplars for the interest of the reader.

This incremental evolution of the basic concept of patient-centricity, leaving behind a purely pharmaceutical product-focussed agenda of patient engagement in the drug development process, is important and welcome [4-6]. It is true to say that pharma now recognises that its own understanding of patient-centricity is logically informed by the thinking of the global person-centered healthcare movement. This recognition has led pharma to embrace the clinical reality that patients are not simply complex biological machines manifesting one pathophysiological organ and system dysfunctions which can be dealt with by specific pharmacological and technical interventions, but rather that they are whole persons with a multiplicity of needs which go way 'beyond the pill', and extend into the realm of the personal and the often socially complex [7-11,20].

Nevertheless, key challenges remain. Notable current constraints to the pharmaceutical industry's progress in contributing to the person-centered agenda take the form of a necessity to comply with strict industry regulations in addition to the requirements of internal approval processes. It appears likely that internal leadership and a clear process to support teams on when and how to conduct patient engagement activities will continue to prove critical in this context.

Conclusion

Whether or not the pharmaceutical industry adopts the description of 'person-centered healthcare' in preference to 'patient-centricity', remains to be seen. For sure, this is not a matter of linguistic preference or semantics, but a deeply important matter rooted in the philosophy of medicine itself [19]. Irrespective, there has been an evident shift to a working understanding of the former. And this is for the best. Indeed, as Robinson has said, there are three things that will drive the person-centered mindset change within pharma. Firstly, it is the right thing to do. Secondly, it makes commercial sense. Thirdly, regulators will soon expect it.

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