



COLLABORATE

Working together for adult rare diseases

COLLABORATE Multi-Stakeholder Summit

13–14 October 2022

Non-promotional meeting organized and funded by Pfizer.



Our Summit at a glance

1.5

Days to COLLABORATE: a first-of-its-kind Multi-Stakeholder Summit for Adults with Rare Disease

+20

Countries represented from all around the world (Canada, Latin America, Europe, and Asia) patients and patient organizations, carers, healthcare professionals and policy experts

11

Speakers and panelists with in-depth expertise in the field who helped lead our discussions on co-creation activities and best practice sharing for policy changes that achieve health equity

2

Workshop sessions to identify key challenges and plans of action. A novel, **experience** helping doctors, patient advocates and policy makers to be heard and to exchange, align and ideate



Workshop outcomes - summary

KEY CHALLENGES

SOLUTIONS

Disease recognition and diagnosis



- lack of self-value of older adults
- stigma & taboo surrounding RDs
- low awareness of RDs in the primary care setting
- lack of cohesion and linked infrastructure for diagnosis at the healthcare system level



- coordination and dissemination of collective expertise in RDs through annual coordination meeting between CoEs & PAGs
- awareness campaigns on RDs in older adults across primary care physicians
- addition of a rare diseases core module to medical school curriculums

Living with the disease / Continuum of care



- lack of coordinated, comprehensive care delivered by healthcare and social systems (incl. lack of social and psychological support for patients and families)
- lack of HCP awareness and understanding of RD and what is needed for person-centred care



- cross-functional/multidisciplinary reference programme to treat adults with RDs
- framework for coordinated multidisciplinary care
- activities / “coordinator” role to improve HCP communication with patients in hospitals

Access to diagnostics & treatment



- lack of awareness amongst HCPs, hindering timely access to diagnostic testing
- lack of knowledge among policy makers which undermines their commitment and motivation to drive initiatives to improve access and reimbursement of treatment
- lack of navigation information for patients which impedes patients’ confidence and ability to self-advocate



- establishing disease-specific, international, multistakeholder networks to connect the knowledge chain for a given disease, involving HCPs, CoEs and expertise, imaging centres and labs, patients and caregivers
- creating a comprehensive, mobile-based and easy-to-use RD platform to provide patients with easy access to information and recommendations for treatments, lifestyle support and navigating healthcare

RD: Rare Disease; CoE: Centre of Excellence; PAG Patient Advocate Group



Agreed next steps

Next steps for COLLABORATE

WRITE

a **consensus paper** with a call to action using the insights from the summit



DEVELOP

a **platform** for ongoing COLLABORATION **between stakeholders**



PRIORITISE

solutions and develop a **tactical roadmap** for clinical, educational, and political activities **to improve care for adults with rare diseases**



Some feedback from the participants

“ This was an amazing event. We feel privileged and honored to have been invited to this fantastic event. Congratulations to all organizers and speakers ”

“ Brilliant Summit! This has started something that we need to follow through on. Congrats to Pfizer for your leadership vision impact! ”

“ One of the most interactive summits I've ever attended, fruitful discussions, solid conclusions ”

IT'S NOT ABOUT AGE
IT'S ABOUT CARING FOR RARE



The Rare Disease Community



**Together, we begin working towards a better future
for adult rare disease care and treatment**



