

# Successful Research Strategies the Patient Community is using in times of Covid-19

Tuesday 23<sup>rd</sup> June 2020

## Webinar Summary

### Collaboration

- Collaboration amongst all stakeholders continues to be the theme upon which successful strategies are based. Whether it is among patient communities, KOLs or regulators, the way and the extent by which different groups are exploring new ways of working is going to continue to remain a key element of future research. This can only bode well for future and more complex patient engagement as the two share common skills such as communicating clearly, actively listening to others, taking responsibility for mistakes, and respecting the diversity of colleagues. This collaborative skill set is vital to ensure that all the previous learnings from the patient communities is incorporated into new developments such as decentralised trials and ensuring other chronic illnesses remain relevant at a time when COVID-19 dominates the health care agenda.

### Training the next generation of patient advocates

- The shift to virtual congresses presents a powerful opportunity to help train the next generation of patient advocates. Patient advocate attendance at international congresses has never been straightforward often needing to navigate regulatory and compliance considerations. The virtual approach offers a way in which advocates can continue to develop their knowledge in a much more user-friendly way than before. Flexibility amongst congress organisers will be needed as they move away from the traditional congress approach to a more digital one, especially in the area of meeting subscriptions to ensure that those patient advocates with a genuine interest in improving scientific and research knowledge can benefit from the changes.

### Don't create a solution for a problem that does not exist.

- It is easy to overgeneralize what patients and patient groups want; while decentralized trials to many may offer many advantages, to others, for example those with a disability who use the external trial as a way to get out of the house, the benefits may not be so clear. While these centralized trials bring the study to the patient's home, so the responsibility of self-management (dosage/ admin) increases and many patients do not want this. They want to keep their illness separate from their home life. Every patient group should have at least two fully trained members who understand the clinical trial process relevant to that disease. At present only the large umbrella groups offer such a service and that is still very general.

No clinical trial is the same. Patients become involved in trials for different reasons and each patient has a skill set which they can bring to the table. Understanding what the range and depth of the skill set needed for a particular trial is in a particular condition helps manage patient expectations and especially the quality of the insight they can bring in during the co-creation phase.