



UCD PPI Ignite

CampusEngage

Network for the Promotion of Civic Engagement in Irish Higher Education

Engaged Research Case Study Template

Health and wellbeing

Project Title (8 words max)

The Patient Voice in Cancer Research (PVCR)

Project synopsis (100 words max) Please give a very short description of the societal challenge, the action taken, and the intended/ achieved result.

PVCR is an initiative to actively engage cancer patients, cancer researchers and other interested parties (patient advocates, families, carers and health care professionals, policy makers) in discussions and decision making processes which positively impact on cancer research, cancer treatment and outcomes for patients.

The PVCR helps match cancer researchers and patients to activities that best suit their mutual interests in cancer research and/or a specific type of cancer. We also facilitate education and training opportunities to improve the skills and knowledge of both the patients and researchers in a two-way dialogue about cancer research.

The goals of the project included:

1. To build connections between patients and cancer researchers.
2. To facilitate a two-way dialogue between patients and cancer researchers ensuring mutual trust, respect and understanding between the patient and the researcher.
3. To provide education and training for patients and cancer researchers to **(i)** improve communication between both parties ensuring that cancer research is seen as a joint venture to overcome the disease, **(ii)** to improve the understanding of cancer research in a concise and clear message to the wider community.
4. Inform policy and healthcare of research needs that will benefit cancer patients.

Higher Education Institution:

UNIVERSITY COLLEGE DUBLIN UCD

Engaged Research Partners (civic, civil society organisations, Social enterprises, public or professional service or product users, policy makers, members of the public).

- Patients/ patient advocates
- High risk patients "Previvor"
- Survivors
- Family members

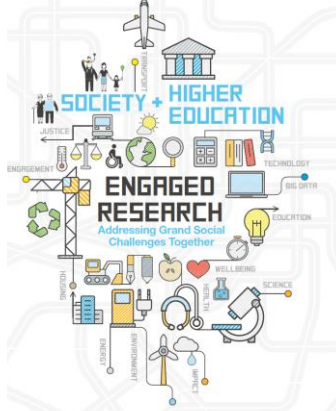


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	<ul style="list-style-type: none"> • Members of the medical and nursing community • Cancer charities/ employees • Cancer researchers • Any member of the public with an interest in cancer research
<p>Engagement (research method or activity) (100 words max)</p>	<ol style="list-style-type: none"> 1. Co-design of Terms of Reference, Mission statement, PVCR outputs and bespoke workshops. 2. Tours of the Cancer Research Facilities in the UCD Conway Institute and Systems Biology Ireland. 3. Patient Voice in Cancer Research Workshop events in the April and September of each year. Five such workshops have been arranged to date since April 2016 in topics suggested by patient consultants on the PVCR committee.
<p>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:</p> <ul style="list-style-type: none"> • 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. 	<p>The outputs are as follows:</p> <ol style="list-style-type: none"> 1. The PVCR Committee was established in 2016. It consists of ~30 members drawn from the patient and cancer research communities with the remit to develop PPI within PVCR. 2. Since 2016, five workshops have been hosted by PVCR in topics suggested by the patient consultants. <p>The outcomes are as follows:</p> <ol style="list-style-type: none"> 1. Patients will form part of the steering group committee and contribute to the strategic development of the UCD Centre in Translational Oncology. 2. Cancer survivors now form part of the Irish Association for Cancer Research (IACR) Council and input on all aspects of the running of this <i>all-Ireland</i> Annual Conference.



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<p>Longer term anticipated areas for Impact (Choose from below):</p> <p>Economic Policy & Public Service Societal Engagement Health & Wellbeing Professional services Environmental New knowledge Human Capacity</p>	<ul style="list-style-type: none"> • Policy & Public Service • Societal Engagement • Health & Wellbeing • New knowledge
<p>Funding source:</p>	<p>Mater Foundation, Breast Predict, UCD Conway Institute and the UCD School of Medicine (SoM)</p> <div style="display: flex; justify-content: space-around; align-items: center;"> <div data-bbox="885 817 1077 929">  </div> <div data-bbox="1077 873 1348 929">  </div> </div> <div style="display: flex; justify-content: space-around; align-items: center; margin-top: 10px;"> <div data-bbox="901 996 1133 1064">  </div> <div data-bbox="1189 996 1508 1086">  </div> </div>
<p>For more information contact:</p>	<p>Amanda McCann (UCD) amanda.mccann@ucd.ie</p>