Patient involvement in research: The future of collaborative research. Lessons from the field of rheumatology and beyond

SP0058  PATIENT INVOLVEMENT IN RESPIRATORY RESEARCH

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The European Lung Foundation (ELF) mission is to bring together the public and patients with respiratory professionals to improve lung health. ELF was founded and works in a unique partnership with the European Respiratory Society (ERS), a membership society for respiratory professionals. A core part of ELF’s activities is to ensure that the perspectives of people living with a lung condition help to inform research, treatment and policy activities at a European level. ELF has extensive experience of facilitating patient engagement in research and clinical projects, including in EU-funded consortia, and has published extensively on the topic. During this session, ELF will share its experience of involving patients in respiratory research collaborations. Focusing on three projects as exemplars of different stages of the research process, ELF will share some of the lessons, challenges, and key benefits of involving patients in research and will highlight how these can be transferred to projects beyond the respiratory field.

Research priority setting: the European Asthma Research and Innovation Partnership (EARIP) set out to develop a coordinated and integrated approach to the future of asthma research and development by creating a roadmap of the components needed to reduce the burden of asthma, in terms of the impact on individuals and on healthcare systems across Europe. ELF led a research priority setting process in which patient perspectives played a central role. The resulting research priorities have been taken forward by research funders and consortia, helping to ensure that the future research agenda is patient-centred. Key lessons:

- how to involve patients in research priority setting
- how to build consensus between patient, clinical, research and industry stakeholders

Clinical trials: the ground-breaking U-BIOPRED (Unbiased Biomarkers for the Prediction of Respiratory Disease Outcomes) project involved patients with severe asthma as equal partners. Up until this point, many projects funded by the EU Innovative Medicines Initiative (IMI) had limited or no involvement of patients. As a result of the successful partnership between patients and professionals, IMI asked the project to develop a guide to patient involvement in EU-funded research so that the experience could be transferred to other disease areas. U-BIOPRED is still considered a pioneering project in terms of its level of patient involvement and many new studies use the approach as the exemplar for how to engage patients as partners. Key lessons:

- how to involve patients as equal partners in clinical research
- how to maximise the opportunities for patient input
- where patients can add value to clinical projects

Disease registries: the European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) is an ERS Clinical Research Collaboration dedicated to improving research and clinical care for people with bronchiectasis. EMBARC has created a European Bronchiectasis Registry, funded by the ERS and by the EU IMI programme. Patients have played a central role in defining the scope, ethics, governance and data protection processes for the registry and the next phase of the project will include a patient-powered registry in order to capture patient-important outcomes directly from people affected by bronchiectasis. Key lessons:

- patients’ and clinicians’ recommendations for involvement in research – dos and don’ts
- how to involve patients from rare disease communities in research

Conclusion: Patient involvement in respiratory research has grown significantly over the last decade. Patient perspectives are increasingly considered to be a core component of every research project and the wider respiratory community values the important role patients now play. ELF has facilitated the involvement of people with lung conditions in a wide range of research projects and the lessons learned are highly transferable to other disease areas and settings.

REFERENCES:


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SP0059  EULAR’S PATIENT RESEARCH PARTNER NETWORK – PATIENTS’ FUTURE INVOLVEMENT IN RESEARCH

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Research in the field of RMDs, particularly in Europe, has advanced significantly in the last years. In particular, the interest in developing Patient Reported Outcomes (PROs) and forms of participatory research has grown. In the field of rheumatology there have been undertaken many initiatives to explore and implement participatory research. Substantial unmet needs in the area of research, highlighted in the RheumaMap (developed by EULAR), will however require an altogether higher level of commitment and innovation. Implementation of the distinct elements contained in RheumaMap will rely on scientists, patients and health professionals. In this regard EULAR PARE has developed recommendations for patient-researcher collaboration and also established a network of 40 trained patient research partners of whom 6 have also graduated for the EU-PATI training course.

Last year it was created a platform (under the name of Study Group for Participatory Research) for knowledge exchange regarding patient participation in rheumatology care and research with the aim of establishing a group of researchers and patient research partners with an interest in developing innovative methods to elicit the voice of patients in rheumatology research, to stimulate the dialogue about the rationale, principles and conditions for patient involvement in research and to discuss and develop the nomenclature and methodology of evaluating the process, results and impact of patient participation in research and health care innovation. The Learning Objectives of the session are as follows:

- To learn from best practices of patient engagement in different disease areas
- To explore patient involvement in guideline development and health care innovations
- To explore how to evaluate patient involvement
- To explore how to cease the moment, how to have fun in the process

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