



UCD PPI Ignite 

CampusEngage

Network for the Promotion of Civic Engagement in Irish Higher Education

## Engaged Research Case Study Template

### Health and wellbeing

<p><b>Project Title (8 words max)</b></p>	<p>The Patient Voice in Arthritis Research</p>
<p><b>Project synopsis (100 words max)</b> Please give a very short description of the societal challenge, the action taken, and the intended/ achieved result.</p>	<p>We aim to change our research from being disease-focused to being patient-focused. Our goal is to have patients involved in all research and in the setting of our research priorities. By working together we believe our research will be better, more relevant and have a bigger impact on a patient's quality of life, and on society as a whole.</p>
<p><b>Higher Education Institution:</b></p>	<p>University College Dublin</p>
<p><b>Engaged Research Partners</b> (civic, civil society organisations, Social enterprises, public or professional service or product users, policy makers, members of the public).</p>	<p><b>Public:</b> People living with arthritis and rheumatic disease, their carers and family. Anyone with an interest in arthritis and rheumatic disease.  <b>Patient advocacy groups:</b> Arthritis Ireland and iCAN (Irish Children's Arthritis Network). ENCA (European Network for Children with Arthritis). PARE, the European patient advocacy group for arthritis and rheumatic disease (part of EULAR- The European League against Rheumatism). CRMO.org, a US based advocacy group for a rare disease called CRMO and a member of CARRA (Childhood Arthritis and Rheumatology Research Alliance).  <b>Professional Associations:</b> The Irish Society for Rheumatology. Irish Society for Chartered Physiotherapists.  <b>Funders and Policy Makers:</b> Medical Research Charity Group, HRB, Arthritis Research UK, National Children's Research Centre.</p>
<p><b>Engagement (research method or activity) (100 words max)</b></p>	<p>Co-developed Patient and Public Involvement Strategy (PPI) with patients and the public. Methods of engagement to date include discussion forums, workshops, community events, online engagement, direct collaboration, co-development of workshops and events, membership on research advisory groups, production of animations about our research, invitation to governance boards and strategy development boards.</p>



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**Project outputs and outcomes: (600 words max)**

Please describe briefly the target audience and activities that occurred and short terms results.

This information could include:

- who you worked with;
- issue to be addressed
- what actions you took;
- the geographical location;
- any shorter-term outcomes or changes in local situation and circumstances, knowledge and skills attitudes or behaviour, policy, practice, organisational development etc, decision-making.

The outputs are as follows:

- We have had members of the PVAR PPI group critically review plain English summaries of our research on seven of our research projects to date.
- We have patient members of the research advisory groups on five of our research projects. Our research project into self-management has a panel of seven patients that act as primary advisors on this project. Our laboratory based projects have between one to two patient advisors per project.
- A grant currently submitted includes a patient advocated as a co-applicant with a formal, defined role in the research project on a par with all applicants and has been a critical part of developing the research project.
- Patient insight partners have been authors on three conference papers and acknowledged in a variety of communications, including a scientific paper currently under review.
- Members of PVAR are co-chairs for all sessions of a National conference being hosted in UCD (funding received from HRB). Two members of the UCD Patient Voice have been funded to develop and deliver a communications workshop to improve research communications to the public. The conference is delivered in Plain English and is open to the public. There are workshops designed specifically for the public, developed directly in response to input from our PVAR members. Patients have the opportunity to share their experience of living with rheumatic disease through Patient Journey Maps, which will be displayed at the conference.
- Our research centre has been reorganised to include patient representatives (two) on the steering committee. We aim to have at least one representative on all research project advisory groups going forward. We have had a patient representative as part of the Board



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of Assessors and Interview panel for the appointment of a researcher to the project they are advisor to.

- We have increased our communications with the general public and increased our efforts to raise awareness of rheumatic diseases. We have produced animations about our research, increased our media presence (radio interviews, newspaper articles), increased our engagement with community groups (attending local and national community meetings), and improved our online presence to make finding out about our research and how to get involved much easier.
- Feedback and keeping patients and the public up to date was a key message from our PVAR group. In response we started News Rheum, a patient-researcher co-produced newsletter produced every 4 months. Patients write articles about their experience. Researchers write pieces about their research, which is reviewed and edited by patients to ensure it is understandable. We invite questions from the public about a specific topic and have those questions answered by professionals in the next issue. We feature one researcher each edition, who is interviewed by a member of the public about their work.

The outcomes are as follows:

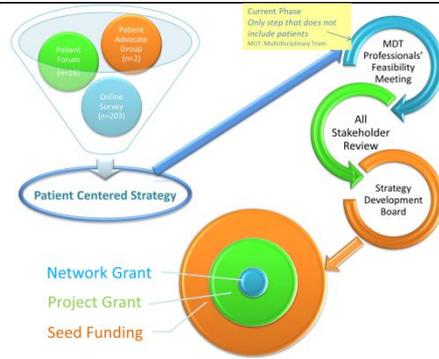
- In response to patient requests, we have started research into fibromyalgia, a rheumatological condition that we previously had not studied. We are developing a multidisciplinary approach to fibromyalgia with research priorities set completely by fibromyalgia patients (input from 221 patients to date). The approach taken is outlined in figure below.



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- Patients have been invited to act as mentors for our staff and students to improve our communications and to inform us about the experience of living with, and interacting with the health service for management of, rheumatic disease.

**Longer term anticipated areas for Impact** (Choose from below):

- Economic
- Policy & Public Service
- Societal Engagement
- Health & Wellbeing
- Professional services
- Environmental
- New knowledge
- Human Capacity

**Economic**

More relevant and informed research reduces research waste and increases impact and value for money.

**Policy & Public Service**

Taking a holistic approach to disease and ensuring our research is actionable helps it translate from research into policy and practice. A unified voice is stronger. By working together, we increase our sphere of influence, and have a greater chance of both raising awareness and influencing policy.

**Societal Engagement**

By working with the community and keeping the community informed about our research we can learn a huge amount about the societal factors that influence disease and the stresses associated with disease. In turn, we can expand our research to account for these, thereby increasing the impact of our research to society as a whole.

**Health & Wellbeing**

The goal of improving diagnosis and treatment of arthritis and rheumatic disease has direct impact for patients. Improving our involvement with patients in order to do this can have a less obvious impact. Have a chronic disease creates a burden of stress that



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	<p>affect every aspect of a patient and their family’s life. Patients were traditionally passive recipients of healthcare. This can add to the stress and burden of disease. Improving communications, becoming more transparent in research and including the patient voice in the decision making process around research can restore some of the personhood lost through living with the disease.</p> <p><b>Professional Services</b> The patient educator part of this project, whereby patients use their knowledge and experience to teach medical and biomedical students and early career researchers will help improve health care professionals and health research professionals.</p>
<p><b>Funding source:</b></p>	<p>HRB Wellcome/HRB/SFI Biomedical Partnership Institutional Strategic Support Fund Irish Research Council</p>
<p><b>For more information contact:</b></p>	<p>Patientvoicearthritis@ucd.ie</p>