

Project PATIO: Towards an improved quality of life through lived patient and caregiver engagement in oncology

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The project PATIO (Patient Involvement in Oncology) aims to engage persons directly and indirectly affected by prostate cancer in research and development to advance efforts towards improving their lives after the diagnosis of prostate cancer. The following article provides insights into the aims of the project more generally and into working methodologies and first results, such as the “PATIOSpots” app, more specifically.

POS (ACSC2022) 009

1. Introduction

According to recent statistics, around 65.525 men were living in Austria at the end of 2020 who were affected by prostate cancer (PCa) [1]. This already large number of persons was accompanied by an even larger, unknown number of caregivers. Those directly and indirectly affected by PCa hold valuable experience of everyday life with the disease. On the subject of quality of life (QoL) after the diagnosis of PCa, the PATIO (**Patient Involvement in Oncology**) team aims to create a **direct link between empirical knowledge and specialized research**, because to-date it has not been captured which strategies PCa patients and their caregivers have developed to overcome challenges before, during and after therapy. Using open innovation in science (OIS) approaches as well as design-thinking methodologies, a core team of trained researchers together with 14 co-creators develop a digital guide in the form of an app and accompanying website. The inclusion of lived experiences of those affected, makes it possible to successfully implement the app and platform “PATIOSpots”. At the same time, the team promotes awareness for the challenges and opportunities related to PCa through public communication, supported by testimonials, i.e., well-known persons from media and television.

2. Aims & Methods

PATIO is an OIS and PPIE (Public and Patient Involvement and Engagement) project. The overall aim of the project is to **improve the QoL of persons directly and indirectly affected by PCa** [3]. For this reason, the project team, including 14 co-creators (13 PCa patients and one caregiver), **jointly conceptualized a digital support tool** that is intended to make everyday life easier for those affected by PCa. Results are planned, determined and reviewed together with actors from different areas, including both academics and non-academics. A small nation-wide survey in the early project phase served for collecting insights on the purposes affected persons use or want to use digital media with regard to living with PCa.

In terms of methodologies, the project draws on a number of different Open Science and

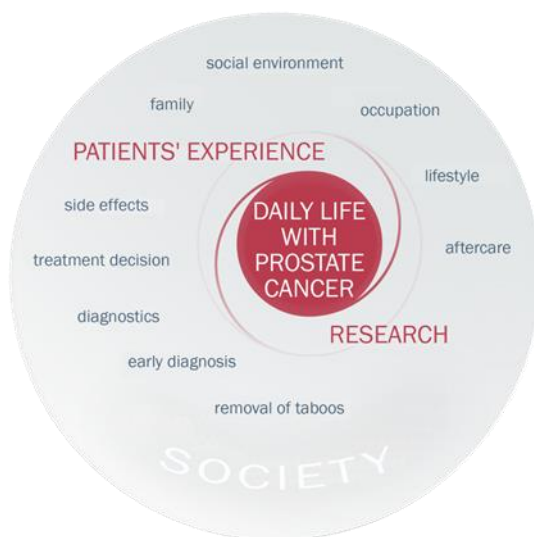


Fig.1 Graphic representation of focus areas that affect both patients and caregivers.

OIS approaches. For the **recruitment** of co-creators (patients and caregivers), **broadcast and pyramid search techniques** were applied [2]. Priority setting and development workshops were supported by lead users, **design-thinking loops, co-creation and co-design methods**. This enables the integration of practical knowledge throughout the entire research and development process. In **round tables**, members of the core team meet co-creators and health experts to brainstorm, discuss relevant topics, plan processes and take further strategic decisions. The combined use of these methodologies has proven effective in mixed interactions, both online and face-2-face.

Figure 1 presents relevant topics for patients and caregivers when dealing with PCa in their daily lives. In this respect, the patients' lived experience also plays a vital role. As a major step in mapping preferences, needs, and gaps in current health care, a nationwide survey directed at the PCa community was co-created and carried out. The aim was to get comprehensive insights and opinions from affected persons to evaluate their needs and help improve their well-being. Thereby insights into the use of digital media were collected and narrowed down what measure of support for PCa patients and caregivers would be needed.

3. Results

Finding reliable, qualitative, and easily accessible information is one of the first actions patients take after being diagnosed with PCa. What seems like a simple task can become yet another challenge, adding to the already high psychological burden on those directly or indirectly affected by PCa. Based on workshops and an Austria-wide survey, the team was able to **design a practice-oriented tool for those affected**. With the help of an iterative process involving the entire team as well as specialist groups, the format best suitable for the sustainable participation of the broad masses was defined. The outcome of these processes is the co-developed communication and involvement tool “PATIOSpots”. While the first module of the digital health guide has been established, further modules and features are being developed in future iterations.

The app “PATIOSpots” is available via [Google Play](#) and [App Store](#) free of charge. Users can easily find, rate and add places that are relevant to PCa sufferers near their current location. These locations can be **toilets**, but also **other important points of information and contact** that can **support improving their QoL**. Patients could benefit from the app just as well as the wider public since the app is not limited to a specific community only. Additionally, a corresponding website has been established for more detailed information on general treatment and therapy options, FAQs as well as important contact details and checklists. The website is useful for affected persons regardless of whether they are before, during, or after therapy and it is also a useful resource for healthcare experts who might contribute with information that is relevant for patients and caregivers. Users and readers get **access to easily understandable information** about PCa through the practice-oriented solution - the “PATIOSpots” platform.

4. Conclusion & Outlook

The PATIO project aims at serving as a best-practice example for an ecosystem in healthcare, in which the **voices of patients and those indirectly affected** make a valuable contribution in the scientific, medical and societal fields. The metaphor of ‘pulling together on the same string’ describes well how **all actors join forces** to contribute to a coordinated effort for the interests of the patients. PATIO has created a team dynamic in which people with very different types of expertise come together for a common goal. Additionally, PATIO also serves as a best-practice example for the Sustainable Development Goals (SDGs) [4]. Future efforts aim at advancing the other modules of the “PATIOSpots” app and website in order to increase and improve the support and the QoL for as many PCs affected persons as possible.

5. Acknowledgements

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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