

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

Abstract

Patients and Public Involvement in every stage of the patient-centred health research cycle is the key to the development of innovative solutions with an impact on patients' care. 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. 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 and 4) coordination and dissemination activities. This network will improve research by ensuring that patients and carers have an active role in the co-creation of impactful solutions for asthma.

Key words

Patient and public involvement; Citizen Science, Patient-centred health research; Asthma; Chronic Respiratory Diseases

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.

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: i) alignment of the mission and values of the network; ii) training of elements for better involvement in research and definition of ways to disseminate; iii) carrying out a study to evaluate the viability of the network; iv) analysis and dissemination of results. Involving patients and carers 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.

List of abbreviations

PPI - Patient and Public Involvement

mHealth - mobile health

CRD - Chronic Respiratory Diseases

INAsma - Portuguese National Asthma Survey

GDPR-EU - European General Data Protection Regulation

PI - Principal Investigator

Manuscript accepted for publication

1 Introduction

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

8 Patients and members of the public are getting involved as valuable members in
9 innovative health solutions. In Portugal, examples of initiatives to actively involve
10 patients and carers are the “MAIS PARTICIPAÇÃO Melhor saúde” - a collaborative
11 initiative focused on PPI in the health politics (2); and the “Patient Innovation” - a web
12 platform and network available to the public and patients to submit and share their
13 innovative health solutions (3). Regarding health research, according to INVOLVE, a
14 leading PPI organization in the UK, patients may be involved in every stage of the
15 research cycle: identifying and prioritizing, commissioning, designing, managing,
16 undertaking, disseminating, implementing, and evaluating impact (1). This involvement
17 may happen in several forms: consultation (patients give their opinion on specific
18 issues), collaboration (shared-decisions between researchers and patients), and patient-
19 led research (patients deliver and manage research) (4,5). The patient involvement in
20 the development of Patient Reported Outcome Measures (PROMs) is essential to
21 ensure that they are relevant and patient-centred, yet patients are not always involved
22 and few studies involve patients in the early phases (6). Likewise, the PPI in the
23 development of mobile health (mHealth) technology is strongly encouraged (7). Patients
24 contribute with a different and complementary perspective to research, by adding
25 personal knowledge and experience, and ensuring research priorities are aligned with
26 their needs. PPI in health research is thus believed to improve its quality, relevance and
27 ethics despite posing challenges in terms of time expenditure, required training and
28 support, and power sharing (8). Organizations such as the INVOLVE (9), the Canada's
29 Strategy for Patient-Oriented Research (10) and the Patient-Centred Outcomes
30 Research Institute in the USA (11) are examples of successful establishment of PPI in

31 health research. Despite its recognised importance, and the fact that a growing number
32 of scientific journals now require statements on how patients have been involved in
33 research, to our knowledge, there is no such established group in Portugal, specifically
34 in asthma research.

35 Chronic respiratory diseases (CRD), such as asthma, are a source of substantial burden,
36 with increased morbidity and mortality (12). Within patients with asthma, those with
37 severe asthma have disproportionate higher morbidity, mortality, and costs than
38 patients with non-severe asthma, representing an unmet clinical need (13). In Portugal,
39 the first and only Portuguese National Asthma Survey estimated that the prevalence of
40 asthma in the Portuguese population was 6.8% (95%CI 6.0-7.7) (14). Almost half (43%)
41 of the patients had non-controlled asthma, associated with worse health-related quality
42 of life (15). Patients involvement in every stage of the research cycle is the key to the
43 development of innovative solutions with impact on patients' care. This includes
44 collaboration in the development of the research question, in supporting ethical
45 approval submissions, in carrying out the research, and in the discussion and
46 dissemination of the research findings. The European Lung Foundation (ELF) has been
47 remarkable in the involvement of patients with CRD and other lung conditions in
48 research and guideline development (16). In Portugal, patients' associations (Respira
49 (17), Associação Portuguesa de Asmáticos (18)) play an important role supporting
50 patients with CRD. However, no established group dedicated to PPI in health research
51 for asthma has been developed to date. To improve the quality of research projects and
52 strengthen their relevance and impact, and to provide valid scientific evidence in plain
53 language for patients to understand and share, it is essential to involve patients and
54 public, including carers, in every phase of the research cycle in future projects.

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

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

62 Materials and methods

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

72 The tasks and respective milestones schedule to be developed in the fourteen months
73 (Figure 1).

74 Task 1. Definition of the network mission and governance

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

78 T1.1 Invitation to potential patients' representatives as members.

79 This subtask will identify potential interested members (patients/carers) to integrate the
80 network, through initial contacts with patients (>600 from previous studies that gave
81 authorization to be contacted for future studies) and physicians (>275 physicians from
82 75 different centres) collaborating with our research group (PaCeIT- Patient Centered
83 Innovation and Technologies)(19,20). Portuguese patients' and carers' associations
84 (Associação Portuguesa de Asmáticos, Respira, Associação Nacional Cuidadores
85 Informais) and scientific societies and networks (Sociedade Portuguesa de Alergologia e
86 Imunologia Clínica, Sociedade Portuguesa de Pneumologia, Fundação Portuguesa do
87 Pulmão, Rede de Especialistas em Asma Grave) will be also contacted for the nomination
88 of patients' representatives to join ConectAR. Participants will also be invited through
89 social media channels, such as Facebook and Instagram. The patients/carers interested
90 in joining the ConectAR will complete an application form available through the

91 “Inquéritos UP” platform. Patients/carers recruitment is represented in Figure 2.
92 Additionally, the interested members will be invited (not mandatory) to participate in
93 free online/in-person learning programme for patients and carers to gain knowledge
94 and confidence to get involved in different areas of patient involvement (e.g. the
95 European Patient Ambassador Programme (21); Patient Engagement Through Education
96 (22)).

97 T1.2 Definition of mission, vision and governance

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

111 A kick-off meeting with members (identified in Subtask 1.1) and the research team for
112 discussion and approval of the mission and governance will mark the official creation
113 data of the network. The meeting will take place at the host institution, but participants
114 will also be given the possibility to attend via tele-conference.

115 By the end of this task, it is expected to have the creation of the network (Milestone1,
116 Figure 1), a group of patients’ representatives engaged with the project and willing to
117 participate in Tasks 2 and 3; the submission of a paper and a lay summary with the
118 results of the qualitative study, including the PPI impact in it and the content to be used
119 in Task 2.

120 Task 2. Communication strategy and tools

121 This task aims to establish the communication strategy and tools to increase awareness
122 of the network activities, to promote training and engagement opportunities for active
123 members and to attract new people to join the network. Involving patients in designing
124 and developing these tools can strengthen the recruitment of patients and carers to
125 become members of the network, by ensuring that the recruitment process and the
126 strategies for the maintenance of communication are practical, attractive and feasible.
127 This task has the duration of 6 months.

128 T2.1. definition of communication strategy and tools

129 This subtask will organize a workshop to involve patients in the establishment of the
130 most effective communication strategies for future recruitment and retention of the
131 network members. This ensures that the generated contents reach patients with
132 different backgrounds and literacy levels, allowing its representativeness among
133 network members. The workshop will be specifically focused on the definition of a
134 sustainable communication strategy, mainly on digital marketing (website, social media
135 and e-mail), but also including innovative dissemination initiatives, such as establishing
136 science-arts collaborations and activities. Connecting the participants with distinct
137 artistic expressions and actors and involving them in the co-creation of a series of arts-
138 based science communication experiences, ultimately making use of the arts as an
139 innovative means to translate complex scientific knowledge and information into
140 engaging and meaningful experiences; creative driven, two-way team building activities,
141 reinforcing the participants group cohesion and motivation, while being simultaneously
142 activities that for its inherent creative and ludic dimensions generate unique material
143 for social media dissemination. A workshop will be held with patients and public to
144 discuss the strategies to: 1) motivate ongoing engagement of members; 2) to encourage
145 new people to join the network; 3) to keep people informed throughout the group
146 activities and 4) to disseminate results to all that were consulted and collaborated during
147 the project. The workshop will be prepared with the support of the team members with
148 expertise in social science, in communication science and digital media, in collaboration
149 with a consultant expert in PPI in research.

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

152 T2.2 Implementation of the network communication strategies and tools

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

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

164 T2.3 Content updates processes

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

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

174 Task 3. Collaborative setup of research priorities for asthma and roadmap 175 for the PPI in health projects

176 This task will be the pilot study to test the feasibility of the collaborative network in the
177 design, implementation and dissemination of a qualitative study on the research
178 priorities for asthma in Portugal, based on patients' perspectives. Study design will be
179 built collaboratively with the network (defined in Task 1). Yet, the following aspects are
180 anticipated. This study will be implemented in three phases: 1) identification of the main

181 daily challenges of the patients and associated research questions; 2) prioritization of
182 the research questions and 3) setting a roadmap for the PPI in asthma research projects
183 for the next 3 years. This task has the duration of 6 months.

184 T3.1 Identification of patients' main challenges

185 In phase 1, we will explore the main daily challenges experienced by participants
186 collected through the self-recording of audio-diaries. At least 15 patients with mild,
187 moderate and severe asthma (or their carers), will be invited to participate through the
188 network communication channels (Task 2) for a recruitment period of 2 months. Patient
189 eligibility criteria are: 1) medical diagnosis of asthma; 2) at least 18 years of age; 3) ability
190 to use the voice-recorder functionality in smart devices and access to an Internet
191 connection. The participants will be invited to make daily recordings for a seven-day
192 period and then send it to the project team. The network members (identified in Subtask
193 1.1) and the research team will develop a guide for completing the diary with a given
194 number of open-ended prompts to support the generation of narratives, including
195 sources of anxiety, disposition for physical exercise and social events, medication and
196 healthcare services issues and challenges, relationship with healthcare professionals.
197 Participants will be provided with this guide but will be informed they are not restricted
198 to these.

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

201 T3.2 Prioritization of the main research questions

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

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

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

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

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

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

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

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

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

244 During this task it is expected to have 1) the preparation and submission of applications
245 to the ethics review board; 2) the implementation of a collaborative shared online folder
246 for the project team; 3) the definition of the requirements for the services that will be
247 purchased, namely for the implementation of the communication plan (e.g. digital
248 communication and marketing strategy, website design, etc.); 4) the involvement of
249 patients' associations, scientific societies and other collaborative initiatives as project
250 partners; 5) dissemination activities, including at least one original paper and results to
251 be presented in at least two scientific meetings.

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

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

266 Ethical considerations

267 To create the network, which will be a group of patients with asthma and carers involved
268 as co-researchers in health research, concerns with privacy and personal data protection
269 will be considered. Ethical approval will not be needed as patients and carers in this

270 group act as equal partners with academic researchers and healthcare professionals,
271 instead of being subjects under investigation. By becoming a member of the network,
272 patients and carers will have the opportunity to actively participate in every phase of
273 health research, and potentially contribute to improving patient-physician interactions
274 and the quality of care for themselves and others with a similar condition. Personal data,
275 namely name and email contact, will be collected and securely stored/managed in a
276 centralized database at the host institution following the European General Data
277 Protection Regulation (GDPR-EU 2016/679) standards.

278 Qualitative studies (Tasks 1 and 3) will be conducted according to the Declaration of
279 Helsinki and Oviedo Convention. Patients' personal data will be collected and treated
280 according to the Portuguese law on Data Protection (Law number 67/98, October 26th)
281 and the GDPR-EU, executed and enforced in Portugal by Laws 58 and 59/2019.
282 Specifically, to conduct these studies, ethical and institutional approvals will be
283 obtained. Written informed consents will be obtained prior to any data collection from
284 patients in accordance with GDPR-EU requirements. Informed consents will include
285 information to the participants regarding the types of personal and sensitive data that
286 will be collected, how it will be processed, for what purposes and what security
287 measures will be in place to provide for their privacy, as well as the conservation period
288 or their elimination, after the project ends. In the qualitative study of Task 1, patients
289 with asthma and carers with at least 18 years of age will be involved. For the qualitative
290 study of Task 3 patients' eligibility criteria will be: i) medical diagnosis of asthma; ii) at
291 least 18 years of age; iii) ability to use the dictaphone functionality in smart devices and
292 access to an Internet connection.

293 As there will be no change in any prescribed medication, besides those associated with
294 standard clinical practice, no risks are anticipated for patients in relation to the
295 participation in this study. Researchers will emphasize that participation will be
296 voluntary, and patients and physicians will be assured that they can withdraw at any
297 time, without giving any reason and without a negative impact on the care received. The
298 privacy of the patients/carers in both studies will be ensured by pseudo-anonymization
299 techniques, which generate an anonymous univocal numeric code for each subject and
300 the coding key will be encrypted and securely stored and managed, separately from

301 patients' personal and health related data. All data analyses will be performed within
302 the pseudo-anonymized versions of the original databases. The computers that contain
303 patient personal data will be subjected to password protection only known by the
304 Principal Investigator (PI) and the Co-PI. The storage of patient's data will be managed
305 through a centralized database structured in order to guarantee privacy and personal
306 data protection. Only the PI will have access to the original database. This database will
307 be saved in a server of the host institution, with daily backups and firewall protection.
308 All paper documents that are not possible to be scanned in time, and that include
309 personal data, will also have protection measures with physical access control provided
310 to only authorized researchers.

311 **Expected Results and Discussion**

312 By the end of ConectAR, we expect to have a fully established network of patients with
313 asthma and their carers involved in health research, including a communication strategy
314 supported by a website and social media channels. This network adds value in several
315 domains. Firstly, patients within the network will be empowered, will develop new skills,
316 will have the opportunity to network and to learn about cutting-edge research.
317 Following, this network will improve research at the host institution and will ensure that
318 patients and carers are at the heart of what is done, having an active role in the co-
319 creation of impactful projects and solutions. On the other hand, the establishment of
320 the research priorities for asthma in Portugal based on patients' perspectives will foster
321 their involvement in future projects with different research teams. Additionally, the
322 network may enable the participation of patients with asthma in the definition of health
323 policies in Portugal.

324 Despite the benefits for the patients, research and society of this ground breaking
325 project, some difficulties are to be expected. One of the major barriers for the PPI in
326 health research is the frustration with the time constraints of patients and researchers,
327 namely, the time patients and carers invested for training and attendance, the extra time
328 needed to participate in research and meetings (25). To address these difficulties, clear
329 expectations on the mission of the network, and the role of patients and researchers
330 within the network will be explicitly described and documented (Task 1); patients will

331 be supported and trained alongside researchers. Moreover, within this project it is
332 expected to spend time to build reciprocal relationships (between patients and
333 researchers), fostering mutual respect, namely by including in its communication and
334 dissemination plan innovative activities and events such as arts-based science
335 communication and creative driven team building experiences (Task 2). Another
336 limitation related to patients' training is that the initiation courses for PPI in research
337 (Task 1) are not yet available in Portuguese. As so, the first patients involved are
338 expected to have an above average level of literacy and, in a future project, will translate
339 and adapt these courses into the Portuguese language and culture. There is also the risk
340 to include as members of the network the most motivated and informed patients,
341 however to capture and maintain the interest of a broader profile of patients, the active
342 members will be part of the building process of the full network and its communication
343 strategies (Tasks 2 and 4), creating new ways of working between patients, carers and
344 researchers and also will be invited to mentor newer members, to help ensure
345 integration into the group. In future, after being settled for asthma research, the
346 network will expand its scope to other respiratory diseases, and even other chronic
347 diseases.

348 Conclusions

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

354

355 Conflicts of interests

356 The authors declare that they have no conflict of interests.

357

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433 Legends

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

440 Figure 2: Patient recruitment and involvement in ConectAR collaborative network.