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Welcome



The past year has been an exciting one for the Patient Voice in Cancer Research (PVCR) initiative. In April 2019, we received funding from the Irish Cancer Society for a twelve-month period. Specifically, we have (i) expanded the PVCR network, forged new alliances and hosted workshop events in Cork and Galway that you can read about in this issue, (ii) we have formalised and streamlined governance and operations, and (iii)

provided training to researchers on involving patients and the public in their work.

The funding also allowed us to employ Dr Barbara Hughes on a part-time basis to coordinate activities. Finally, we have established an identifiable brand for PVCR that we believe brings to life our vision to put the patient voice at the centre of what we do in research.

We firmly believe that this initiative is valuable to patients and their families as well as to the research community. As we look towards the future, we want to sustain the momentum achieved so far, work with our new steering committee and network to secure funding to sustain our work. We acknowledge that the COVID-19 crisis is a difficult time for everybody, and especially for cancer patients and their families and carers. We postponed our April 2020 workshop and moved meetings to the virtual world of Zoom so as not to compromise the health of participants.

We wish you, and your families, resilience and strength at this time of vulnerability.

Best wishes,
Professor Amanda McCann
Chair, PVCR Steering Committee



Dragons' Den – Involving Patients and Carers in Cancer Research

The second regional meeting of the Patient Voice in Cancer Research (PVCR) was held in Galway on Tuesday, 25 February 2020. This patient involvement workshop was jointly hosted with the National Cancer Research Institute (NCRI), a UK-wide partnership of research funders working together to maximise the value and benefits of cancer research for patients and the public.



Richard Stephens, Margaret Grayson and Professor Amanda McCann.

Richard Stephens, former Chair, NCRI Consumer Forum and Margaret Grayson, MBE, Chair, Northern Ireland Cancer Research Consumer Forum co-facilitated the event.

Professor Amanda McCann, PVCR Chair said, *“This has been a wonderful opportunity for those who have been on a cancer journey to shape and improve current and future research projects. Equally, it was an incredible privilege for researchers to gain valuable insight on specific questions or challenges facing them in their respective cancer research projects.”*

THE AIM OF THIS WORKSHOP WAS FOR RESEARCHERS to get input on specific questions or challenges that they are facing in their research projects from those individuals with a lived experience of cancer.

This was the first time for a *Dragons' Den* style patient involvement event to be held in Ireland. The format is often used by the NCRI during their consumer forum meetings.

Ten research groups from around Ireland were shortlisted to host tables at the event. Each research group presented their specific question or challenge to a group of seven patients, family members, carers or patient advocates for discussion and feedback.

Topics ranged from developing an e-Health online portal to alleviate the information deficit experienced by cancer patients and survivors;

...EACH RESEARCH GROUP PRESENTED THEIR SPECIFIC QUESTION OR CHALLENGE TO A GROUP OF SEVEN PATIENTS, FAMILY MEMBERS, CARERS OR PATIENT ADVOCATES...

gaining feedback on a home-based device for fluid management in late-stage cancer and improving awareness of cancer associated thrombosis.

In addition, several patient support, advocacy and charity groups attended the event. They included the East Galway Cancer Support, Men Against Cancer, CanCare4Living, WigWorld, Lynch Syndrome Ireland, Precision Oncology Ireland, Breakthrough Cancer Research and the Irish Cancer Society.

Each researcher group is committed to providing feedback to the patient participants who gave input to their challenge. A summary report of the key points from all ten tables has been compiled by Yvonne Darcy, Darmah Research, and will be circulated to all event participants.



Participants at round-table discussions during *Dragons' Den* event.



Suzanne Bracken, Blánaid Mee, Anne Cullen, Sharon O'Toole, Niamh Clarke, National Biobanking Working Group hosted by Clinical Research Development Ireland.



Streamlining patient involvement in research biobanks

The first regional meeting of the Patient Voice in Cancer Research (PVCR) took place in Cork on 9 October 2019. This patient involvement workshop was jointly hosted with the National Biobanking Working Group.

THE AIM WAS TO HAVE PUBLIC INPUT IN DRAFTING

two harmonised documents that could be used by research teams nationally in future when asking people to take part in health research biobanks.

Biobanking is the collection and use of human samples, such as blood or tissue, and associated healthcare data for health research.

The Working Group, facilitated by Clinical Research Development Ireland, was formed in January 2019 to address concerns researchers have in terms of consent and the use of patients' samples and data specifically for research purposes.

Researchers nationally want to ensure that patients/participants legal rights are respected; their choice to give their samples and data for health research is informed and freely given; and that samples and associated data are stored, managed and used both in an ethically and legally compliant way.

In addition to patients and family members, patient support, advocacy and charity groups attended the event. They included Men Against Cancer, Theya Healthcare, WigWorld, Amare wigs, Supreme Silhouette, Browtique Cork, All Woman, the Irish Cancer Society and the Marie Keating Foundation.

Professor Amanda McCann, PVCR Chair, co-facilitated the workshop with patient advocate, Stephen

Teap who is part of 221+, the CervicalCheck Patient Support Group. A summary report of the key points from the round table discussions was compiled by Yvonne Darcy, Darmah Research and circulated to all event participants. The National Biobanking Working Group has also been discussing the report findings with the Data Protection Commission (www.dataprotection.ie) in an effort to progress their work.



Patient advocates, John Wall and Stephen Teap.



Meet cancer researcher: Dr Maria Prencipe

Dr Maria Prencipe is a research fellow in UCD Conway Institute, a member of the PVCR Steering Committee and a member of the PVCR Communications sub-committee. Maria is a strong believer in the interaction between researchers and patients to improve the quality of research by keeping it in line with patients' main interests and expectations.

"I AM A CANCER RESEARCHER IN UCD. My research is currently funded by Science Foundation Ireland and focuses on prostate and breast cancer; specifically looking at the mechanisms of resistance to current therapies with the remit of identifying better therapeutic strategies. Despite the huge improvement in the treatments available for prostate and breast cancer when they are diagnosed early, we still lack effective treatments for metastatic disease (when cancer cells spread into other parts of the body). The aim of my research is to understand why cancer cells do not die in response to some treatments and to use this information to develop new drugs that will work better, leading to clinical trials of new therapies which are urgently needed.

I am very passionate about science communication and firmly believe in scientists' responsibility to engage and interact with the public. However, as a cancer researcher I don't get to meet people affected by cancer often. Considering that my research will affect them the most, I think that it is only natural to engage



Dr Maria Prencipe

with people living with cancer, which is why I joined the PVCR. My involvement for the past few years has confirmed my idea that the interaction between researchers and patients will improve the quality of the research by keeping it in line with patients' main interests and expectations.

I like to think that my work is adding small and yet important pieces to solve a big jigsaw. I get very excited about new experiments in the lab because they will hopefully contribute to discovering new therapies for cancer patients. By working in partnership with patients, we can see pieces of the jigsaw that once were missing and get a better picture in the end."



PPI Opportunity EU Cancer Plan Submission

The EU has been actively working to reduce the incidence of cancer for decades. The first 'Europe against Cancer Plan', dating back to the late 1980s, resulted in important EU legislation on tobacco and occupational health. Since then, EU member states have committed to reducing mortality from chronic diseases, including cancer.

Against this background Commission President Ursula von der Leyen has committed to a European plan to fight cancer, to support member states and stakeholders in improving cancer control and care to reduce the suffering caused by this disease.

The Commission intends to design the plan to cover the entire cycle of the disease starting from prevention and early diagnosis to treatment and quality of life of patients and survivors. With this public consultation, the European Commission invites all interested individuals or organisations to share their views and experiences to feed into a European cancer plan putting European citizens at the centre.

We encouraged individuals and support groups to contribute to 'Europe's Beating Cancer Plan', which closed on 7 May. We also completed a submission on the behalf on the PVCR, which consisted of an online questionnaire of 23 questions. Email queries can be sent to: sante-cancer@ec.europa.eu. We look forward to reading the outcomes of this plan.



Patient Perspectives

Ramon Whelan

Ramon Whelan is a member of the PVCR Steering Committee and has been involved with the initiative since 2016. He was diagnosed with testicular cancer in April 2006 and volunteers with the Irish Cancer Society in their peer support group.

“I WAS DIAGNOSED WITH TESTICULAR CANCER IN APRIL 2006 and after a couple of surgeries and rounds of chemotherapy, I thankfully recovered. Due to my own personal cancer experience I started to volunteer with the Irish Cancer Society (ICS) in 2009 as peer support, which involves talking with newly diagnosed patients and their families.

It was through the ICS that I was made aware of the first workshop of the Patient Voice in Cancer Research (PVCR) which was taking place in UCD. At the end of the workshop they asked for people to get involved and join the committee. It was something that really interested me but I was a bit reluctant. I wasn't sure what I could offer as what do I know about research or science

as my last involvement with science was my inter cert!

Getting involved has been one of the best decisions I have ever made. Firstly, by meeting so many researchers who have enormous passion for what they do and secondly, meeting other like-minded patients and hearing their stories and knowing how much each of us wants to help. The helping is twofold as one is helping researchers in their work and the other is by trying to make the journey that new patients face easier.

Since joining the committee, I have been involved in areas I thought I would never have the opportunity to be able to influence. For example, I have assisted in workshops for researchers who are making applications for grants and require



Ramon Whelan, patient advocate and PVCR Steering Committee member.

help with the plain language summaries. I have spoken at the PVCR workshop in Cork and a National Cancer Registry Ireland event. I was part of a patient panel for the launch of Precision Oncology Ireland and facilitated their table at the PVCR event in Galway. I was interviewed on my involvement in PPI for RTÉ's Nationwide. I was also a guest speaker at the 55th Irish Association for Cancer Research conference in Belfast in 2019.

Being involved in the PVCR gives me a great sense of personal achievement, knowing that by helping the researchers I am helping future cancer patients and making their journeys a bit easier.”

Tina O'Sullivan

Tina O'Sullivan is a member of the PVCR Steering Committee. She was diagnosed with breast cancer in 2002 and again in 2013; with BRCA1 in 2014; had preventative surgeries in 2014/2015 and diagnosed with a pituitary tumour in 2016.

“I'VE BEEN A PATIENT ADVOCATE WITH THE PVCR SINCE 2016. At the age of 39, I was diagnosed with breast cancer and lymphoedema, which unfortunately returned 11 years later. At this time, I discovered that I had a BRCA1 mutation, which led to a number of preventative surgeries and was recently diagnosed with a pituitary tumour.

While recovering from my second breast cancer, I came across an advertisement for lab tours at UCD Conway Institute. I found this introduction to the world of research enlightening and I suppose what struck me the most was the level of interest and engagement between these researchers and cancer patients. I was then invited to join



Tina O'Sullivan

the PVCR steering committee. This was an opportunity for me, as a patient, to contribute to research, and although my lack of a scientific

...I THINK THE PUBLIC PATIENT INVOLVEMENT MOVEMENT IS A WONDERFUL WAY FOR PATIENTS AND RESEARCHERS TO CONNECT AND WORK TOGETHER AND TO BREAK DOWN BARRIERS OR MISCONCEPTIONS...

background made me slightly nervous, it was my experience as a patient that was more important. I quickly realised the complexity and importance of clinical trials. Ironically, as a result of COVID-19, I think the whole world now realises the importance of clinical trials and that they require extensive expertise, time and finance and that these researchers and scientists, along with our medical staff and frontline

workers are the new superstars! Since 2016, I have been involved and contributed to many PVCR projects, committee meetings, workshops, and seminars. I am currently involved with one of the PVCR sub-committees connecting with cancer support groups and charities nationally and ensuring the PVCR reaches local communities far and wide throughout the country.

When I was diagnosed with BRCA1, there were no support groups in Dublin for hereditary cancers. I then heard about the BRCA LINK (Northern Ireland) support group, again through the PVCR, and I attended their seminars in Belfast, which turned out to be invaluable to me and for many patients from the south. In 2019 The Marie Keating Foundation set up a 'peer to peer support group' and they also hold annual seminars for the BRCA

community in Ireland with medical contributors who specialise in this area sharing information with the BRCA 1/2 and Lynch Syndrome patients.

I think the Public Patient Involvement movement is a wonderful way for patients and researchers to connect and work together and to break down barriers or misconceptions. We are all unique, no two patients are the same, and as such each experience is going to be quite different.

I am excited for the future of cancer research and I have been impressed with the enthusiasm and drive of the researchers who have contributed greatly to the PVCR. I feel privileged to be part of this new venture in PPI. It gives patients great hope for their future treatments and survivorship."



Upcoming Event: Dragons' Den

There was significant interest from researchers in the Dragons' Den event that we ran in February and we were unable to include all the groups who submitted challenges for patient input. We had hoped to run a similar but smaller event on 8 April 2020 in UCD to coincide with the annual UCD 'Relay for Life'. Unfortunately given the COVID-19 crisis, we postponed this event until a later date yet to be confirmed.

One of the researchers who will host a table at the next Dragons' Den event is Ananya Gupta, PhD who is the director of the Cancer Treatment and Rehabilitation research group at the School of Medicine, NUI Galway. Anita would like patient input on

how to develop and implement a community-based exercise rehabilitation programme for cancer survivors.

Exercise therapy has been shown to significantly improve functional capacity in cancer patients. This, when complemented with appropriate nutrition and psychological support can reduce anxiety, prevent long-term illness and recurrence.

Healthcare professionals have realised the need for developing comprehensive support services for patients recovering from cancer. However, there is very little research and information available regarding



Ananya Gupta, PhD

the exact nature of the patients' post-treatment needs.

Ananya says, "I am looking for input to this study to understand the patients' perspective on post-treatment service needs and plans to develop an adaptive and individualised rehabilitation programme that will support the management of those needs."



Event Participation

The PVCR team have been taking to the road and bringing exhibition stands to promote the initiative at conferences such as Living Well with and Beyond Cancer 2019; the National Survivorship Conference 2019 and Choirs for Cancer 2020, an awareness event marking World Cancer Day hosted by Marty Morrissey and Miriam O'Callaghan.



1 Choirs for Cancer 2020 hosted by Marty Morrissey and Miriam O'Callaghan.



2 Ciara McNamara, patient advocate appeared on RTÉ's Nationwide.



3 Professor Amanda McCann & Tom Hope, patient advocate (PVCR and Men Against Cancer).

2. PVCR Steering Committee members, Ciara McNamara and Ramon Whelan appeared with Professor Amanda McCann in a segment for an episode of **Nationwide on RTÉ (7 February 2020)**. The segment looked at the ground-breaking work of Precision Oncology Ireland in cancer research. This new consortium is led by University College Dublin and aims to develop new diagnostics and therapeutics for personalised cancer treatment. There was an emphasis on the involvement of patients in research generally and as part of the PVCR.

3. PVCR and Precision Oncology Ireland are collaborating with CÚRAM, the SFI Research Centre for Medical Devices and Galway Film Centre on this year's **'Science on Screen'**; a competitive process to create a short scientific documentary focused on cancer research. Researchers and patients from the PVCR network including Professor Amanda McCann, Tom Hope, Ciara McNamara and Ramon Whelan spoke at an information day for film-makers and producers at the Galway Film Centre on 26 February 2020.



Valerie Murphy, patient advocate; Luciana Herda, UCD; Michelle Lowry, Irish Cancer Society and Ciara McNamara, PVCR.



Dr Sharon O'Toole, Trinity College Dublin and Director, OvaCare with Professor Amanda McCann, Living Well with and Beyond Cancer 2019 conference.



Dr Emma Dorris (joint awardee, Patient Voice in Arthritis Research), Professor Andrew Deeks, UCD President and Professor Amanda McCann (PVCR).



Grainne Prendergast, ARC Cancer Support Cork and Dr Barbara Hughes, PVCR.

6. Professor Amanda McCann received a **UCD Values in Action award in December 2019** for her ground-breaking efforts to involve patients in research and treatment of disease. The award recognises colleagues who bring the University's values to life. Amanda is a cancer researcher whose research group is focused on breast cancer to understand why some patients do and others do not respond to treatment. Amanda established the PVCR in 2016 to engage the general public and cancer survivors in cancer research ensuring a two-way dialogue between patients and researchers. As President of the Irish Association for Cancer Research (2017-2020), Amanda led on patient involvement with cancer researchers across Ireland particularly as part of the annual conference programme.



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