PAAI – Interactive online self-learning programme for patients with asthma: Protocol for co-creation and impact

PAAI – Programa de auto-aprendizagem interativo e online para pessoas com asma: Protocolo para cocriação e avaliação de impacto

Cristina Jácome[1] iD, Nancy Fonseca[2] iD, Tânia Rodrigues[2,3,4] iD, Silvana Fernandes[2,5] iD, Emília Dias da Costa[6] iD, Rita Amaral[1] iD, Paula Matos[2] iD, Margarida Areia[7] iD, Liliana Dias[7] iD, Marisa Vilaverde[8] iD, Cláudia Chaves Loureiro[9] iD, José Laerte Boechat[2,10] iD, António Baía Reis[11] iD, Daniela Figueiredo[12] iD, Ana Luísa Neves[1,13] iD, Pedro Simões[14,15,16] iD, Luis Taborda Barata[13,14,17] iD, João Almeida Fonseca[1,18] iD, Ana Sá-Sousa[1] iD

[1] CINTESIS@RISE, MEDCIDS, Faculty of Medicine of the University of Porto, Porto, Portugal
[2] CINTESIS – Center for Health Technology and Services Research, University of Porto, Porto, Portugal
[3] Centro Hospitalar Vila Nova de Gaia Espinho, Vila Nova de Gaia, Portugal
[4] MEDCIDS – Department of Community Medicine, Information and Health Decision Sciences, Faculty of Medicine, University of Porto, Porto, Portugal
[5] Human Reproduction Unit, Centro Hospitalar Universitário de Coimbra, Coimbra, Portugal
[6] Design Department, Faculty of Fine Arts, University of Porto, Porto, Portugal
[7] Allergy and Clinical Immunology Unit, Centro Hospitalar Vila Nova de Gaia/Espinho, Vila Nova de Gaia, Portugal
[8] Faculty of Medicine, University of Porto, Porto, Portugal
[9] Pneumology Unit, Hospitais da Universidade de Coimbra, Centro Hospitalar e Universitário de Coimbra, Coimbra, Portugal
[10] Basic and Clinical Immunology, Department of Pathology, Faculty of Medicine of the University of Porto, Porto, Portugal
[11] Media and Communication Department, University of Passau, Passau, Germany
[12] CINTESIS@RISE, University of Aveiro, School of Health Sciences, Aveiro, Portugal
[13] Department of Primary Care and Public Health, Imperial College London, London, UK
[14] CICS-UBI Health Sciences Research Centre, University of Beira Interior, CACB-Clinical Academic Centre of Beiras, Covilhã, Portugal.
[15] UBIAir – Clinical & Experimental Lung Centre, University of Beira Interior, CACB-Clinical Academic Centre of Beiras, Covilhã, Portugal.
[16] UCSP Fundão, ACeS Cova da Beira, Portugal
[17] Department of Immunoallergology, Cova da Beira University Hospital Centre, CACB-Clinical Academic Centre of Beiras, Covilhã, Portugal
[18] Allergy Unit, Instituto CUF Porto e Hospital CUF Porto, Porto, Portugal.

1

Cristina Jácome, Nancy Fonseca, Tânia Rodrigues, Silvana Fernandes, Emília Dias da Costa,
Rita Amaral, Paula Matos, Margarida Areia, Liliana Dias, Marisa Vilaverde, Cláudia Chaves Loureiro,
José Laerte Boechat, António Baía Reis, Daniela Figueiredo, Ana Luísa Neves, Pedro Simões,
Luis Taborda Barata, João Almeida Fonseca, Ana Sá-Sousa

RESUMO

O envolvimento dos doentes e cidadãos na investigação (PPI) deve ocorrer em todas as etapas do ciclo de investigação. No entanto, a inconsistência nos níveis educacionais e na experiência de investigação pode ser um entrave significativo de uma participação ativa. Assim, ações de formação e suporte são recomendadas. Em Portugal, não existe formação específica para capacitar os doentes nas suas decisões de saúde, ou para se envolverem em investigação. O objetivo principal é desenvolver e tornar acessível o primeiro programa educacional online de elevada qualidade para doentes adultos com asma e seus cuidadores, com base nas suas necessidades e preferências. O projeto inclui 4 tarefas. Na tarefa 1 iremos identificar os tópicos mais importantes na área da asma e investigação em saúde, a partir da identificação das necessidades educacionais de doentes/cuidadores e da experiência de especialistas em asma, usando o método Delphi. Na tarefa 2 pretendemos desenhar e implementar um programa de elevada qualidade, gratuito e online, baseado em fontes de informação fiáveis e nas preferências de doentes/cuidadores. Na tarefa 3 vamos disseminar o programa e avaliar a sua exequibilidade, aceitabilidade e impacto. A tarefa 4 irá incidir na gestão e disseminação do projeto. Doentes e cuidadores estarão ativamente envolvidos em todas as tarefas do projeto como coinvestigadores, onde se inclui a escrita deste protocolo. No final deste projeto, esperamos ter implementado o primeiro programa de auto-aprendizagem de elevada qualidade, gratuito e online para a asma e investigação em saúde, adaptado para doentes/cuidadores com asma. Este programa irá capacitar doentes e cuidadores para aumentar o seu conhecimento sobre a doença, para desenvolver novas competências, e será uma oportunidade para aprenderem sobre investigação. Este programa permitirá também a introdução a conhecimentos necessários para doentes e cuidadores se fazerem representar e influenciarem as políticas em saúde em Portugal.

Palavras-Chave: *Capacitação, auto-aprendizagem, envolvimento de doentes e sociedade, ciência cidadã, e-Health, asma.*

ABSTRACT

Patient and Public Involvement (PPI) in research should focus on the engagement of patients/carers in every stage of the research cycle. However, the inconsistent level of education and research experience may compromise this involvement and training and support are recommended. In Portugal, consistent training to empower patients in their health decisions, or to be involved in research is neither available nor adapted for the patients and public. Our main goal is to develop and deliver the first high-quality and comprehensive online educational programme for adult patients

with asthma and their carers, based on patients'/carers' needs and preferences. The project includes four tasks. In Task 1, we will identify and organise the most important topics on asthma and health research, based on the identification of educational needs of adult patients/carers with asthma and the expertise of asthma specialists, using Delphi methodology. In Task 2, we will design and implement a high-quality, free, online self-learning programme based on reliable sources of information and on patients'/carers' preferences. In Task 3, we will assess its feasibility, satisfaction and impact. Finally, Task 4 will be centred on the management and dissemination. Patients and carers will be actively engaged in all stages of this project as co-researchers, including the writing of this protocol. By the end of this project, we expect to have implemented the first high-quality, free-of-charge, online self-learning programme on asthma and health research, adapted for adult patients with asthma and their carers. It will be available for all patients/carers not only from Portugal but also from all Lusophone countries. This programme will empower patients and carers to increase their knowledge about the disease, develop new skills and have the opportunity to learn about research. Ultimately, it will introduce the knowledge patients/carers need to represent themselves and influence health policies in Portugal successfully.

Key-words: Empowerment, self-learning, patient and public involvement, citizen science, e-Health, asthma.

INTRODUCTION

Patients and members of the public are getting involved as valuable members in innovative health solutions. The National Institute for Health Research (NHS) in the United States (1), Canada's Strategy for Patient-Oriented Research (2), and European Lung Foundation (ELF) (3) are examples of successful establishment of Patient and Public Involvement (PPI) in health research. In Portugal, the collaborative network ConectAR – patient and public engagement to advance respiratory disease and digital health research, is one of the most recent examples of initiatives to actively involve patients and carers as co-researchers in patient--oriented research (4,5). PPI in research is focused on the engagement of patients/carers in every stage of the research cycle: identifying and prioritizing, commissioning, designing, managing, undertaking, disseminating, implementing, and evaluating impact (6). 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 (6). PPI in health research is thus believed to improve its quality, relevance and ethics and ultimately improve patients' outcomes. Along with the acknowledgment of its importance, many guidance documents, frameworks and reviews have been developed on patients' involvement in health research (7).

Challenges of PPI have been reported in terms of patient selection, time, training, governance and power-sharing (8–13). The inconsistent level of education and research experience is one of the main causes of disappointment, frustration and powerlessness. Training and support covering topics such as the research cycle, an overview of different research methods and research terminology are recommended to help patients/carers understand the value of their perspective, recognise the skills and experience they bring from other areas of life, and understand where they fit within the research team (6,14). Training may take many formats, for example,

Cristina Jácome, Nancy Fonseca, Tânia Rodrigues, Silvana Fernandes, Emília Dias da Costa,
Rita Amaral, Paula Matos, Margarida Areia, Liliana Dias, Marisa Vilaverde, Cláudia Chaves Loureiro,
José Laerte Boechat, António Baía Reis, Daniela Figueiredo, Ana Luísa Neves, Pedro Simões,
Luis Taborda Barata, João Almeida Fonseca, Ana Sá-Sousa

group sessions, high-quality written materials, attending conferences, networking and shared learning with peers, online activities and university or college courses. In Portugal, patients' associations, such as *Respira* (15) and *Associação Portuguesa de Asmáticos* (16), play an important role in supporting patients with chronic respiratory diseases and provide written articles and leaflets on specific disease topics, but to our knowledge do not offer consistent training to empower patients in their health decisions, or to be involved in research or politics. Likewise, the *Sociedade Portuguesa de Alergologia e Imunologia Clínica* (SPAIC); *the Sociedade Portuguesa de Pneumologia* (SPP) and *Grupo de Estudos de Doenças Respiratórias* (GRESP) are committed to the medical and scientific training of their members by offering conferences, courses, webinars, etc, however, these initiatives are commonly not available nor adapted for the patients and public. To engage patients/carers in health research, aiming for the improvement of quality, relevance and impact of research, it is essential to provide high-quality training tailored to patients'/carers' needs and preferences and grounded on attractive and easily disseminated formats.

OBJECTIVES

Our main goal is to develop and deliver a high-quality and comprehensive online educational programme for adult patients with asthma and their carers, based on patients'/carers' needs and preferences. Specifically in this project, we aim to:

1) design an interactive online educational programme in co-creation with patients and carers;
2) assess the feasibility and acceptability of the programme;
3) assess the impact of the programme on participants' knowledge, and self-efficacy in asthma self-management and interest to be involved in research.

METHODS AND ANALYSIS

This self-learning programme will target adult patients with asthma and their carers. It is meant to be delivered online, free of charge and each person may complete it at his/her own pace.

The project includes four tasks: the identification of patients' and carers' needs (Task 1); design and delivery of the self-learning programme based on patients'/carers' preferences (Task 2); evaluation of the feasibility, acceptability and impact of the self-learning programme (Task 3); and the management and dissemination of the project (Task 4). Patients and carers will be actively engaged in all stages of this project as co-researchers. The tasks, described in detail in the following section, are scheduled to be developed in eighteen months (Figure 1).

Tasks

Task 1. Identification of patients'/carers' needs

This task aims to identify and organise the most important topics on asthma and health research, based on the educational needs of adult patients/carers with asthma and the expertise of asthma specialists. We will use the Delphi method (17) to reach a consensus on the importance of the topics to be addressed (Task 1.1). Then we will organise the most important topics into modules (Task 1.2). This task will take 3 months.

T1.1 Reaching consensus on the educational topics

Adult patients with asthma and carers from the ConectAR network as well as physicians and researchers linked to our research team will be invited to participate in online anonymous web surveys. Multiple interactions (response and feedback) will take place until a consensus on the most important topics to be addressed in an educational programme is reached (defined by a concordance of at least 80% for those classified as "very important"/ "important").
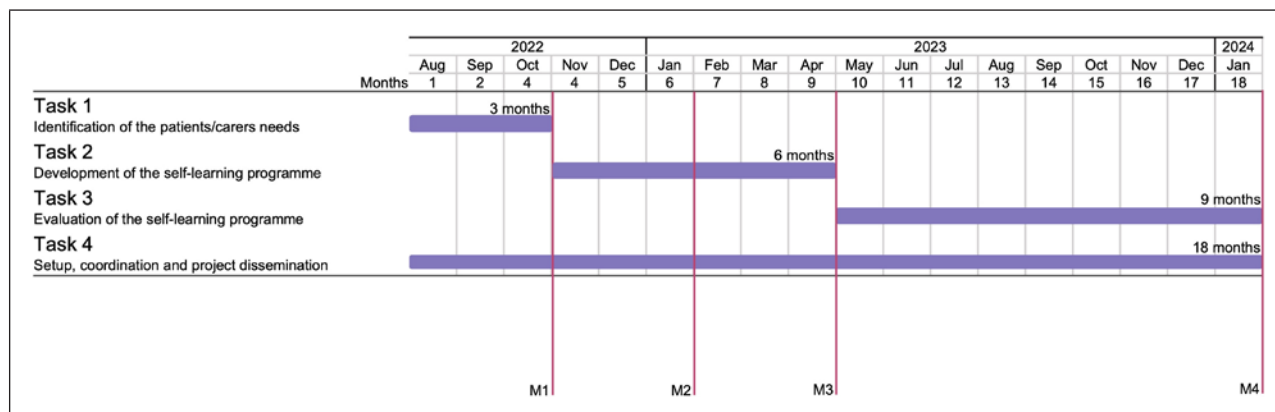
M1 – Consensual list of educational topics to be addressed; M2 – Content script; M3 – Self-learning programme available online; M4 – Summary of the impact of the self-learning programme.

Figure 1. Timeline of the project, with its tasks and milestones (M).

Round 1: A list of topics built by researchers and patients to be addressed in an educational programme will be presented to two independent panels: 30 patients with asthma/carers and 30 asthma specialist physicians and researchers. Both panels will be asked to rank each topic as "very important"/ "important"/ "less important"/ "non-important" and to suggest additional topics. For each topic, the degree of importance and the concordance between panels will be analysed and summarised. A common list of topics, including those added by patients/carers and experts, will be created.

Round 2: The list created in round 1 will be presented and ranked for importance by the same two panels of patients/carers and experts. Each participant will be independently asked to agree/disagree and make further comments.

From the ranking being observed in round 1, the research team believes two rounds will be enough to obtain consensus. Nevertheless, further Delphi iterations repeating the process described in round 2, may be needed.

T1.2 Organising the topics in modules

Based on the consensus from T1.1, the most important topics (those classified as "very important"/ "important") will be grouped into three educational modules.

Less important topics (consensually classified as "less important" or "non-important") will be dropped from this initial programme. For each module, the learning objectives will be determined, and the sources of information for content production will be identified among the most recent, high-quality sources of knowledge. This will be delivered to Task 2.

At the end of this task, we expect to have a consensual list of the most important topics to be addressed in the educational programme (Milestone 1, Figure 1). This list will be identified based on the educational needs of adult patients/carers with asthma and the expertise of asthma specialists and will be organised into modules with learning objectives and sources of information established for each module.

Task 2. Development of the self-learning programme

This task aims to develop a high-quality, free-of-charge, online self-learning programme for adult patients with asthma and their carers. The programme will be designed upon reliable sources of information and based on patients'/carers' preferences (T2.1) and inputs. Then it will be implemented on a web platform (T2.2) and its usability will be tested (T2.3). This task will take 6 months.

Cristina Jácome, Nancy Fonseca, Tânia Rodrigues, Silvana Fernandes, Emília Dias da Costa,
Rita Amaral, Paula Matos, Margarida Areia, Liliana Dias, Marisa Vilaverde, Cláudia Chaves Loureiro,
José Laerte Boechat, António Baía Reis, Daniela Figueiredo, Ana Luísa Neves, Pedro Simões,
Luis Taborda Barata, João Almeida Fonseca, Ana Sá-Sousa

T2.1 Designing the self-learning programme

The programme will be iteratively designed through several in-person/online meetings with a multidisciplinary working group. This group will include at least 3 adult patients with asthma, 1 carer of a patient with asthma, 2 researchers, 2 medical specialists, 1 adult education expert, and 2 multimedia experts.

Content will be produced for each module and learning objectives (Milestone 2, Figure 1). Based on the sources of information identified in the T1.2, the information will be retrieved, selected, and adapted to lay language. Additional resources will be identified and adapted to attractive formats, to provide to the attendee if needed. This content will be produced in different formats (short text, simple scheme, audios and videos). The diversity of contents from the "European Patient Ambassador Programme", developed by the European Lung Foundation, will be used as an example as this self-learning programme was also produced with the help of patients. A short exercise for knowledge self-assessment will be created for each module. At the end of each module, a satisfaction survey regarding time, layout, content, language, and suggestions for improvements will be created.

T2.2. Implementing the self-learning programme

The content produced (T2.1) will be deployed on a web platform. To accelerate the implementation of the programme, existing e-learning platforms used by scientific societies, health institutions and/or health e-learning companies to provide online courses to health professionals will be sought. During the implementation of the content by the multimedia experts, the remaining team will act as beta testers of the platform to detect most errors/bugs during this stage.

T2.3. Usability of the self-learning programme

The usability of the implemented self-learning programme will be assessed. At least 8 patients will be recruited from the ConectAR network (convenience sample) to allow the detection of 50-80% of the issues (18).

Use of questionnaires such as the User Experience Questionnaire and System Usability Scale are anticipated. Reported technical issues will be then solved (T2.2).

At the end of this task, we expect to have the online self-learning programme with three modules implemented, available online, free of charge, upon registration (Milestone 3, Figure 1) and ready to be tested with a large audience.

Task 3. Evaluation of the self-learning programme

This task aims to assess the feasibility, acceptability and impact of the self-learning programme. The self-learning programme will be made available to patients/carers with asthma (T3.1), after three months its feasibility and acceptability assessed (T3.2) and after 6 months its real-life impact evaluated. This task has the duration of 9 months.

T3.1 Delivering the self-learning programme

The self-learning programme will be available to the target audience – adult patients with asthma and carers. Minors (patients or carers) will not be eligible as contents will not be adapted to the paediatric population. To reach this audience, the self-learning programme will be disseminated across all ConectAR network, Portuguese patients' and carers' associations (*APA, Respira, ANCI - Associação Nacional Cuidadores Informais*), and scientific societies and networks (SPAIC, SPP, GRESP, Fundação Portuguesa do Pulmão, Rede de Especialistas em Asma Grave/REAG). The programme will also be disseminated to the larger community through social media and healthcare units.

The self-learning programme will be free of charge upon registration, which will include profile (patient/carer/health professional, other), age and gender. Attendees will be additionally asked to submit their learning needs and their interests in health research before starting and will be asked to participate in the impact evaluation study (not mandatory) (T3.3). The programme will be flexible so attendees can choose the order of the modules, can stop, and start whenever they want and can see their

progress continually. A certificate will be issued at the end of each completed module.

T3.2. Assessing feasibility, satisfaction, and acceptability

The self-learning programme will be evaluated three months after being available. Feasibility will be assessed based on the following outcomes: (i) characterisation of patients' profile (patient/carer, age, gender); (ii) retention rate (the number of participants who concluded at least one module divided by the number of registered participants); (iii) completion rates (the number of attendees who completed the self-learning programme divided by the number of registered participants). The attendees' satisfaction (time, layout, language, areas of improvement) will be analysed. Acceptability will be assessed through a focus-group interview with at least 6 participants with different profiles and behaviours (patients/carers; completers/non completers). A semi-structured guide will be used to explore participants' perspectives about the appropriateness of the programme contents, structure and procedures; its impacts, benefits and disadvantages; barriers and facilitators for participation.

T3.3 Evaluating impact

An observational, prospective study will be conducted. Ethical approval will be obtained (please see section Ethics and diffusion activities). All the attendees of the self-learning programme will be asked to fill in a questionnaire on 1) the knowledge, 2) confidence in the ability to use information/explain to others, and 3) intention to be actively involved in research, at three time-points: before starting, immediately after and six months after completing the programme. Questionnaires such as Knowledge, Attitude, and Self-Efficacy Asthma Questionnaire (KASE-AQ) (19) will be used.

Based on patients' feedback, gathered during T3.2 and T3.3, a report with the improvements needed in the self-learning programme will be produced to inform future updates. The results of the feasibility and impact of the self-learning programme will be disseminated in the format of a scientific publication (abstract or original article) (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 inclusion of the patients' perspectives, both patients with asthma and carers are taking an active role as members of the study steering committee. Also, the involvement of patients will enable the creation of content in clear, user-friendly and non-technical language, to ensure that the self-learning programme is accessible to the lay public. An example is already in place in this proposal, as patients and carers of the research team built the public summary of this proposal. The dissemination of the results of the project includes the writing and production of scientific outputs and diffusion to the general public. This task runs throughout the entire project.

The management of this project will include a Steering Committee, composed of three patients with mild, moderate-to-severe and severe asthma and a carer of a minor with asthma as well as three researchers. Advisory board will include an expert on adult education, an expert on communication science and digital media, an expert on asthma and an expert on mHealth/e-Health solutions.

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

A kick-off meeting will be organised, to establish general procedures and to discuss the roles of the team members throughout the project.

During this task it is expected to achieve 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

Cristina Jácome, Nancy Fonseca, Tânia Rodrigues, Silvana Fernandes, Emília Dias da Costa,
Rita Amaral, Paula Matos, Margarida Areia, Liliana Dias, Marisa Vilaverde, Cláudia Chaves Loureiro,
José Laerte Boechat, António Baía Reis, Daniela Figueiredo, Ana Luísa Neves, Pedro Simões,
Luis Taborda Barata, João Almeida Fonseca, Ana Sá-Sousa

requirements for the services that will be purchased, namely for the implementation of the self-learning programme; 4) dissemination activities, including at least one original paper and results to be presented in at least two scientific meetings.

ETHICS AND DIFFUSION ACTIVITIES

For the consensus process, in which participants 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. Personal data, namely name and email contact, will be collected and securely stored/managed in a centralised database at the host institution following the European General Data Protection Regulation (GDPR-EU 2016/679) standards.

The feasibility and impact studies (Task 2 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 26th) and the GDPR, executed and enforced in Portugal by Laws 58 and 59/2019. Specifically, to conduct these studies, ethical approvals will be obtained. Written informed consents will be obtained prior to any data collection from patients in accordance with GDPR 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.

There are no risks anticipated for patients in relation to the participation in this study. The privacy of the patients/carers in both studies will be ensured by pseudo-anonymisation 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-anonymised 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 patients' data will be managed through a centralised 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 on a server of the host institution, with daily backups and firewall protection. All paper documents that cannot be scanned in time, and that include personal data, will also have protection measures with physical access control provided to only authorised researchers.

The project's results, including the self-learning programme, will be disseminated among patients, the 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 the self-learning programme to the public.

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

EXPECTED RESULTS AND POSSIBLE LIMITATIONS

The expected results at the end of each task are explained in the Methods and analysis section. By the end of this project, we expect to have implemented the first high-quality, free-of-charge, online self-learning programme on asthma and health research, adapted for adult patients with asthma and their carers. The programme will be designed upon reliable sources of information and based on patients/carers' needs and preferences. It has the additional advantage of being available for patients/carers not only from Portugal, but also from other Luso-

phone countries. This attractive self-learning programme will empower patients to increase their knowledge, develop new skills and have the opportunity to learn about research. Ultimately, it will introduce the knowledge patients/carers need to represent themselves and influence health policies in Portugal successfully.

Despite the benefits for patients and society, some difficulties are expected during this project's implementation. As stated before, one of the major barriers to the PPI in health research is the frustration and the time constraints, namely the time patients and carers need to invest in training and support. To overcome these barriers, researchers and healthcare professionals involved in this project are made aware of the need to improve specific competencies (20) namely, participation, communication, use of common vocabulary, teamwork and conflict/tension management. To improve these soft skills and increase awareness on how to address patients/carers, the present self-learning programme will also be available for healthcare professionals and researchers.

A selection bias is also expected since this programme is expected to attract younger patients/carers and with higher levels of education and digital literacy. Other training formats, such as group sessions, networking and shared learning with peers will need to be explored later to reach older patients and/or with lower literacy levels.

Another limitation is that this programme focuses specifically on asthma. In future, the methodology of the present project can therefore be replicated for other chronic respiratory diseases, such as chronic obstructive pulmonary diseases and lung cancer.

Acknowledgments

We thank all the patients, carers, citizens and healthcare professionals from the ConectAR network.

Conflict of interest

The authors declared no potential conflicts of interest in relation to the subject of this article.

ORCID

Cristina Jacome 0000-0002-1151-8791
Nancy Fonseca 0000-0003-4504-7200
Tânia Rodrigues 0000-0003-4813-0771
Silvana Fernandes 0000-0003-4418-0202
Emilia Dias Costa 0000-0001-5166-8076
Rita Amaral 0000-0002-0233-830X
Paula Matos 0000-0003-0559-1041
Margarida Areia 0000-0002-8274-2686
Liliana Dias 0000-0003-2285-4333
Marisa Vilaverde 0000-0002-7306-8976
Cláudia Chaves Loureiro 0000-0003-0438-6126
José Laerte Boechat 0000-0002-9738-8210
António Baía Reis 0000-0001-7451-1725
Daniela Figueiredo 0000-0002-3160-7871
Ana Luísa Neves 0000-0002-7107-7211
Pedro Simões 0000-0001-9480-7726
Luis Taborda Barata 0000-0001-6649-8890
João Almeida Fonseca 0000-0002-0887-8796
Ana Sá-Sousa 0000-0002-9429-6863

Corresponding author:
Ana Sá-Sousa
CINTESIS@RISE, MEDCIDS,
Faculty of Medicine of the University of Porto
Rua Dr. Plácido da Costa, 4200-450 Porto – Portugal
E-mail: anasasousa@gmail.com

REFERENCES

1. Planning and improving research: public-involvement [Internet]. [cited 2022 Aug 5]. Available from: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/

Cristina Jácome, Nancy Fonseca, Tânia Rodrigues, Silvana Fernandes, Emília Dias da Costa,
Rita Amaral, Paula Matos, Margarida Areia, Liliana Dias, Marisa Vilaverde, Cláudia Chaves Loureiro,
José Laerte Boechat, António Baía Reis, Daniela Figueiredo, Ana Luísa Neves, Pedro Simões,
Luis Taborda Barata, João Almeida Fonseca, Ana Sá-Sousa

2. Strategy for Patient-Oriented Research [Internet]. [cited 2022 Aug 5]. Available from: https://cihr-irsc.gc.ca/e/41204.html

3. European Lung Foundation [Internet]. [cited 2022 Aug 5]. Available from: https://europeanlung.org

4. Sá-Sousa A, Rodrigues T, Fernandes S, Santos AM, Garcia-Lema I, Costa ED, et al. ConectAR: Collaborative network of patients with asthma and carers actively involved in health research. A protocol for patient and public involvement. Eur Ann Allergy Clin Immunol [Internet] 2022 Mar 10 [cited 2022 Aug 5];(online first). Available from: http://www.ncbi.nlm.nih.gov/pubmed/35261226 doi: 10.23822/EurAnnACI.1764-1489.249.

5. Conectar: collaborative research network advancing patient and public involvement in respiratory and digital health [Internet]. [cited 2022 Aug 5]. Available from: https://cintesis.eu/en/portfolio-items/conectar-collaborative-research-network-advancing-patient-and-public-involvement-in-respiratory-and-digital-health/

6. INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research. Eastleigh; 2012.

7. Edwards HA, Huang J, Jansky L, Mullins CD. What works when: mapping patient and stakeholder engagement methods along the ten-step continuum framework. J Comp Eff Res [Internet]. 2021 Aug 1 [cited 2022 Aug 5];10(12):999–1017. Available from: https://pubmed.ncbi.nlm.nih.gov/34082571/ doi: 10.2217/cer-2021-0043.

8. Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: A systematic review. BMC Health Services Research 2014 Feb 26;14. Avaliable from: https://pubmed.ncbi.nlm.nih.gov/24568690/ doi: 10.1186/1472-6963-14-89.

9. Martineau JT, Minyaoui A, Boivin A. Partnering with patients in healthcare research: A scoping review of ethical issues, challenges, and recommendations for practice. BMC Medical Ethics 2020 May 11;21(1). Avaliable from: https://pubmed.ncbi.nlm.nih.gov/32393230/ doi: 10.1186/s12910-020-0460-0.

10. Shen S, Doyle-Thomas KAR, Beesley L, Karmali A, Williams L, Tanel N, et al. How and why should we engage parents as co-researchers in health research? A scoping review of current practices. Health Expectations 2017 Aug 1;20(4):543-54. Avaliable from: https://pubmed.ncbi.nlm.nih.gov/27516003/ doi: 10.1111/hex.12490.

11. Courvoisier M, Baddeliyanage R, Wilhelm L, Bayliss L, Straus SE, Fahim C. Evaluation of the partners in research course: a patient and researcher co-created course to build capacity in patient-oriented research. Research Involvement and Engagement 2021 Dec 1;7(1). Avaliable from: https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-021-00316-8 doi: 10.1186/s40900-021-00316-8.

12. Bird M, Ouellette C, Whitmore C, Li L, Nair K, McGillion MH, et al. Preparing for patient partnership: A scoping review of patient partner engagement and evaluation in research. Health Expectations 2020 Jun 1;23(3):523-39. Avaliable from: https://pubmed.ncbi.nlm.nih.gov/32157777/ doi: doi: 10.1111/hex.13040.

13. Tambor E, Shalowitz M, Harrington JM, Hull K, Watson N, Sital S, et al. Engaging patients, clinicians, and the community in a clinical data research network: Lessons learned from the CAPriCORN CDRN. Learn Health Syst [Internet] 2019 Apr 1 [cited 2022 Aug 5];3(2):e10079. Available from: http://www.ncbi.nlm.nih.gov/pubmed/31245603 doi: 10.1002/lrh2.10079.

14. INVOLVE. INVOLVE (2012) Developing training and support for public involvement in research. [Internet]. Eastleigh; 2012 [cited 2022 Aug 5]. Available from: www.invo.org.uk/resource-centre/training-resource/

15. Respira [Internet]. [cited 2022 Aug 5]. Available from: http://www.respira.pt/#/

16. Associação Portuguesa de Asmáticos – asma em portugal [Internet]. [cited 2022 Aug 5]. Available from: http://apa.org.pt/

17. Hsu CC, Sandford BA. The Delphi Technique: Making Sense of Consensus. Practical Assessment, Research, and Evaluation. 2007;12:10. Avaliable from: https://scholarworks.umass.edu/cgi/viewcontent.cgi?article=1177&context=pare. doi: 10.7275/pdz9-th90

18. Macefield R. How to specify the participant group size for usability studies: A practitioner's guide. Journal of Usability Studies 2009;5(1):34-45. Avaliable from: https://uxpajournal.org/how-to-specify-the-participant-group-size-for-usability-studies-a-practitioners-guide/

19. Wigal JK, Stout C, Brandon M, Winder JA, McConnaughy K, Creer TL, et al. The knowledge, attitude, and self-efficacy asthma questionnaire. Chest [Internet] 1993 [cited 2022 Aug 5];104(4):1144-8. Available from: https://pubmed.ncbi.nlm.nih.gov/8404182/ doi: 10.1378/chest.104.4.1144.

20. Frisch N, Atherton P, Doyle-Waters MM, MacLeod MLP, Mallidou A, Sheane V, et al. Patient-oriented research competencies in health (PORCH) for researchers, patients, healthcare providers, and decision-makers: Results of a scoping review. Research Involvement and Engagement [Internet] 2020 Feb 10 [cited 2022 Aug 5];6(1):1-14. Available from: https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-020-0180-0 doi: 10.1186/s40900-020-0180-0.

RESUMO PARA O PÚBLICO

Um diagnóstico de doença respiratória crónica frequentemente é, numa fase inicial, considerado uma sentença pesada tanto para o doente como para um seu eventual cuidador. Usar medicamentos e procurar reduzir comportamentos que possam aumentar o risco de crises respiratórias agudas são componentes do tratamento geralmente aceites pelos doentes e cuidadores, embora de forma variável. Neste contexto, doentes bem informados e esclarecidos acerca da sua doença conseguirão tomar melhores decisões, aderir melhor aos tratamentos prescritos e criar um laço de maior confiança com os profissionais de saúde e a comunidade científica. No entanto, é comum pessoas com asma e/ou seus cuidadores terem alguns receios e muitas dúvidas em relação à sua doença e tratamentos. Assim, para que os avanços da medicina possam ser aplicáveis às situações reais dos doentes, estes não devem ser colocados à margem dos processos de decisão e, pelo contrário, devem ser considerados como parte essencial, não só dos cuidados em saúde, mas também da investigação. De facto, complementar os estudos científicos com a experiência de sintomas e reações pessoais dos doentes, bem como melhorar a comunicação entre estes, os seus eventuais cuidadores e o profissional de saúde/investigador, permite programar tratamentos mais personalizados e adequados a cada doente e aumenta a probabilidade de se melhorar o estado de saúde e o bem-estar quotidiano. É, por isso, essencial esclarecer doentes e cuidadores e fornecer informações fidedignas sobre a asma e seu tratamento, o que é praticamente impossível numa consulta médica. Assim, uma base de formação complementar, fundamentada em fontes fiáveis e credíveis, que sustente as opções de tratamento existentes, comportamentos a adotar e clarifique a linguagem e métodos científicos utilizados pelos profissionais de saúde, poderá ser uma mais-valia para que a perceção de sentença pessoal inicialmente dada pelo diagnóstico se altere. No entanto em Portugal não existe nenhum programa de formação adaptado ao doente com asma e/ou seu cuidador. Este projeto pretende desenvolver e disponibilizar um programa educacional abrangente de alta qualidade, disponibilizado online para pessoas adultas com asma e/ou seus cuidadores, baseado nas necessidades e preferências dos doentes/cuidadores. Para que os conteúdos e linguagem utilizada sejam relevantes e compreendidos pela comunidade, este programa vai ser desenvolvido pela própria comunidade de doentes e cuidadores em conjunto com investigadores e profissionais de saúde. Com este programa de autoaprendizagem pretendemos fornecer às pessoas com asma e/ou seus cuidadores, as ferramentas necessárias para aumentarem o seu conhecimento sobre a doença, desenvolverem novas competências e proporcionar oportunidades para aprenderem sobre investigação. Acreditamos que este projeto aproximará as pessoas com asma dos vários intervenientes, de forma a que possam questionar e interagir diretamente com os profissionais de saúde num diálogo aberto e construtivo, defenderem-se a si próprios e influenciarem as políticas de saúde em Portugal.

STRENGTHS AND POSSIBLE LIMITATIONS OF THIS STUDY

- This is the protocol for the delivery of the first high-quality, free-of-charge, online self-learning programme on asthma and health research in Portugal, adapted for adult patients with asthma and their carers, based on patients/carers' needs and preferences.
- Patients and carers are involved as co-researchers from the design and writing of the protocol to the end of the development and implementation phases. Thus, the programme will be designed not only upon reliable sources of information but will also be based on patients'/carers' needs and preferences.
- A selection bias is expected since this delivery format is expected to attract younger patients/carers with higher levels of education and digital literacy. Other training formats are already being planned to reach other audiences.
- Another limitation is that this programme focuses specifically on asthma. In future, the methodology of the present project should therefore be replicated for other chronic respiratory diseases.