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# ConectAR: Collaborative network of patients with asthma and carers actively involved in health research: a protocol for patient and public involvement

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## KEY WORDS

*Patient and public involvement; citizen science; patient-centered health research; asthma; chronic respiratory diseases.*

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## Summary

**Background.** Patients and Public Involvement in every stage of the patient-centered health research cycle is the key to the development of innovative solutions with an impact on patients' care. **Methods.** This protocol describes the development of ConectAR, a network to promote the involvement of patients with asthma and their carers in the health research cycle. **Results.** This protocol comprehends 4 tasks: 1) define the mission, vision, governance and activities of the network through focus groups; 2) establish the communication strategy and tools; 3) test the feasibility of the network in a Delphi study on the research priorities for asthma in Portugal; 4) coordination and dissemination activities. **Conclusions.** This network will improve research by ensuring that patients and carers have an active role in the co-creation of impactful solutions for asthma.

## IMPACT STATEMENT

*ConectAR will be a collaborative network involving patients as active stakeholders in research, to empower them to become agents of change in asthma research and care.*

## Introduction

Patient and Public Involvement (PPI) in research refers to “research being carried out ‘with’ or ‘by’ members of the public (including patients, potential patients, carers and people who use health and social care services) rather than ‘to’, ‘about’ or ‘for’ them” (1). Implementation of PPI in research is inevitable, not only for reasons based on democratic principles of citizenship, accountability and transparency but also because the public offer unique, invaluable insights.

Patients and members of the public are getting involved as valuable members in innovative health solutions. In Portugal, examples of initiatives to actively involve patients and carers are the “MAIS PARTICIPAÇÃO Melhor saúde” – a collaborative initiative focused on PPI in the health politics (2) –, and the “Patient Innovation” – a web platform and network available to the public and patients to submit and share their innovative health solutions (3). Regarding health research, according to INVOLVE, a leading PPI organization in the UK, patients may be involved in every stage of the research cycle: identifying and prioritizing, commissioning, designing, managing, undertaking, disseminating, implementing, and evaluating impact (1). This involvement may happen in several forms: consultation (patients give their opinion on specific issues), collaboration (shared-decisions between researchers and patients), and patient-led research (patients deliver and manage research) (4, 5). The patient involvement in the development of Patient-Reported Outcome Measures (PROMs) is essential to ensure that they are relevant and patient-centered, yet patients are not always involved and few studies involve patients in the early phases (6). Likewise, the PPI in the development of mobile health (mHealth) technology is strongly encouraged (7). Patients contribute with a different and complementary perspective to research, by adding personal knowledge and experience, and ensuring research priorities are aligned with their needs. PPI in health research is thus believed to improve its quality, relevance and ethics, despite posing challenges in terms of time expenditure, required training and support, and power sharing (8). Organizations such as the INVOLVE (9), the Canada’s Strategy for Patient-Oriented Research (10), and the Patient-Centered Outcomes Research Institute in the USA (11) are examples of successful establishment of PPI in health research. Despite its recognized importance, and the fact that a growing number of scientific journals now require statements on how patients have been involved in research, to our knowledge, there is no such established group in Portugal, specifically in asthma research.

Chronic respiratory diseases (CRD), such as asthma, are a source of substantial burden, with increased morbidity and mortality (12). Within patients with asthma, those with severe asthma have disproportionate higher morbidity, mortality, and

costs than patients with non-severe asthma, representing an unmet clinical need (13). In Portugal, the first and only Portuguese National Asthma Survey (INAsma) estimated that the prevalence of asthma in the Portuguese population was 6.8% (95%CI 6.0-7.7) (14). Almost half (43%) of the patients had non-controlled asthma, associated with worse health-related quality of life (15). Patients’ involvement in every stage of the research cycle is the key to the development of innovative solutions with impact on patients’ care. This includes collaboration in the development of the research question, in supporting ethical approval submissions, in carrying out the research, and in the discussion and dissemination of the research findings. The European Lung Foundation (ELF) has been remarkable in the involvement of patients with CRD and other lung conditions in research and guideline development (16). In Portugal, patients’ associations (Respira (17) and Associação Portuguesa de Asmáticos (18)) play an important role supporting patients with CRD. However, no established group dedicated to PPI in health research for asthma has been developed to date. To improve the quality of research projects and strengthen their relevance and impact, and to provide valid scientific evidence in plain language for patients to understand and share, it is essential to involve patients and public, including carers, in every phase of the research cycle in future projects.

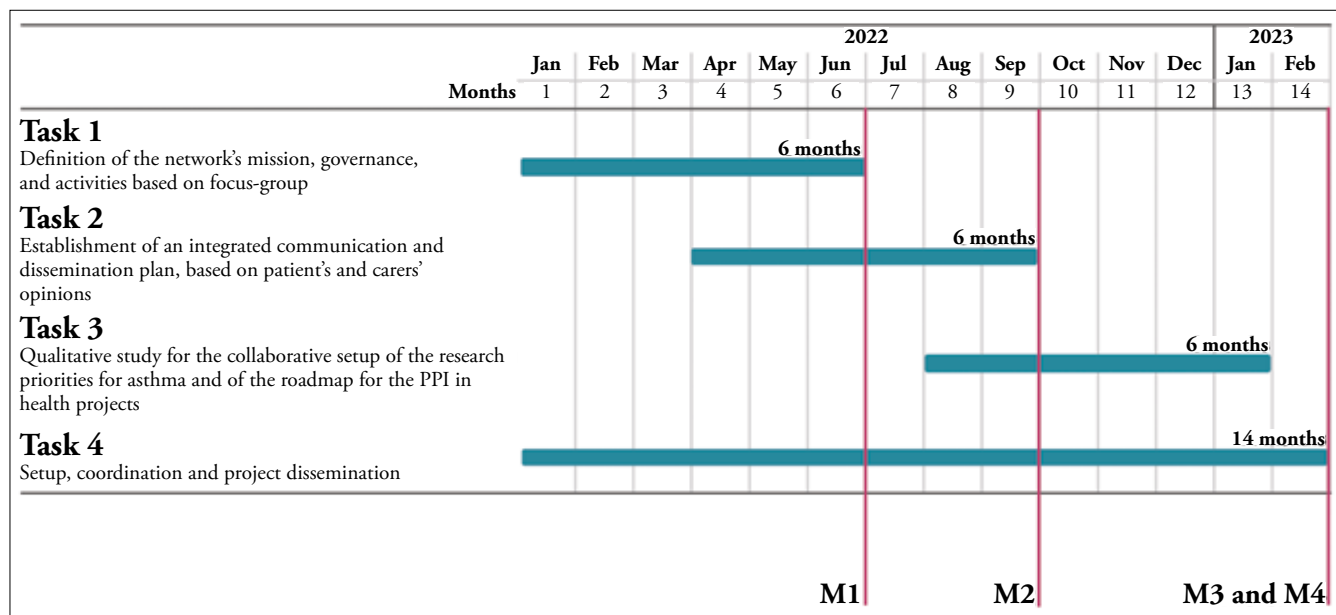
Our main goal is to foster the involvement of patients with asthma and their carers in every phase of the health research cycle.

Specifically, in this project we aim to 1) create a collaborative network – definition of its mission, vision and governance based on shared decision-making; 2) develop communication strategies and tools to recruit and engage patients and carers as co-researchers within the network; 3) setup research priorities for asthma in Portugal and the roadmap for the involvement of the network in future projects.

## Materials and methods

The ConectAR project includes three patients (with mild asthma, with moderate-to-severe asthma, and with severe asthma) and a carer of a patient with asthma as team members, which were involved from inception and contributed to this proposal. Patients will be fully engaged in all stages of this project: in the definition of the network (Task 1), in the development of the communication strategy and tools (Task 2), in the design, analysis and interpretation of the results of the qualitative study for the setup of the research priorities for asthma and a roadmap for the throughout involvement of the network in future projects (Task 3), and in the management and dissemination of the project (Task 4).

The tasks and respective milestones schedule to be developed in the fourteen months (**figure 1**).

**Figure 1** - Timeline, tasks and milestones for the creation of the ConectAR collaborative network.

M1 – Milestone 1: Official creation of the network; M2 – Milestone 2: Communication plan established and a website and social media channels will be ready to be used for the network dissemination and support; M3 – Milestone 3: Public summary (in plain and simple language) of the research priorities for asthma, based on the results of the qualitative study; M4 – Milestone 4: Proposal of a 3 years roadmap for future PPI in asthma health research, identified based on patients' experiences.

### **Task 1. Definition of the network mission and governance**

This task aims to define the mission, vision, governance and activities of the network, to ensure that the network has relevance for patients and its outcomes are of their interest. This task has the duration of 6 months.

#### *T1.1. Invitation to potential patients' representatives as members*

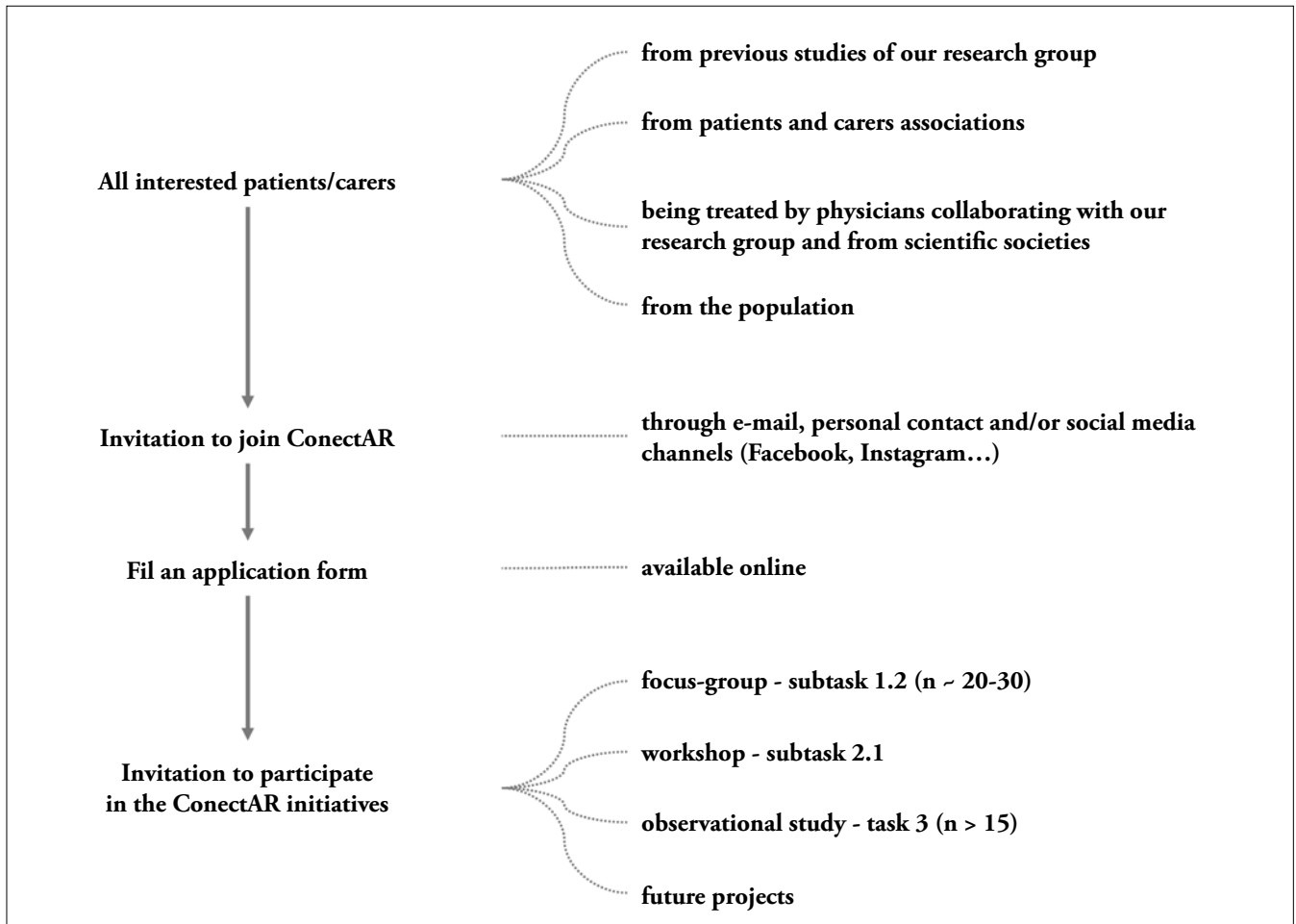
This subtask will identify potential interested members (patients/carers) to integrate the network, through initial contacts with patients (> 600 from previous studies that gave authorization to be contacted for future studies) and physicians (> 275 physicians from 75 different centers) collaborating with our research group (PaCeIT – Patient Centered Innovation and Technologies) (19, 20). Portuguese patients' and carers' associations (Associação Portuguesa de Asmáticos, Respira, Associação Nacional Cuidadores Informais) and scientific societies and networks (Sociedade Portuguesa de Alergologia e Imunologia Clínica, Sociedade Portuguesa de Pneumologia, Fundação Portuguesa do Pulmão, Rede de Especialistas em Asma Grave) will be also contacted for the nomination of patients' representatives to join ConectAR. Participants will also be invited through social media channels, such as Facebook and Instagram. The patients/carers interested in joining the ConectAR will complete an application form available through the "Inquiridos UP" platform. Patients/carers recruitment is represented in **figure 2**. Additionally, the interested members will be invited (not man-

datory) to participate in free online/in-person learning program for patients and carers to gain knowledge and confidence to get involved in different areas of patient involvement (*e.g.*, the European Patient Ambassador Programme (21) and Patient Engagement Through Education (22)).

#### *T1.2. Definition of mission, vision and governance*

A qualitative study will be conducted to explore patients and carers' expectations regarding their involvement in asthma research, namely the network name, mission, vision, governance, inclusion criteria, activities and roles. This study will be grounded on focus-group interviews due to its ability to enhance interaction amongst participants and generate a rich understanding of people's experiences and beliefs. For studies similar to ours, a sample size gathered in 3 focus groups has been advised (23). Thus, we plan to include between 18 to 24 patients (identified in Subtask 1.1), divided in groups of 6-8 members. By doing this, patients will contribute to reshape and clarify the focus of this network in a democratic approach, mostly rooted in people's lives and experiences, instead of researchers' expectations. This democratic approach is explicit about the distribution of power, collective action and empowerment. Each focus-group will be recorded digitally, transcribed verbatim and analyzed by two independent researchers using thematic analysis. A kick-off meeting with members (identified in Subtask 1.1) and the research team for discussion and approval of the mis-

**Figure 2 - Patient recruitment and involvement in ConectAR collaborative network.**



sion and governance will mark the official creation data of the network. The meeting will take place at the host institution, but participants will also be given the possibility to attend via teleconference.

By the end of this task, it is expected to have the creation of the network (Milestone 1, **figure 1**) – a group of patients’ representatives engaged with the project and willing to participate in Tasks 2 and 3 – and the submission of a paper and a lay summary with the results of the qualitative study, including the PPI impact in it and the content to be used in Task 2.

**Task 2. Communication strategy and tools**

This task aims to establish the communication strategy and tools to increase awareness of the network activities, to promote training and engagement opportunities for active members and to attract new people to join the network. Involving patients in designing and developing these tools can strengthen the recruit-

ment of patients and carers to become members of the network, by ensuring that the recruitment process and the strategies for the maintenance of communication are practical, attractive and feasible. This task has the duration of 6 months.

*T2.1. Definition of communication strategy and tools*

This subtask will organize a workshop to involve patients in the establishment of the most effective communication strategies for future recruitment and retention of the network members. This ensures that the generated contents reach patients with different backgrounds and literacy levels, allowing its representativeness among network members. The workshop will be specifically focused on the definition of a sustainable communication strategy, mainly on digital marketing (website, social media and e-mail), but also including innovative dissemination initiatives, such as establishing science-arts collaborations and activities, connecting the participants with distinct artistic expressions and

actors and involving them in the co-creation of a series of arts-based science communication experiences, ultimately making use of the arts as an innovative means to translate complex scientific knowledge and information into engaging and meaningful experiences. The workshop will involve creative driven, two-way team building activities, reinforcing the participants group cohesion and motivation, while generating unique material for social media dissemination. A workshop will be held with patients and public to discuss the strategies to 1) motivate ongoing engagement of members; 2) to encourage new people to join the network; 3) to keep people informed throughout the group activities; 4) to disseminate results to all that were consulted and collaborated during the project. The workshop will be prepared with the support of the team members with expertise in social science, in communication science and digital media, in collaboration with a consultant expert in PPI in research.

The results of this workshop and the first content for the website will be shared with the network members to gather feedback and reach a co-produced final version.

#### *T2.2. Implementation of the network communication strategies and tools*

This subtask includes the creation of a brand for the network, its website and social media channels according to the results of the workshop (Subtask T2.1). All the content on the mission, topics of research and activities of the network (from Task 1) will be included in the website. It is expected that this website includes features for registration (to allow involvement of new members) and sharing of ideas (dedicated forum). The website will be built following the host institution security standards and the database with registered users will be stored at a secure local server. The network members will be invited to test and provide feedback throughout the website development process.

The process of transforming the ideas given by patients in the workshop into a communication strategy and tools will be supported by a digital marketing agency (external services provider).

#### *T2.3. Content updates processes*

Content developers will be identified among the participants of the focus-group (Subtask 1.2) and of the workshop (Subtask 2.1). They will produce regular updates in lay and user-friendly language for patients and carers outside the network, including information on the upcoming study (Task 3.3). These patients will also be responsible for the selection of educational content to feed the network website.

By the end of this task, it is expected to have an integrated communication and dissemination plan (Milestone 2, **figure 1**) with a focus on digital marketing strategies, and fully operational and engaging website and other communication tools that will support network activities, namely the qualitative study in Task 3.

### ***Task 3. Collaborative setup of research priorities for asthma and roadmap for the PPI in health projects***

This task will be the pilot study to test the feasibility of the collaborative network in the design, implementation and dissemination of a qualitative study on the research priorities for asthma in Portugal, based on patients' perspectives. Study design will be built collaboratively with the network (defined in Task 1). Yet, the following aspects are anticipated. This study will be implemented in three phases: 1) identification of the main daily challenges of the patients and associated research questions; 2) prioritization of the research questions; 3) setting a roadmap for the PPI in asthma research projects for the next 3 years. This task has the duration of 6 months.

#### *T3.1. Identification of patients' main challenges*

In phase 1, we will explore the main daily challenges experienced by participants collected through the self-recording of audio-diaries. At least 15 patients with mild, moderate and severe asthma (or their carers), will be invited to participate through the network communication channels (Task 2) for a recruitment period of 2 months. Patient eligibility criteria are: 1) medical diagnosis of asthma; 2) at least 18 years of age; 3) ability to use the voice-recorder functionality in smart devices and access to an Internet connection. The participants will be invited to make daily recordings for a seven-day period and then send it to the project team. The network members (identified in Subtask 1.1) and the research team will develop a guide for completing the diary with a given number of open-ended prompts to support the generation of narratives, including sources of anxiety, disposition for physical exercise and social events, medication and healthcare services issues and challenges, relationship with healthcare professionals. Participants will be provided with this guide but will be informed they are not restricted to these.

Content analysis of the transcriptions of the daily challenges of the patients with asthma will inform the main research questions.

#### *T3.2. Prioritization of the main research questions*

In phase 2, one month after phase 1, the participants will be invited to participate in a real-time Delphi study to give his/her opinion on the priority of the main challenges and research questions identified (Subtask 3.1). In contrast to the traditional Delphi, the real-time approach is round-less and offers a constant iteration by providing immediate (real-time) individual and aggregated feedback. Based on the results of the study, the network members (identified in Subtask 1.1) and the research team will summarize the research priorities for asthma in Portugal.

### *T3.3. Collaborative setup of the roadmap for the PPI in asthma research projects*

In phase 3, after prioritizing the research questions, a meeting with the network members (identified in Subtask 1.1), the research team and invited partners (*e.g.*, associations, scientific societies, networks and collaborative initiatives) will be held to set a roadmap for the PPI in asthma research projects for the next 3 years.

By the end of this task, it is expected to have a draft of an original paper for submission, a summary in plain and simple language (Milestone 3, **figure 1**) on the research priorities for asthma in Portugal. Additionally, a roadmap will be set for the PPI in asthma health research for the next 3 years (Milestone 4, **figure 1**).

### **Task 4. Setup, coordination and project dissemination**

Setup and coordination are critical for the management of the project, from its design to dissemination. To ensure the patients' perspective is maintained throughout the project and that patients are effectively supported, patients with asthma and carers are taking an active role as members of the study steering committee. Also, the involvement of patients in the dissemination will enable the creation of public summaries of the research findings in clear, user-friendly and non-technical language, to ensure the findings are accessible to the lay public. As an example, patients and carers of the research team built the summary for the general public of this paper (**online supplements appendix 1**). The dissemination of the results of the project includes the writing and production of scientific outputs and diffusion to the general public and support to the network communication updates. This task has the duration of 14 months.

The management of this project will include a Steering Committee, constituted by three patients with mild, moderate-to-severe and severe asthma, and a carer of a minor with asthma, four researchers and three physicians. An advisory board will include an expert in engaging and involving the public in innovative ways around complex topics, an expert in communication science and digital media, an expert on asthma and mHealth.

The Steering Committee will make strategic decisions about the project, such as the management of the scientific and financial components of the project, management of services providers agreements, and organize monthly meetings. Their main role will be to guarantee the smooth running of the project, efficient coordination between team members to achieve project goals.

A kick-off meeting will be organized, to establish general procedures and to discuss the roles of the team members throughout the project. Team building activities will be carried to stimulate soft skills and promote group interactions between the project team and the network members.

During this task it is expected to have 1) the preparation and submission of applications to the ethics review board; 2) the implementation of a collaborative shared online folder for the

project team; 3) the definition of the requirements for the services that will be purchased, namely for the implementation of the communication plan (*e.g.*, digital communication and marketing strategy, website design, *etc.*); 4) the involvement of patients' associations, scientific societies and other collaborative initiatives as project partners; 5) dissemination activities, including at least one original paper and results to be presented in at least two scientific meetings.

The project results will be disseminated among patients, general public, researchers, health professionals, decision-makers and educators. The project will use its own social media channels and other media (*e.g.*, press communications) to attractively diffuse project results to the public. Since this research involves diverse science communication activities, it is important to pause and consider the ethics of knowledge and the ethics of making knowledge public: who's knowledge? for whom? for what reason? at what (social and economic) cost? (24). Therefore, and considering that science communication is a hybrid field incorporating media and communication practices and scientific research, during this research project we will adopt and adapt an approach combining ethical principles and guidelines drawn from media and communications, scientific research, and other fields to respond to science communication and this research project's hybrid and participatory driven foundations.

Scientific outputs of the project include at least one original paper and results to be presented in at least two scientific meetings.

### **Ethical considerations**

To create the network, which will be a group of patients with asthma and carers involved as co-researchers in health research, concerns with privacy and personal data protection will be considered. Ethical approval will not be needed as patients and carers in this group act as equal partners with academic researchers and healthcare professionals, instead of being subjects under investigation. By becoming a member of the network, patients and carers will have the opportunity to actively participate in every phase of health research, and potentially contribute to improving patient-physician interactions and the quality of care for themselves and others with a similar condition. Personal data, namely name and email contact, will be collected and securely stored/managed in a centralized database at the host institution following the European General Data Protection Regulation (GDPR-EU 2016/679) standards.

Qualitative studies (Tasks 1 and 3) will be conducted according to the Declaration of Helsinki and Oviedo Convention. Patients' personal data will be collected and treated according to the Portuguese law on Data Protection (Law number 67/98, October 26<sup>th</sup>) and the GDPR-EU, executed and enforced in Portugal by Laws 58 and 59/2019. Specifically, to conduct these studies, ethical and institutional approvals will be obtained. Written informed consents will be obtained prior to any data

collection from patients in accordance with GDPR-EU requirements. Informed consents will include information to the participants regarding the types of personal and sensitive data that will be collected, how it will be processed, for what purposes and what security measures will be in place to provide for their privacy, as well as the conservation period or their elimination, after the project ends. In the qualitative study of Task 1, patients with asthma and carers with at least 18 years of age will be involved. For the qualitative study of Task 3 patients' eligibility criteria will be: 1) medical diagnosis of asthma; 2) at least 18 years of age; 3) ability to use the dictaphone functionality in smart devices and access to an Internet connection.

As there will be no change in any prescribed medication, besides those associated with standard clinical practice, no risks are anticipated for patients in relation to the participation in this study. Researchers will emphasize that participation will be voluntary, and patients and physicians will be assured that they can withdraw at any time, without giving any reason and without a negative impact on the care received. The privacy of the patients/carers in both studies will be ensured by pseudo-anonymization techniques, which generate an anonymous univocal numeric code for each subject and the coding key will be encrypted and securely stored and managed, separately from patients' personal and health related data. All data analyses will be performed within the pseudo-anonymized versions of the original databases. The computers that contain patient personal data will be subjected to password protection only known by the Principal Investigator (PI) and the Co-PI. The storage of patient's data will be managed through a centralized database structured in order to guarantee privacy and personal data protection. Only the PI will have access to the original database. This database will be saved in a server of the host institution, with daily backups and firewall protection. All paper documents that are not possible to be scanned in time, and that include personal data, will also have protection measures with physical access control provided to only authorized researchers.

### **Expected results and discussion**

By the end of ConectAR, we expect to have a fully established network of patients with asthma and their carers involved in health research, including a communication strategy supported by a website and social media channels. This network adds value in several domains. Firstly, patients within the network will be empowered, will develop new skills, will have the opportunity to network and to learn about cutting-edge research. Following, this network will improve research at the host institution and will ensure that patients and carers are at the heart of what is done, having an active role in the co-creation of impactful projects and solutions. On the other hand, the establishment of the research priorities for asthma in Portugal based on patients'

perspectives will foster their involvement in future projects with different research teams. Additionally, the network may enable the participation of patients with asthma in the definition of health policies in Portugal.

Despite the benefits for the patients, research and society of this ground breaking project, some difficulties are to be expected. One of the major barriers for the PPI in health research is the frustration with the time constraints of patients and researchers, namely the time patients and carers invested for training and attendance, the extra time needed to participate in research and meetings (25). To address these difficulties, clear expectations on the mission of the network, and the role of patients and researchers within the network will be explicitly described and documented (Task 1); patients will be supported and trained alongside researchers. Moreover, within this project it is expected to spend time to build reciprocal relationships (between patients and researchers), fostering mutual respect, namely by including in its communication and dissemination plan innovative activities and events such as arts-based science communication and creative driven team building experiences (Task 2). Another limitation related to patients' training is that the initiation courses for PPI in research (Task 1) are not yet available in Portuguese. As so, the first patients involved are expected to have an above average level of literacy and, in a future project, will translate and adapt these courses into the Portuguese language and culture. There is also the risk to include as members of the network the most motivated and informed patients, however to capture and maintain the interest of a broader profile of patients, the active members will be part of the building process of the full network and its communication strategies (Tasks 2 and 4), creating new ways of working between patients, carers and researchers and also will be invited to mentor newer members, to help ensure integration into the group. In future, after being settled for asthma research, the network will expand its scope to other respiratory diseases, and even other chronic diseases.

### **Conclusions**

The collaborative network will empower patients and will improve research by ensuring that patients and carers have an active role in the co-creation of impactful solutions for asthma. On the other hand, the creation of this network and the establishment of the research priorities for asthma in Portugal based on patients' perspectives will foster their involvement in future projects and in the definition of health policies in Portugal.

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### Contributions

ASS, CJ, ALN, JAF, ABR: conceptualization. ASS, CJ, ALN, TR: writing - original draft. All authors: writing - review & editing.

### Conflict of interests

The authors declare that they have no conflict of interests.

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***Appendix 1 - Summary for the general public.***

Asthma is a debilitating disease whose limitations are often difficult to be reported and understood by health professionals. Patients with asthma and carers should be involved in research, as it is already the case in other countries. However, in Portugal, there is no recognized body with this function. This project aims to create a network of patients with asthma and carers who will work in collaboration with researchers to address relevant asthma research questions.

The project will be developed during fourteen months, in four main tasks:

1. alignment of the mission and values of the network;
2. training of elements for better involvement in research and definition of ways to disseminate;
3. carrying out a study to evaluate the viability of the network;
4. analysis and dissemination of results.

Involving patients and cares at all stages of a study will have enormous benefits. It is expected that this collaborative network will encourage sharing about asthma and stimulate further research considering the patient's experience. This approach will result in solutions adequate to the limitations and real-life needs of patients with asthma.