



# Successful Training of Patients to Intervene in Health Education and Clinical Research at Grenoble Patient School

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## Abstract

The primary goal of patient and public involvement (PPI) in healthcare is to improve individual and population health outcomes. This study reports on the successful training of patients to be involved in patient education as peers and clinical research at Grenoble Patients' School (GPS). GPS was founded by patients as an independent association to train patients to the above objectives tasks. The training team was multi-professional and included expert PPI who were part of the professional team. Medical faculty members and 45 patients, 59% females, 52 ± 6.4 years old, trained between 2016 and 2017, showed high satisfaction at the end of the training courses. Almost all the trained patients were involved as peer educators and 4 were involved in clinical research projects at different stages under the guidance of medical teams. Patient involvement at GPS provided strong benefits to trainees and had some impact on education and obtaining research grants. The outcome of this patient training program resulted in the creation of a Patients' Department within the Medical and Pharmacy Schools at the Université Grenoble Alpes in 2020, <https://medecine.univ-grenoble-alpes.fr/departements/departement-universitaire-des-patients/>.

## Keywords

Patient and public involvement (PPI), guidance for reporting patient and public involvement (GRPPI), health education, patients as teacher

## Introduction

The main benefit of patient and public involvement (PPI) in healthcare is to improve individual and population health outcomes (1,2). This public and patient involvement (PPI) is accompanied by a paradigm shift in the way health education and clinical trials are viewed as activities that are done “with” or “by” patients or the public rather than “to,” “about,” or “to” them (1). The most integrated model is the co-called Montreal model where patients are true partners whether in care, in the organization and delivery of health services, in teaching, and in research (3). For PPI in health education, it ranges from the creation of teaching materials to a formal position in a medical school, according to a proposed 6-level scale (4,5). In France, patients are allowed to intervene in multi-professionals health education programs as partners if they have completed the so-called 40-h session for health educators. In the field of clinical research, there is increasing evidence that clinical trials have difficulty

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attracting and retaining patients for the duration of trial (6). PPI in health education and clinical trials has been one of the ways to address the above problems. Indeed, PPI can be involved in recruiting patients for clinical trials, developing clinical protocols with clinicians, participating in ethical review, or steering committees with medically qualified staff.

In the United Kingdom, the number of PPIs has significantly increased as it is associated with funding procedures whereas, in the United States and Europe, initiatives are rare and not a priority in the universities studied (4). Among the many barriers to the PPI in teaching and research (1) are poor medical literacy and a potential lack of training in healthcare (4).

There is strong evidence that PPI is associated with a high degree of satisfaction among peer educators, patients, and health professionals, while short- and long-term benefits in healthcare are at this stage being less assessed (4,7,8). Networks such as those involved in mental health (9), the National Health Service in the United Kingdom (2) or the Haute Autorité de Santé in France (10) indicate the added value of having PPI in education, guidelines development, clinical trials, and research. However, they do not provide much detail on whether and how PPIs are trained. Indeed, publications on PPI training are rare and the first to do so were on arthritis education (11–14). In France, patient schools within or outside Universities training PPIs in health care were founded in Paris in 2009 (15), Marseille in 2012 (16), and Grenoble in 2014. However, reports on PPI recruitment and training are scarce (14).

This publication aims to report the successful training of PPI in health education and clinical research at Grenoble Patients' School (GPS) to subsequent intervention as peer educators. A primary objective was to evaluate the success of this training based on the satisfaction of trainees and faculty members including PPI experts. A secondary objective was the impact that trainees had on education and clinical research.

## Methods

### History of the GPS

GPS was created as an association on October 6, 2014, following the law of 1901 (17) in Grenoble. The founders were 5 patients, headed by the first author of this manuscript, a patient with a long, continuous, and strong history of commitment to healthcare and to democratic values in healthcare. The President of the Université Grenoble Alpes (UGA), as well as the Deans of Medicine and Pharmacy schools of the UGA, the Director of Centre UGA (CHUGA) were implicated from the beginning in helping GPS. GPS remained independent from UGA and CHUGA.

### Selection of Patients Trained at GPS

Patients were invited to join GPS training programs through the internet, magazines, patient associations, or their health

professionals. These volunteers showed a clear willingness to join GPS to help patients and were interviewed individually to be accepted into the program. As long as no personality or psychiatric problems were identified or raised during the interview, they were accepted as volunteers. Patients with a history of mental health and psychiatric disorders were interviewed in more detail to ensure that they could complete the training and volunteer task. No qualifications were required of the patients and their own experiences in health and social fields were the most important criterion. Most applicants' fees were funded by public health agencies or patient organizations and honoraria were available for the teachers outside UGA or CHUGA.

### GPS Training Programs

Two training programs were available for the patients in the health field (Tables 1 and 2). The first in the field of chronic somatic disease was entitled: Becoming a peer educator for

**Table 1.** Becoming a Peer Educator for Chronic Somatic Conditions in GPS, Syllabus and Teaching Tools.

Modules	Syllabus and teaching tools
Module I <i>day 1, day 2, day 3</i>	Introduction to the principles of liability, confidentiality, patient rights, and obligations. Initiation to patients' education including role of PI, health behaviors of patients with chronic conditions; listening techniques with analysis of interviews and role-playing games.
Module II <i>days 4-5</i>	Technical aspects of health education with its 4 stages: 1—develop an educational diagnosis; 2—define a personalized program of health education for the patient, which involves formulating with the patient the skills to be acquired or mobilized with regard to his or her project, 3—to plan and implement collective and/or individual health education sessions for the patient. The objective is to propose, according to the patient's needs and preferences, a planning of the patient's health education sessions; 4—carry out an individual assessment.
Module III <i>days 6-7</i>	Designing specific educational sessions including choices of the appropriate communication tools to address specific aims in the context of patients' education. Personal and future patient projects were first discussed in small groups and then presented to all students and faculty members at the end of the training. Barriers and facilitators to PPI together with experiences in the field of faculty members and patients as teachers were shared. Exchanges were set-up on the representations that patients and caregivers have of each other.
Module IV <i>day 8</i>	Wrapping up the training program. Open discussion upon opportunities of complementary university courses if needed for the PPI projects.

**Table 2.** Becoming a Peer Educator in Mental Health, Syllabus and Teaching Tools.

Schedule Syllabus and teaching tools	
day 1	Introduction to peer helping, recovery, patient health education, public health mental issues
day 2	Developing the recovery process: why and how? "Not one without the other"; Starting with verbal testimony. Define the needs. Addressing risky health behaviors, addictions, various pathologies. Integrate the notion of commitment and peer support. Use of narrative practices, co animation with a patient peer mediator. Ask participants to write their life stories for the next session.
day 3	Literature review and presentation of the possibilities of university courses at the end of the course. Life story discussions and editorial preparation.
day 4	Work on peer helper. Knowledge of the disease, the journey, the networks, the social repercussions. The posture of the peer. Dedramatization of the environment. A lived experience of recovery. Notion of the patient resource and peer helper. Facilitation by a patient trained to become a health educator
day 5	Work on de-stigmatization, prejudices. The representations: "I'm not a sick person, I'm a cared-for person" The notion of an ambassador. Illustration by different experiences.
day 6-7	Classification update: mental health, illness benchmarks. Discovery of health education, practicalities, regulations, maintenance techniques, evaluation. Definition of the word educate. Practical cases, situations: work in 3 groups, pedagogical tools. Patient expert and patient resource co-facilitation.
day 8	Putting words on recovery, strengthening one's will to recover. Health education practices and representations; concepts of psycho-education and health education. Roles and collaborations between the different actors. Co animation with a peer health mediator patient.
Day 9	Future prospects for the training process and roles of promoters. What happens at the end of the training, diaries, and university courses? Presentation of life stories, 5 to 10 mm per participant: exchanges, situational exercises, working in pairs: peer-assisted postures, active listening, complete listening, reformulation, note taking.
Day 10	Rights and obligations of patients in their relations with careers. Regulations, ethics Recovery and stabilization. Video testimony of a participant on his experience. Co-facilitation in pairs of patient experts and trainers.
Day 11	Exchanges and future prospects of the participants. Imagining the co-construction of collaborative projects with caregivers. Practical information. Creation of an action plan and presentation of different models.

chronic somatic conditions, Table 1, and the second in the field of mental health was entitled: "Becoming a peer educator in mental health," Table 2. In both programs, patients received training in peer health education. They were introduced to the French health system and the rights and obligations of patients. This was followed by principles of health

communication, training, and education through slide shows, publications, and multiple exchanges. Teaching techniques, mostly borrowed from patient education techniques (18) involved the use of photographs, flowcharts, narrative practices, forum theatre, websites (19), and facilitation methods. These teaching tools were used either in plenary sessions or in small groups (18). Validation of the training required participation in all courses and presentation of the health educators' projects to all students and the teaching staff.

### *Becoming a Peer Educator in Chronic Somatic Conditions*

The objectives were to (Table 1):

1. Discover the goals and methods of empowerment and education for patients with chronic somatic diseases.
2. To accompany the health education in their future project during the 4 modules with a shared plenary presentation of each personal future health educator project on day 8.
3. Offer to follow an additional university course if necessary at the UGA.
4. Promote social reintegration through participation in health education, patient associations, initial, or continuous education, public institutions such as hospitals, universities, or health public agencies. The teaching team was multi-professional and included experts patients, members of GPS, the Transversal Unit for Therapeutic Patient Education (UTEP) of the CHUGA (20), the French-speaking Association for the Development of Therapeutic Education (Afdet) (21), the network for prevention, accompaniment and therapeutic education of liver diseases (Prométhée) (22) and teachers from the CHUGA (23) and the UGA (24). Teaching was organized around 4 modules of 1 to 2 days, plus a 2-day training session on setting up a health educator project, all within 4 to 6 months. The participants worked mainly in small groups and experienced different facilitation techniques that they will use when involved in patients education (18,19).

### *Becoming a Mental Peer Educator*

The objectives were to (Table 2):

1. Acquire personnel skills like active listening and motivational interviewing.
2. Act in a collaborative project as a peer in mental health networks as a carer or as a research participant. The teaching team was again multi-professional including PPI expert from GPS and the Centre Ressources Métiers et Compétences en Psychiatrie (25). Teaching was organized over 11 independent

days plus 2 days of training sessions related to the peer educator project of the future students. All was delivered within 6 months. The items and themes were partially common with the previous program concerning facilitation, exchanges techniques, and the potential of peer education in mental health. Specific themes included the unique role of PPI alongside health professionals, the value of shared experience between PPIs and patients. PPIs contributed to the destigmatization of mental illnesses or disorders, developed an understanding of mental health recovery, and promoted recovery based on their own experience, Table 2.

### Course Evaluation by Trainees and Faculty Members

We conducted a one-line survey to assess trainee and faculty satisfaction. We also a specific survey on of trainees' new commitments after their training. Everything was done in compliance with the regulations on the security of personal data rules at CHUGA. Questions to trainees dealt with their profiles as age, gender, knowledge, and practice of patients' education before and after training. Satisfaction with the course, current, and future involvements according to the 6-level scales (4), a choice to take additional academic courses at UGA were assessed. Free comments were encouraged. For the faculty members, additional specific items were asked to their professional situation, the student selection process, and their involvement in the courses.

### Participation in Research

Members of the UGA faculty were asked to volunteer to participate in various research projects. It varied from defining objectives, design, collection of data, and participation in analysis and/or dissemination of results as expected in an ongoing trial where patients were involved in all stages (26).

### Ethics

Written and informed permission to conduct such a survey was obtained from the legal authority in charge of data protection and confidentiality at the CHUGA. Everything was done in compliance with the regulations with the CHUGA regulations on personal data security.

### Results

#### Patient Participation and Satisfaction with the GPS Training Courses

A total of 45 patients were trained between 2016 and 2017, 35 attended the program "Becoming a peer educator for chronic somatic conditions at GPS" within 4 classes of 8 to 9 students. Ten students followed the program "Becoming a peer educator in mental health" in one class.

They were 45 students,  $52 \pm 6.4$  [26–71] old, 59% female, some retired, most were unemployed due to disability; they were from Isère 59%, Savoie 11%, and Lyon 11%, France. Out of 45 participants, they were 3 drop-outs during the course, 1 death after the course, we lost track of one of them and one did not wish to participate in the course survey. A total of 24 students out of 40 that were contacted completed the online survey after 2 reminders. Students approached the GPS through either website, magazines, or personal relationships in 27%, or with patient associations in 52%, or 31% after the advice from health professionals. The satisfaction of both participants and faculty was very high, Table 3. *Verbatim* reports from students and faculty were reported; see representative ones in Online Supplemental Material.

#### Involvement of Trainees Before and After Their Participation in GPS

Before training, 16 patients were involved mainly in patient education, and most of them after training were involved in educational/research activities. After training, 5 patients reached the "highest level" according to the 6-levels PPI

**Table 3.** Satisfaction of Patients Trained and Teachers of the Grenoble Patient School Centre (GPS).

Patient trained	Satisfied	Very satisfied	Faculty members	Satisfied	Very satisfied
Program as a whole <sup>a</sup>	20.8	75	Program as a whole*	62.5	25
General organization	33	62.5	General organisation	50	37.5
Welcome at GPS	16.7	83.3	Welcome at GPS	12.5	37.5
Faculty team	12.5	87.5	Technical means implemented by GPS	37.5	50
Program	29.2	70.8			
Teaching methods	12.5	87.5			
Coaching during and after the program	04.2	87.5	Logistical means implemented by CHUGA	50	25
	29.2	41.7			
Coaching for your own development	16.7	66.7	Co-construction of programs with faculty team and patients	50	50

<sup>a</sup>Results are expressed in % of 24 out 45 trained patients and in 8 out 12 faculty members.

**Table 4.** Changes in Patient Participation Before and After Training at the Grenoble Patients School Centre.

Levels of patient involvement according to (27)	Prior training	After training	Comments
1 PI involved in creating learning materials to be used in patient education and used by faculty.	7	12	In the context of patient therapeutic education
2 Standardized or volunteer patients in a clinical setting.	3	9	Intervention at the request of the teachers within the framework of the simulation.
3 PI shares his/her experience with medical students within a faculty-directed curriculum.	3	9	Either as a witness in pair with a teacher or as part of simulation exercises.
4 PI and faculty teachers are involved in teaching or evaluating medical students	1	6	In pairs with a teacher or alone in the context of teaching.
5 PI as partners in student education, evaluation, and curriculum development. PI educators are involved in multiple program areas.	1	6	Students are mainly solicited for the co-construction of programs
6 PI at institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation, and curriculum development. Patients are given a formal position in the institution.	1	6	5 are user representatives at the university hospital 4 PI founded the new Patients' Department at UGA in 2020 and among them, one is its Director 1 is acting at the ethical review board

**Table 5.** Patients' Participation in Collaborative Research Projects After GPS Training.

Research acronym, <i>Funding</i>	Objectives, Design Specialties	GPS implication
<b>NovEthics</b> What ethical support for innovations? <i>National call 2017/2018</i>	Ethical and political dimension a place in the process of emergence and validation of innovation	2 workshops: writing a deontological charter and a protocol.
<b>Health trajectories</b> A generic concept of self-directed web-based learning will be used by all stakeholders and patients via the French national e-university UNES UGA-CHUGA	Understand the individual trajectories of patients in their ecosystem. Predict individual health trajectories.	Participation in the design, drafting, and engineering of the project
<b>SentinHealth</b> Implantable devices and a philosophical and social science method to facilitate the patient's responsibility UGA	Helping patients and healthy citizens to control their own health with the help of a "symbiotic sentinel" working in their gut, using the best of new technologies	Participation in the design of the project
<b>CRISH</b> Co-creating innovative health solutions Education program that brings together key stakeholders, including patients and informal caregivers <i>EIT Health, UGA</i>	Learning to engage, co-create and co-design lab-to-lab research projects and innovative healthcare projects through patient experience,	Participation in workshops to co-construct innovative solutions

EIT Health, European Institute of Innovation and Technology for Health.

classification in health education (27): one as an active member at our institutional review board and 4 in the new UGA medical and pharmacy school patient department <https://medecine.univ-grenoble-alpes.fr/departements/departement-universitaire-des-patients/> opened by the end of 2020 thanks to the success of GPS (Table 4).

### PI in Research

Four students and almost all patients' faculty members at GPS have contributed to research projects at different stages. Representative examples are displayed in Table 5 among increasing solicitations.

### Discussion

This study showed the success of training PPI to become peer educators in somatic chronic and mental conditions within GPS. GPS was an independent association founded by patients and linked to UGP and Centre Hospitalier Grenoble Alpes. Training the first 45 PIs was very successful with a high degree of satisfaction from the trainees and the teaching staff. In addition, thanks to these 2 training, PPI has significantly increased their interactions with patients in the field of health and mental education. A new PPI department was created in 2020 within the UGA Schools of Medicine and Pharmacy following this successful PPI training and its significant results.

It is now recognized that PPI is essential to improve the quality and efficiency of health systems (1–4,27,28). To support PPI, education is crucial, and more and more universities, patient organizations, and medical societies are organizing patients education to teach (4,29).

The high levels of PPI satisfaction in this training course were probably related to its novelty, the multidisciplinary teams, and the involvement of expert GPS patients. Above all, the main originality was the central role played by patients who founded the GPS and who lead this project with a strong collaboration with the university and its hospital (1). Satisfaction of PPI and faculty members in such training programs have been reported by others in Europe, the United Kingdom, or the United States of America (1,4,8,11,12,30,31).

It is far too early to measure the impact of PPI training on the healthcare system. However, preliminary results in terms of post-course health on the PPI itself and its effects on health professionals are very encouraging. Indeed, studies such as ours report overwhelming benefits for patients and no negative effects (32).

Beyond satisfaction reported in most of the PPI studies, we believe that tools are needed to monitor and report the work of PPI in healthcare. The GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) has already established a checklist with different elements to clearly report the role of PPI in research (33). We believe that similar tools should be in place and followed for work done when patients are taught and when they intervene. Indeed, there is little or no reporting of PPI studies on how they are trained if not at all reported. Previous PPI training ranged from a few hours of information, leaflets, simulated interaction, focus group, and up to 50 h of teaching within 6 weeks for PPI in rheumatoid arthritis (11–13).

This study gives a picture of how PI are recruited and trained in Grenoble. We believe it is important to understand why, how, in what context and for whom, and why PPI agrees to be trained. Our detailed GPS training schedule and methods have resulted in participant satisfaction and high participation in teaching and, to a lesser extent, involvement in research projects. It should be noted that there appears to be a marked scepticism or a low priority of PPI in healthcare in Europe with the exception of the United Kingdom. A 2011 survey on “Can patients be teachers?” showed, in general, patient/user involvement in the education of health professional education was not high on the agenda of influential leaders in health professional education, either at the institutional or national level (4). This is probably related to many issues such as funding, knowledge, but also a lack of reporting on how PPI is implemented and its supposed benefits for patients and the health system. Sharing and strengthening the interactions between these initiatives to learn how best to implement PPI would go a long way to demonstrating the beneficial role of PPI in healthcare.

We recognize several limitations. Results may be skewed by survey self-selection although dissatisfied people are more likely to testify in such satisfaction surveys. We trained a

limited number of trainees within 2 years from 2016 to 2017 and one of our priorities is to recruit and train more trainees. The real impact to these new peer health educators at CHUGA, for example, is not yet measurable.

## Conclusion

Our training of PPI has brought strong benefits to the trainees. The number of PPI who are trained and involved in healthcare should increase steadily with the establishment of a department of patient education and counseling within the medical and pharmaceutical schools in Grenoble. Grenoble Patients’ School has moved from being a patient association to a formal university department “Département Universitaire des Patients Grenoble Alpes” within the UGA schools of medicine and pharmacy by the end of 2020. This department is now led by 4 patients including the director, 2 professors, one in medicine and one in pharmacy, vice deans for the curriculum of schools of medicine and pharmacy, and 2 CHUGA directors responsible for innovation and user relations respectively. We are now well set up to initiate new courses and research projects.

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## Supplemental Material

Supplemental material for this article is available online.

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