

Case Study

Facilitating expanded access for a rare disease therapy utilising a Virtual Delphi panel methodology

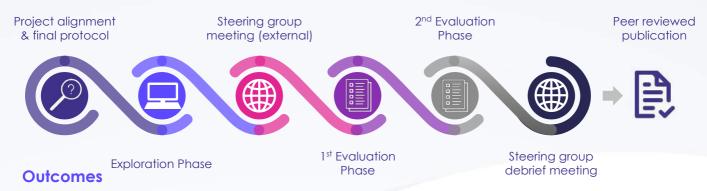
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Client's Challenges

- Clients rare disease product had been granted restricted access at launch by NICE, meaning that only the most severely impacted patients could be prescribed their therapy
- The launch of the product had been successful, capturing a large proportion of patients that met the
 restricted criteria, meaning there was a significant risk of growth plateauing in the next two years if access was
 not expanded
- The commissioning policy stated that the policy would be reviewed when information is received that indicates the policy require revision the challenge therefore was for that information to be provided by the healthcare community in the middle of the pandemic
- The client felt the clinical community wanted broader access for this product, but this was only anecdotal

Our Solution

- · Design a virtual Delphi panel methodology to gain consensus from the clinical and patient community
- Exploration phase conducted by WebEx, capturing views of 8 Consultants, 3 Nurses and the CEO and board member of the relevant patient group, resulting in 41 consensus statements
- An expert panel of consultants were formed, who refined and approved the consensus statements and
 oversaw the evaluation phase which was conducted using an online platform to capture the input of almost
 100 healthcare professionals and patients



- Statements covered a diverse range of topics, from patient management, standardisation of patients review, disease burden, the current commissioning policy and the desired alternatives to this policy
- Consensus was achieved for 40 of the 41 statements including the need to standardise patient reviews
- The community agreed the current NHS England (NHSE) policy was too simplistic, too stringent and was
 resulting in a significant number of patients at a disadvantage
- The steering group were keen to independently publish the results in a peer review journal, a process that is currently being concluded
- Before the study has been published NHSE commenced a review of the commissioning guidelines

Client Feedback

"The MASS Team independently ran and facilitated the project on our behalf in line with Delphi methodology in order to gain consensus from HCPs and patients on current standard of care in a rare disease setting. The team were excellent to work with and delivered great outcomes on this complex project"

Head of Marketing, Top 10 Rare Disease Company

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