

COLLABORATION AND

PARTNERSHIPS

Create partnerships with the pharmaceutical

industry, hospitals, research institutes and other

entities to increase literacy about clinical trials.

Involving citizens/people without disease to

trust in clinical research.

promote a culture of information, transparency and

Compilation of the perspectives and recommendations of the various stakeholders in the clinical trials ecosystem in Portugal, resulting from the workshop "Integrated vision on how to build an informed and active patient community" promoted by EUPATI as part of the Conference "Clinical Trials: Research that gives hope to patients and brings a better life to all" organized by Apifarma on May 17, 2024. The aim is to build a community of people with illness who are informed and actively involved in clinical research activities.



reporting adverse events and clinical research.

promote the safety and efficacy of medicines.

Use established partnerships to disseminate results and

more training in clinical trials.
 - Include

in training and dissemination partnerships,

of health professionals.

AICIB, Apifarma and the pharmaceutical industry

participating in congresses and scientific meetings

DEVELOPMENT EXECUTION DISSEMINATION PRE-DEVELOPMENT • Include the participation of characters in clinical Organize public sessions to present CTIS Include associations of people with the disease in • Promote health literacy programs from an early (Clinical Trials Information System) in trials in soap operas and other popular television the literacy process. age, in the first cycles of education in schools. Portuguese, to explain the type of information programs to increase the audience and the • Involve the Agrupamentos de Centros de Saúde Transforming and training teachers/educators into dissemination of information. HEALTH LITERACYAND (ACES) and School Health in teaching strategies. active public health agents. ACCESS TO INFORMATION Improve access to information on clinical trials by Use morning or evening debate programs to · Include subjects on Clinical Trials in school Adapt health literacy programs to all age groups, empowering people with diseases and their promote discussion and awareness of clinical trials. curricula throughout education. depending on the target audience. caregivers with knowledge and access tools. Promote contact between Promoters and Explaining the research process to people with the Include the tutelage/government in the creation Contract Research Organizations (CRO) with To enable researchers to deal with the reality of the disease and their caregivers, clarifying doubts and of a specific career in clinical trials. "specialist patient", promoting communication and associations of people with the disease in conveying confidence, especially in primary health • Create Clinical Research Departments in Portugal, making them part of the research the approximation of language between academia, Hospital Centres/Local Health Units (ULS), in **CAPACITY BUILDING** promoters, health units and society. Dedicate full-time professionals to the area of partnership with academia, to respond to the AND TRAINING Promoting lifelong learning for professionals Develop specific training in clinical trials for clinical trials, rather than part-time or according to need for professionalization and exclusive working in clinical trials. nurses and other health professionals, as the the needs of each institution. dedication of professionals to the research area. Order of Nurses has done with Apifarma. Implement structured and proven methodologies • Ensure the participation of people with the disease Involve people with the disease and their Identify and promote training tools and to facilitate the involvement of people with the and their associations in Ethics Commissions. caregivers from the earliest stages of the research. approaches that have already been developed (e.g. disease, families and caregivers. • Collaborate closely with promoters and researchers. EUPATI, EURORDIS, eYPAGNet and Create advisory councils for people with the disease • Use training and capacity-building tools, such as and their carers. connect4children). · Include families and caregivers in all areas of **INVOLVEMENT IN** those developed by EUPATI and other Develop a code of good practice for the Valuing high-quality materials produced nationally clinical research, both in pediatric and adult studies. RESEARCH organizations. involvement of people with illness, based on values (e.g. EUPATI and STAND4Kids). Promote partnerships with groups that encourage of relevance, fairness, transparency, trust, equity, Develop transparent mechanisms in research the involvement of family members and Include representatives of people with illnesses on diversity and empowerment. institutions for collaboration with "expert caregivers. the Ethics Commissions, guaranteeing the patients". necessary training. Create and implement a strategic Use social networks, podcasts on various platforms Increase literacy about clinical trials, mitigate · Work on an effective referral strategy for people communication plan that includes social media, and social media channels to publicize clinical trials. stigmas and distribute information materials. with the disease to increase the number of collaboration between stakeholders and the use Promote the dissemination of clinical trials on the • Use each institution's internal network to participants in clinical trials. of existing platforms (e.g. Portugal Clinical **COMMUNICATION AND** official websites of the institutions and through promote and publicize clinical trials. Use digital platforms (e.g. EVITA Platform) to Trials). DISSEMINATION the intranet circuit, including the scheduling of Involving the government in the strategic plan make the process of engaging people with illness Develop a digital platform to engage people to communicate and combat illiteracy in more agile and efficient. tests and access to results. with the disease and the general public, clinical trials. providing clear information and opportunities for participation. Develop awareness campaigns on the value of Invest in awareness campaigns on the importance • Proposing and developing programs on clinical Continue to promote awareness campaigns among clinical research, promoted by associations of of reporting adverse events related to medicines. trials for health television channels. professionals and citizens about the importance of people with the disease. • Promote partnerships with academia to promote

Establish partnerships with health professional

Create partnerships with those responsible for

Mais).

associations for greater involvement and training.

creating television content for large audiences and

with channels dedicated to health (e.g. Canal Saúde