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Published in:
 Breathe

DOI:
[10.1183/20734735.0159-2022](https://doi.org/10.1183/20734735.0159-2022)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
 Publisher's PDF, also known as Version of record

Publication date:
 2023

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Coleman, C., Fulton, O., Boyd, J., Williams, C., Powell, Z., Brightling, C. E., van den Berge, M., Siddiqui, S., & Powell, P. (2023). Principles of patient partnership: integrating patient perspectives into ERS Clinical Research Collaborations. *Breathe*, 19(1), Article 220159. <https://doi.org/10.1183/20734735.0159-2022>

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Principles of patient partnership: integrating patient perspectives into ERS Clinical Research Collaborations

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Shareable abstract (@ERSpublications)

This set of principles aims to help researchers and patients address some common challenges of patient and public involvement in research, with practical tools to develop successful patient-professional partnerships <https://bit.ly/3HQpVXi>

Cite this article as: Coleman C, Fulton O, Boyd J, *et al.* Principles of patient partnership: integrating patient perspectives into ERS Clinical Research Collaborations. *Breathe* 2023; 19: 220159 [DOI: 10.1183/20734735.0159-2022].

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Received: 15 June 2022
Accepted: 27 Jan 2023

Abstract

Patient and public involvement in research is increasingly considered a cornerstone of good research practice, and the research community recognises people with lived experience as valuable stakeholders within the research process. European Respiratory Society (ERS) strongly encourages patient input into its research programme and scientific activities, working in partnership with the European Lung Foundation (ELF) to facilitate this. Based on the ERS and ELF experience and best practice in the field of patient and public involvement, we developed a set of principles to which future ERS and ELF collaborations should adhere. These principles provide guidance on how to address key challenges when planning and conducting patient and public involvement in order to develop successful partnerships with patients and drive forward patient-centred research.

Introduction

Patient and public involvement in research is increasingly considered a core component of the research process across the research community, from funders and regulators to conference organisers and publishers [1]. The ethos behind patient and public involvement in research recognises those living with a health condition as experts by experience and includes patients, parents, carers and loved ones. The European Respiratory Society (ERS) strongly encourages patient input into its scientific activities and has an established partnership with the European Lung Foundation (ELF) to facilitate this [2, 3].

The breadth and level of patient involvement in ERS's research programme has grown significantly over the last 5 years [4]. ELF's patient input process was first developed in 2016 to help professionals identify the areas where patient perspectives can add value to clinical practice guidelines and research design [5]. During this time, ELF and ERS have continued to learn from the experience of bringing patients and professionals together in this way and have emerged as leaders in the field of patient involvement in international research collaborations, guideline development and patient-centred health information [6–10].

While patient involvement has increased across ERS's research portfolio, challenges have emerged. In order to better understand the strengths, challenges and opportunities to improve patient involvement in research, ELF coordinated a workshop with patient and professional representatives involved in the Severe Heterogeneous Asthma Research collaboration, Patient-centred (SHARP) [11].

The online workshop was held in May 2021. 15 members of the SHARP consortium attended, including representatives from the patient, clinician, researcher and pharmaceutical stakeholder groups. The workshop was chaired by the SHARP patient co-chair (O. Fulton). A short presentation provided an overview of



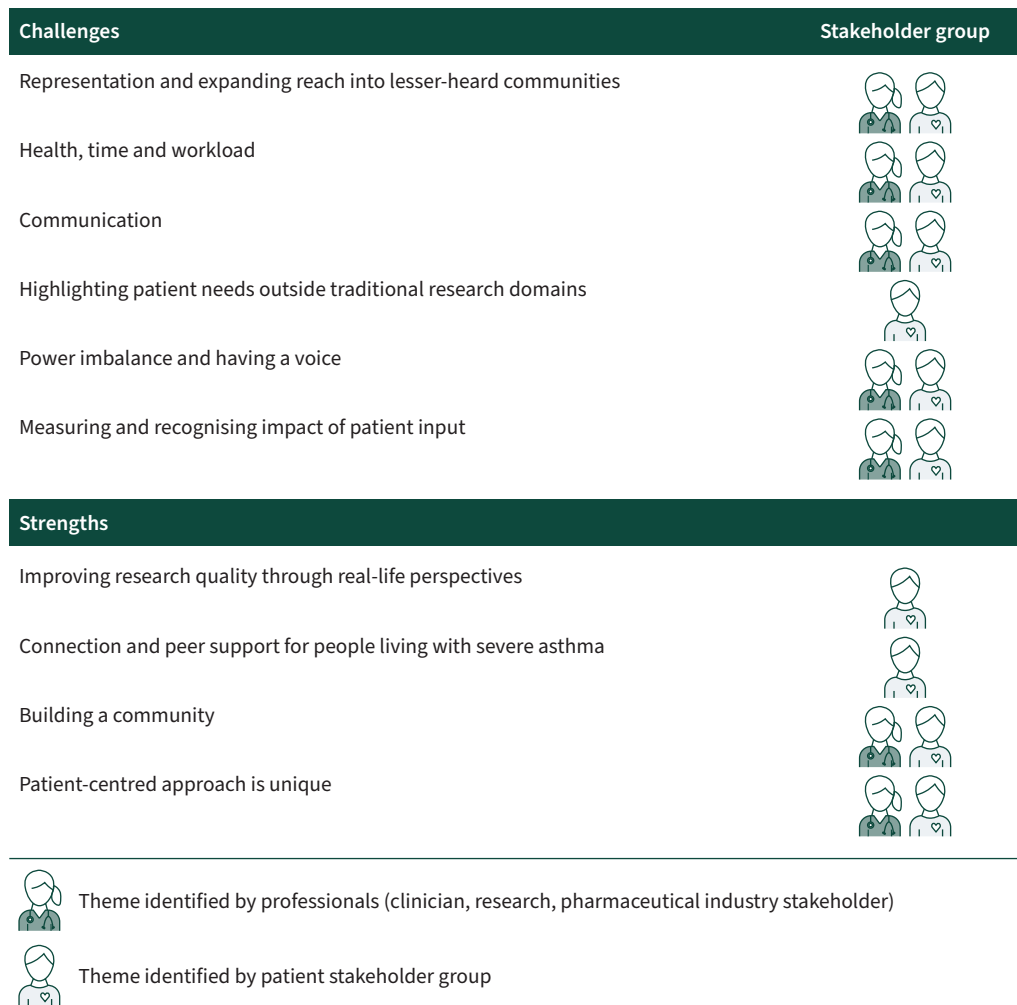


FIGURE 1 Themes identified from the workshop on patient partnership in the Severe Heterogeneous Asthma Research collaboration, Patient-centred (SHARP).

patient and public involvement in research, the channels available within SHARP for patients and professionals to work together and the impact this had demonstrated. Attendees were asked to discuss two key questions. 1) What are the strengths, weaknesses and challenges around patient involvement? 2) What are the opportunities for improvement? Feedback was collected *via* an interactive whiteboard, allowing attendees to provide written comments, and a discussion session invited further reflections. Several interactive polls were used to understand the levels of confidence in involving patients and training needs. An ELF member of staff (C. Coleman) collated written and verbal feedback and identified themes. Themes were discussed and revised with input from co-authors and are summarised in figure 1. Taking the themes as a starting point, good practices in the field of patient and public involvement were identified through online research, publication searches and speaking to experts in the field, in order to identify four key principles to strengthen patient involvement in our work.

In this article, we draw together the learning from the workshop with best practice in patient and public involvement as a set of principles to which future ERS and ELF collaborations should adhere. These principles of patient partnership set out the standards to involve patients and carers within ELF and ERS projects. Table 1 provides an overview to help researchers and patient representatives to implement the principles in practice.

Principle 1: Patient partnership should be part of the culture of research projects – projects benefit when patients are embedded in the development, governance, delivery and dissemination

In practice, this means patients and carers are involved in the management, design and implementation of the project as joint decision-makers. There is a culture of working in partnership with patients, which

TABLE 1 Summary of principles and suggestions for implementation

Principle	Exploring this principle in your approach	Suggestions for implementation
1) Patient partnership should be part of the culture of research projects – projects benefit when patients are embedded in the development, governance, delivery and dissemination	<ul style="list-style-type: none"> Recognise the value that patient representatives bring Consider how to balance patient and researcher priorities Understand the importance of engaging patients at all stages of the research process 	<ul style="list-style-type: none"> Provide guidance and training to support patients in their role and dedicate resources to patient input Tailor opportunities to the needs and capacity of the patient representatives Use a range of tools and opportunities to foster patient partnership across the research process
2) Patients and carers are experts by experience	<ul style="list-style-type: none"> Value the unique insight that patients bring Recognise the individual and systemic biases that make it harder for patient voices to be heard Listen to patient partners to understand where their experiences differ from those of professional partners 	<ul style="list-style-type: none"> Create specific and intentional opportunities to gather patient perspectives Channel patient input into the aspects of research where patients have unique and relevant insight Be aware of the challenges patients may face during meetings and develop ways of working that foster collaboration
3) Inclusive opportunities allow patients and carers with diverse backgrounds to enrich the project	<ul style="list-style-type: none"> Research benefits from involving a diverse group of patient representatives Patient representatives can play a role in gathering experiences from their wider community Remove some of the barriers that patients face, including financial, health, language and social inequalities 	<ul style="list-style-type: none"> Provide open, inclusive and accessible opportunities for patients to get involved Consider ways to make project findings accessible to diverse patient audiences
4) Measuring and recognising the impact of patient and carer input into the project helps to demonstrate its value and creates opportunities to improve practice	<ul style="list-style-type: none"> Demonstrating the impact of patient involvement helps to motivate patient and professional partners Look beyond the individual project to understand how patient input has an impact on the wider community 	<ul style="list-style-type: none"> Monitor, report and celebrate the impact that patient representatives have had Contribute to the literature by sharing your experience of the benefits and challenges around patient involvement Consider how individual patient representatives can share learnings with their communities

recognises them as valued members of the project's research community. All stakeholders understand that the quality of research improves when patients are equal partners.

Exploring this principle in your approach

- Recognise the value that patient representatives bring to the project. Consider ways to develop a culture of patient partnership across the project, going beyond patient involvement as a tick-box.
- Consider how to maximise the input from patients and carers.
- Consider how priorities raised by patients can be addressed within the project.
- Recognise that patient involvement practices and culture vary considerably across Europe, and some patients and professionals may be less familiar working in a partnership model.
- Develop meaningful opportunities for patients to engage throughout the project and avoid only including them at the review stage, when key decisions have already been made.
- Maintain patient confidentiality at all times.
- Balance the communication needs of patients and carers involved in the project to make sure they are well informed, without feeling overwhelmed.

Suggestions for implementation

- Develop clear roles and expectations for patients and carers involved in the project. Clearly outline the anticipated commitment from patient representatives, including the number of meetings per year, if attendance is expected in person or virtually, and any extra commitments such as reading documents or inputting into email discussions.
- Be conscious of overburdening patient representatives, especially if the number of patients involved is small. Input can be maximised by targeting involvement to key areas and minimising attendance at technical meetings.

- Provide training and support for patients and professionals in understanding patient involvement in research and care. The European Patient Ambassador Programme (EPAP) provides introductory training and is available in six languages. It is primarily aimed at patients, although many professionals have also found it beneficial. Develop a training plan to address additional training needs.
- Offer an assigned person from the research team who can act as a mentor to the patient representative. This person can help to answer questions and help patients and carers feel more at ease during meetings. For some patient representatives this will only be needed at the beginning of the project, but others may need ongoing support. Table 2 provides more specific tips on involving patients at meetings.
- Involve patients and carers in strategic planning and governance discussions. Depending on the amount of time they have available, this could include inviting patients to sit on the project steering committee or as project co-chairs.
- Involve a wider group of patients, for example through a patient advisory group. Provide meaningful opportunities for them to input into project design and delivery, such as research priority setting and clinical trial design.
- Take the opportunity to attend meetings with the patient group to discuss issues in more detail or to understand how to address their feedback.
- Ensure patients are represented and specifically consulted within the scoping and approval process for new initiatives, *e.g.* research studies or funding applications. Patient suggestions for improvement should be addressed before initiation of new activities.
- Showcase patient voices in internal and external communications, for example as patient speakers during stakeholder meetings and as partners in discussions with funders.
- Involve patient representatives in any social events that you are holding alongside formal meetings so that they can get to know other project members in a more relaxed setting. Consider “meet the patients” bulletins or events.
- Use online tools such as Microsoft Teams and Google Classroom for document sharing and to foster discussions. This helps provide transparency around different stakeholder groups commenting on documents and can foster new research collaborations between patients and professionals.
- Regularly communicate with patients involved to keep them informed of project progress in plain language. Patients should receive project newsletters and have the opportunity to contribute articles. If the project is delayed, tell the patient representatives when they can expect to hear an update.
- Engage patients early in the preparation of publications to ensure their feedback can be addressed.
- Dedicate resources to facilitate patient input. This includes time of the person coordinating patient involvement in the project, as well as budget for activities such as training, recruitment, translation of surveys and production of patient-facing materials.

TABLE 2 Working in partnership: tips for meetings

Provide a meeting agenda and any working documents at least 2 weeks before the meeting, bearing in mind that patients and carers will need to schedule time to prepare. Provide contact details of the meeting organiser.

Listen to patient representatives, ask questions to make sure you understand their point and take steps during the meeting to address it. If you are unable to address patient comments during the meeting, for example if some research is needed to find the answer, ensure you respond to the patient representatives afterwards. Patient representatives should find opportunities to make sure researchers have understood the patient perspective. Patients may consider providing evidence-based material to support patient insights.

Points raised by patients must be noted in the meeting minutes and actioned where necessary.

Use natural breaks in the discussions to explain to patients what is being discussed.

Make sure there is a mechanism for feedback after meetings to check if patients have any questions and have understood discussions, for example by email, by arranging a time for a debrief meeting, or catching up informally during a coffee break. Consider lay versions of important documents.

Be aware of some challenges that patient representative(s) may face during meetings:

May not be used to attending formal meetings.

May not feel part of the group initially, *e.g.* scientific members may already know each other well.

Unable to participate fully during in-depth scientific discussions.

Difficulties in hearing discussions that may touch on sensitive or potentially upsetting issues, *e.g.* mortality rates, serious complications or ineffectiveness of certain treatments.

May be unfamiliar with some of the clinical terms and acronyms used. Members should explain technical terms during meetings and consider producing a glossary covering key terms.

May feel there is a power imbalance between their experience as a patient compared to the expertise of professionals, and find it challenging to assert themselves.

Principle 2: Patients and carers are experts by experience

All stakeholders involved in a project are experts, either through lived experience or professional experience. Patients and carers bring unique insight into their lung condition. This expertise complements the expertise of health professionals, researchers and other partners.

Exploring this principle in your approach

- Recognise the unconscious biases that individuals may bring to discussions. This can include, for example, professional expertise, areas of research interest, gender, ethnicity and socioeconomic status. These biases can influence the way professionals and patients interact, and the willingness to take patient feedback on board.
- Recognise power dynamics within discussions. Patients tend to be in the minority during discussions and do not usually have an academic or clinical title to add “weight” to their points. This means patients must work harder for their voices to be heard.
- Constructive disagreement is necessary to improve research and care. If a person’s comment makes another stakeholder uncomfortable, the individual should look at that discomfort and challenge themselves to think differently. This might include aspects of the healthcare system, clinical practice or pre-conceived ideas of what it is like to live with the condition.
- Recognise that patients are sometimes dismissed or not believed by healthcare professionals during their treatment and care.
- Listen to what patients are telling you. It may be different from how you think patients feel, or from the things patients tell you during clinic visits.

Suggestions for implementation

- As project chairs and facilitators, give an introduction explaining the role of the patient representatives and encourage stakeholders to be open to patients’ perspectives.
- Devote specific time to collect patient perspectives. Prompt patients to provide input, especially on topics where their views may differ from the professionals’ opinion, and encourage them to challenge and question.
- If a stakeholder comments on patient behaviour, thoughts or feelings, for example “patients tell me that they like...”, use this as an opportunity to check if the patient partners agree or if there is a wider perspective to consider.
- Be aware of the different agendas and hierarchies at play within a research group. Encourage all stakeholders to be transparent about their aims and open to compromise to enable a group consensus to be reached.
- Recognise that patients have different kinds of contribution to add value. Patient input can be very useful to set top-level research priorities, whereas patients are less likely to know the literature and what has been done before. Patient input to improve the experience of study participants through questionnaire design and patient information materials is essential. Involving patients in trial design can help to ensure studies are well adapted to the needs and preferences of participants, for example around visit schedules, acceptability of invasive sampling procedures and preferences for remote monitoring. Patient input is maximised by channelling their input to priority areas and by directing specific and relevant questions towards patients in meetings, rather than expecting them to contribute to all meetings in a more general way.
- Patient partners should feel comfortable declining opportunities to input where they feel it is outside their area of experience.

Principle 3: Inclusive opportunities allow patients and carers with diverse backgrounds to enrich the project

People with lung conditions come from all languages, cultures, genders and backgrounds. Patient and carer representatives involved in the project must reflect this diversity. Consideration around accessibility and meeting the needs of patients and carers can help to ensure all groups have opportunities to get involved.

Exploring this principle in your approach

- Patient representatives should consider how to gather wider perspectives beyond their own personal experience.
- Remember that patient representatives are living with a lung condition. Their health and energy levels may vary. They may also have a range of other commitments that they must balance.
- By only involving patients from similar backgrounds or who have a long history of patient involvement, there is a risk that other voices and perspectives from the patient community will be lost.

Suggestions for implementation

- Use open recruitment methods to attract patient representatives to the project. Consider targeted recruitment to increase involvement from underrepresented groups.
- Be open to using new forms of communication and technologies to foster collaboration, such as automatic translation services for online meetings and a range of social media platforms to engage different audiences.
- Explore wider patient perspectives, *e.g.* by talking to other patients in your country, reading blogs or social media experiences, exploring qualitative research on the topic, conducting polls on social media or running multi-lingual surveys.
- If a patient is asked to comment on something of which they have no direct experience, give them the chance to consult the wider patient community and feed back.
- Provide a range of ways for patients to get involved in the project, not relying solely on attendance at meetings.
- Ensure all costs of involvement are paid by the project, including travel and accommodation costs, video conferencing, childcare and other caring costs. Ideally, expenses should be paid in advance.
- Provide a minimum of 2 weeks for patients to provide feedback. Be aware that availability is often limited during Christmas and summer holidays.
- Recognise that language barriers prevent some patients from getting involved in international projects and many representatives speak English as a second language. Use plain language where possible and consider providing a glossary of key scientific terms.
- Consider ways to communicate project findings to patient audiences in a variety of accessible formats, *e.g.* lay summaries of publications, webinars, easy-read factsheets and materials translated into different languages.

Principle 4: Measuring and recognising the impact of patient and carer input into the project helps to demonstrate its value and creates opportunities to improve practice

Patients and carers arguably have the biggest stake in health research. They get involved because they want to drive research forwards that meets their needs. By evaluating the impact of patient involvement and having systems in place to showcase their work, patients and carers feel valued and are more likely to continue their involvement, and other stakeholders recognise the added value of working in partnership.

Exploring this principle in your approach

- Both patients and professionals need to see patient input having a tangible impact in order to remain motivated and continue working in partnership.
- It can be draining for patients to participate in large international projects, giving up their time and sharing personal details of their health and care.
- Consider how patient input in the project has an impact upon the wider patient community.

Suggestions for implementation

- Make a note of changes made to the project as a result of patient input, *e.g.* inclusion of a research question developed by patients or changes made to patient information materials. Provide feedback to patient representatives on what changes were made, including the rationale for not implementing suggested changes.
- Ensure project awards are open to patients as well as professionals and consider providing a regular opportunity for recognition, *e.g.* an annual patient impact award.
- Report methods and impact of patient involvement within project publications, in line with best practice, in order to contribute to the evidence base for patient involvement in research [12].
- Contributions of individual patients should be recognised within all publications through authorship or acknowledgements.
- Consider ways to showcase patient involvement in the project as a means to engage new patient representatives, share learning and promote partnership working in other areas of research. This may include dedicated patient-facing webinars, engagement on social media, presentations at scientific and other conferences, and publications.

Future focus

The field of patient and public involvement is constantly evolving. While this document sets out current best practices and suggestions for embedding high-quality patient involvement in research collaborations, there is a lack of clarity around the best ways to approach certain challenges.

International patient involvement practices would benefit from further research on how to engage people from lesser-heard communities, including those from diverse geographical, ethnic, social, economic and education backgrounds, and from high- and low-resource health systems. While some localised efforts have found ways to increase diversity in patient and public involvement, others have revealed unforeseen hurdles, where efforts to increase diversity risked alienating those who had contributed their lived experiences to research for many years [13, 14]. In our experience of involving people with respiratory diseases, many countries do not have established patient organisations or groups that bring together patients and carers to share experiences or advocate for improved treatment and care, meaning that it can be difficult to identify people who are interested in getting involved. This is particularly evident when trying to engage representatives from low- and middle-income countries, and those with lived experience of rare and critical respiratory care, such as mechanical ventilation. Consideration should be given to developing and strengthening patient involvement in countries and disease areas where patient advocacy is still in the early stages.

International groups working to involve patients and the public are faced with specific additional challenges due to the nature of cross-border working, including language barriers, differing legislation around diversity monitoring practices and payment for involvement, and variation in the requirement for ethical approval to conduct patient and public involvement [15–17].

Developing a research agenda for international patient partnerships would help to identify priority areas for further research and help to provide guidance to strengthen patient and public involvement practices. One viable avenue for this to be taken forward is through the International Network for Public Involvement and Engagement in Health and Social Care Research, established *via* the Cochrane Consumer Network [18]. By bringing together global stakeholders to share knowledge, promote and build capacity for patient and public involvement in research, this network is uniquely placed to address research gaps and support patient and public involvement practitioners to deliver for health communities globally.

Conclusion

The principles of patient partnership set out best practices in patient involvement in research collaborations and provide practical suggestions for fostering partnership between patients and professionals. The principles bring together the ELF and ERS experience of involving patient representatives in the ERS Clinical Research Collaboration (CRC) programme, along with best practice in the field of patient and public involvement and the experiences of patients and professionals working together in current ERS CRCs.

The ERS CRC programme covers a varied portfolio of disease areas, study types and levels of funding. In order to implement this vision for patient partnership, CRCs will require resources and time, but by doing so they can drive forward a patient-centred research agenda that truly delivers for people living with respiratory diseases.

Acknowledgements: The principles of patient partnership were developed by Courtney Coleman from the European Lung Foundation (ELF) and Olivia Fulton from the ELF asthma patient advisory group following consultation with patient and professional representatives involved in the Severe Heterogeneous Asthma Research collaboration, Patient-centred (SHARP) [11], the ELF united patient advisory group and representatives of other ERS CRCs. The authors would like to thank Michal Shteinberg (Pulmonology Institute and Cystic Fibrosis Center, Carmel Medical Center and the Technion-Israel Institute of Technology, Haifa, Israel), Celeste Porsbjerg (Department of Respiratory Medicine, Respiratory Research Unit, Bispebjerg Hospital, Copenhagen, Denmark), Ratko Djukanovic (NIHR Southampton Biomedical Research Centre, University Hospital Southampton, Clinical and Experimental Sciences, Faculty of Medicine, University of Southampton, Southampton, UK) and Heather Bagley (COMET Initiative, Institute of Translational Medicine, University of Liverpool, Liverpool, UK) for their input.

Conflict of interest: C. Coleman is an employee of the European Lung Foundation. O. Fulton received support from ERS/ELF/SHARP to attend ERS Congress 2022; disclosure made outside the submitted work. J. Boyd is an employee of the European Lung Foundation. C. Williams is an employee of the European Lung Foundation. Z. Powell received honoraria from the ERS, outside the submitted work; and support for attending meetings and/or travel from ELF and Pediatric Cough Seminar, outside the submitted work. C.E. Brightling received grants or contracts from GSK, AZ, Genentech, Roche, Sanofi, Regeneron, Novartis, BI, Chiesi, Mologic and 4DPharma, outside the submitted work; and consulting fees from GSK, AZ, Genentech, Roche, Sanofi, Regeneron, Novartis, BI, Chiesi, Mologic and 4DPharma, outside the submitted work. M. van den Berge has received grants or contracts from GlaxoSmithKline, Chiesi, Novartis, Genentech, Sanofi and Roche, outside the submitted work. S. Siddiqui has

received consulting fees from AstraZeneca, GSK, Chiesi, Boehringer Ingelheim and CSL Behring, outside the submitted work; speaker fees from GSK and Chiesi, outside the submitted work; and is ERS Clinical Research Collaborations (CRCs) Director elect, and Medical Research Council Experimental Medicine Board member, both unpaid positions. P. Powell is an employee of the European Lung Foundation.

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