

PRoF Award abstract – Call 2018

Deadline for submission: Thursday March 1st 2018 (12 o'clock noon)

Please send to: PRoF-Award@uzgent.be.

< PECE - Patient Expertise Center Rheumatology >

1. Research Outline

Acronym	PECE
Project name in English	Patient Expertise Center Rheumatology
Pitch (1 sentence)	Development of a patient expertise center (PEC) to educate patients to become patient experts and to valorize the services of this PEC to various stakeholders (industry, academia, government) to have a structured and harmonized way of patient engagement
Executive summary (max. 10 lines)	
<p>The Patient Expertise Centre aims at empowering patients and increasing patient participation in an increasingly interdisciplinary healthcare ecosystem by 1) supporting peer-to-peer activities (patient expert to patient coaching) and 2) offering services to professionals (like gov, academic centers, research, pharma,..) where patient experts can be hired to give insight and share their experience.</p> <p>The PEC will focus on: standardising the way patients and patient experts can work with professional organisations, provide guidelines on how to work with patients to various stakeholders, making an inventory of patient engagement activities and patient education courses, providing a course to become a patient expert (you need to be knowledgeable in a specific domain and on top of that be a patient that is able to detach emotionally from its own condition + have the skills to work with professionals and peers), projects that involve patient engagement</p>	

2. Cause and context of the research

Over the last years, there has been put more and more importance of including patients' voice in the development of services for patients (like support programs), but also drug development (clinical trial endpoints, protocol reviews,...). There is a strong belief that patient participation has a beneficial effect on the long run on all stakeholders involved, ranging from government, payers, academic research to pharmaceutical industry and others. There is also an increasing demand towards patient organisations to provide patients with sufficient background to participate in these meetings. However, in reality, we see that patient organisations struggle to deliver the right people and to answer every question that comes in. Simultaneously, there is a lack of harmonization how patients are involved: some do it on a volunteer basis, others on a paid basis. Some have contracts, some not. In order to structure the ecosystem of patient involvement and to encourage stakeholders to work with patients in a professional way, a Patient Expertise Center is set up that is the main point of contact for all organisations (non profit, profit and governmental) to work with patients. This patient expertise centre will educate patient experts, coordinate the placement of patient experts with various stakeholders and also very important, it will collect information on the impact of patient engagement projects so more and more evidence can be collected to measure the return on investment on patient engagement projects.

3. Innovation results achieved

To date, a pilot project in rheumatology has been set up with ReumaNet, the umbrella organisation of patient organisations in the field of rheumatology. This pilot project is called PECCR, Patient Expertise Centre Rheumatology. First, a feasibility study has been set up in which various stakeholders have been interviewed to understand the benefits of working patients, but also the concerns. Based on the stakeholder and ecosystem mapping, a framework has been set up that describes the services that can be set up under the PEC. Also the interaction between the PEC with patient organisations and external stakeholders has been addressed. One of the key aspects in the PEC are patient experts. For this, a course has been designed together with Trefpunt Zelfhulp VZW, a non-profit helping organisations in professionalization by offering educational courses. This course combines a communication part (skills required to work on a professional level with peers and professionals) and a medical terminology part (basic information in rheumatology). The formation is mainly done online via usecases that should be commented. There are 3 face to face meetings involved. Simultaneously, there was a call for pilot projects to external stakeholders (academia, industry, government and insurance companies) to finance a project that can serve as a pilot under the PEC framework. For every pilot project, a methodical approach is set up in line with the PEC framework. Based on the learnings in every pilot, the framework will be adapted. The pilots are categorized in two parts: patient support via peer-mentoring and professional services. Under professional services, one example is the use of a patient expert specialized in work-reintegration, together with RIZIV/UNAMI. The aim is to facilitate work (re-)integration for patients with a rheumatologic disease. Under professional services there are projects included

in which patient experts provide feedback on trial protocols and patient communication around the use of biologics for women with childbearing age.

The next step will be to learn from the PECE pilot to set up a general PEC that also covers other indications.

4. Link to the PRoF values

The PEC concept is focused on a multi-disciplinary collaboration while serving the patient values as a top priority. By having patient experts providing feedback to patients (peer-to-peer mentoring) the PEC contributes to patient education in a credible and harmonized way. The patient experts are educated to respect the privacy of patients, how to deal with medical information, but also how to deal with corporate sensitivities in case of the professional services. By creating a new profile as patient expert, the barrier for patients to talk to peers will be softened which could contribute positively to patient engagement and patient participation. On an organisational level, the patient experts are effectively contributing in patient boards as equal partner around the table with other stakeholders.

The PEC is truly interdisciplinary, with various stakeholders leading the steering meeting: patient representatives, physicians, insurances, academic researchers from various universities, government representatives, and representatives of the pharma industrie (via non-profit umbrella). The PEC is always patient led.

A first validation has been set up and is ongoing. With support of the Award, the next steps involve the scalability by projecting the PECE concept to other indications such as diabetes and oncology, while identifying the tasks that can be pulled together in a general PEC that groups all the underlying indications (rheuma, oncology, diabetes, MS,..).

The sustainability is built on a business model in which patient services are charged for via a market conform pricing model.

It is only on a generic PEC level that is indication agnostic that the true benefit can be shown of patient engagement on the political level. The PEC will become the expertise centre on patient involvement by producing key learnings and impact figures that could benefit society and future projects.

5. Applicable IPR rules

Not applicable. The concept of Patient Expertise Center is owned by ReumaNet VZW.

6. Information on the partners



ReumaNET VZW is the project coordinator of the PECR and PEC on the general level. It has allocated 3 individuals to roll out the PECR concept and also coordinate the PEC level with other indications by sharing the learnings of the pilots on PECR. A multi-disciplinary team has been put together (pharma, academia, care providers, patient organisations, insurance,..) to ensure that the activities are creating a win-win for all partners involved.

Note:

If your project is selected as laureate for the Award Symposium, a powerpoint presentation that reflects the project as suggested will be required (in advance), including a future plan how the funding will be used.

If your project is selected as the winner of the Award, you will be invited to present the results achieved thanks to the award during the Award Symposium of the next year.



Addendum: Contact information

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