

Fostering citizen engagement with the PATIO health guide

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PATIO aims to improve the quality of life of directly and indirectly affected persons after the diagnosis of prostate cancer (PCa). A first milestone is the PATIO health guide app “PATIOSpots”, which was developed jointly with affected persons in a co-design and co-creation process. One of the first actions a person takes after the diagnosis PCa is trying to find reliable, high-quality, structured, and easily accessible sources of information. “PATIOSpots” aims to be a game changer and digital orientation guide for patients and caregivers at a time when it's needed the most. The following article provides insights into the app, explains the conceptual phase, the involvement part as well as its development, and the benefits for patients and caregivers. Parts of this manuscript were presented in a talk at the Austrian Citizen Science Conference 2022.

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1. Why Citizen Science and PPIE?

At the end of 2020, 65,525 men were diagnosed with prostate cancer (PCa) in Austria [1], accompanied by an even larger, unknown number of caregivers. Those persons, directly and indirectly, affected by PCa, **carry valuable experience-based knowledge** about everyday life with the disease. However, to date the cases in which medical experts, researchers, patients and caregivers meet completely at eye level are very rare. That's why it is so important **to actively encourage patients** to participate in developing their individual solutions and coping mechanisms for dealing with these complex challenges after such a diagnosis.

The approach of citizen science and PPIE (patient and public involvement and engagement) is an innovative method to overcome societal challenges in a non-traditional way by involving citizens and giving them a role to contribute directly to diverse scientific disciplines [2]. The opportunity to get research insights, learn new things e.g., on a professional level, help and connect as well as exchange with others are the main motivating factors for citizens to participate [3]. Over time, people affected by a life-influencing and changing disease become experts by experience and carry a wealth of knowledge that often remains untapped, whereas it actually could and should be a valuable contribution to science and the larger community.

PATIO (**Patient Involvement in Oncology**) is an ongoing project. The team works together with and learns from people affected by PCa to establish an **orientation guide** and **communication platform** to **improve the quality of life (QoL)** of anyone affected. Also, empowering citizens to open up and talk about their individual challenges raises awareness against the **tabooed** life with cancer and its side effects.

2. How does Citizen Science actually work?

PATIO brings together knowledge from multidisciplinary sciences and the practical experience of healthcare professionals by using PPIE and open innovations in science (OIS) methods. Citizens and patients are directly involved in research by and for those affected. Thereby, they are empowered to shape the project and its outcome with their **experience-based knowledge**. [4]

The PATIO team involves **14 co-creators** (13 PCa patients and one caregiver) who were recruited through a combination of broadcast and pyramiding searches. This was realized with the help of the former chairman of the support group for prostate cancer Austria and additionally with a call for participation on national TV, social media channels of PATIO and other online platforms.

PATIO is supported by health professionals including specialists in urology, nuclear medicine, clinical pharmacy, nursery and physiotherapy. Figure 1 illustrates the three steps needed to establish the basis for "PATIOSpots". Co-creators support the project with their lived experience in order to better understand the needs of the target group. The toolbox includes **co-creation and co-developing workshops, round tables, design-thinking and feedback loops**. Interim and final results are shared within the group regularly to allow for dynamic adaptations. Since co-creators invest their free time and contribute thoroughly, an **honorarium** was provided to compensate for their effort.

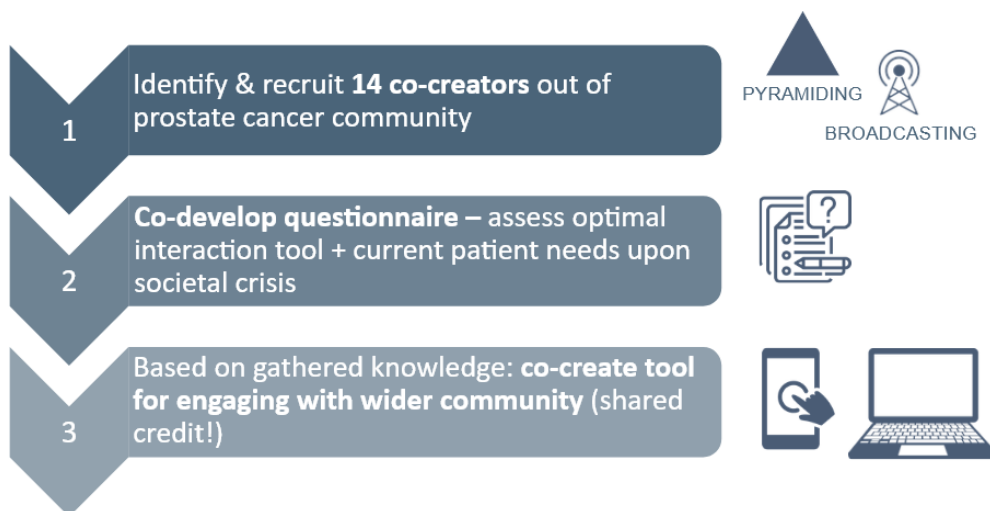


Fig.1 The initial process of PATIO included three steps for involving the PCa community to define the shape and need of an involvement tool.

3. Results through Citizen Science

Based on various round tables with co-creators and an Austria-wide survey, the need and format for a digital practice-oriented communication tool by and for those affected by PCa could be identified. Co-creators were involved in preparing the relevant features and options for the places to be chosen. A questionnaire to identify missing themes were used to confirm and adapt the subcategories of the tool. After prioritizing the focus and shaping the concept together, the team developed the first module of the app "PATIOSpots" with the citizen science experts from "SPOTTERON". With "PATIOSpots", see figure 2, users can easily find and add new spots in close vicinity to the current location to contribute to enhancing the respective QoL.

Since the main challenges, patients need to learn to cope with after the treatment of PCa, are impotence and incontinence, "PATIOSpots" concentrates in a first step on information and contact points in the course of PCa. This includes a "toilet finder" when things have to go fast but also other helpful locations such as support groups, treatments, or rehab centers. This allows patients but also the public to record, find and comment on various information and relevant contact points. This citizen science approach allows a convenient overview of important spots and possible discovery of new places that can help to contribute to an improved QoL.

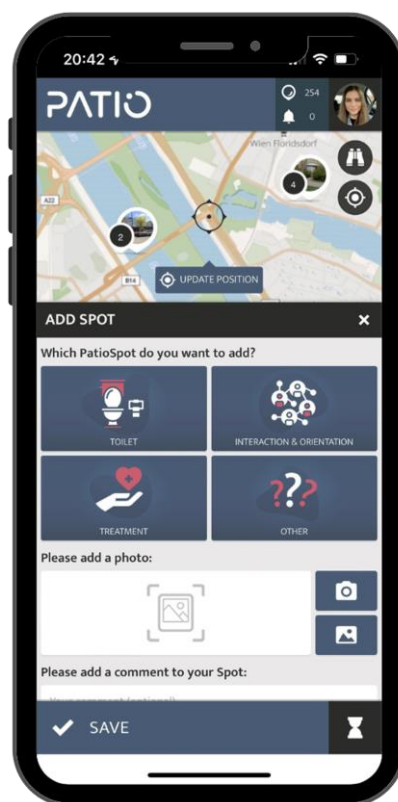


Fig.2 Main menu of "PATIOSpots"

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Main advantages of an app solution:

- active citizen and patient involvement to contribute
- building a network of like-minded people
- interactive map
- anonymous
- orientation guide
- user motivation system
- up to date and timely
- easy to download and share
- quick and ready-to-use applicability

4. Outlook

PATIO is contributing to the empowerment of the PCa community in Austria and can serve as a role model for other communities. The approach should be usable and scalable in the future. Patients need to be supported after the diagnosis on multiple levels (e.g. decision tree of possible treatment options, additional and aftercare, exchange with other affected persons). The initiative helps to understand patient's care preferences which in turn can be used to develop diagnostic and treatment strategies tailored to patients' needs and to increase their QoL.

By being part of the community, patients felt heard and esteemed which contributes to the co-design and co-development process. It also fostered a feeling of togetherness and supporting each other since they have experienced something similar. The setting helps to establish an environment in which patients and the public are directly involved in the field of PCa management.

Further implementation of new modules and additional features of the app are planned in terms of socio-economic information on living with PCa, individual user profiles, coordinated design adaptation in terms of user-friendliness and functionality as well as expansion to additional languages since the map is available worldwide.

5. Acknowledgments

During the establishment phase of the app, we had to say goodbye to Ekkehard Büchler, who accompanied us as chairman of the Austrian support group prostate cancer from the beginning with his advice, actions and support. Despite his advanced age, he was a very modern and progressive-thinking man who supported every idea and discussed all the challenges of prostate cancer together with us without any taboos. He passed away in his 82nd year, leaving a huge void of knowledge, commitment and experience.

We are grateful to all the co-creators, who dedicate and have dedicated their time, experience and energy to our initiative. PATIO and "PATIOSpots" would not exist without them.

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