

## The Patient Voice in Cancer Research - Dragon's Den 3

# INVOLVING PATIENTS AND CARERS IN YOUR RESEARCH



Tuesday 24<sup>th</sup> November 2020

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## Introduction, format of the Virtual Meeting

This is the 4th Dragons Den workshop hosted by the Patient Voice in Cancer Research. It is a unique opportunity for researchers to gain invaluable input and advice from patient representatives (patients, carers, family members, advocates ) with a lived experience of cancer. All the participants in the Dragons Den workshop want to help improve cancer research and are giving generously of their time to do so.

This virtual meeting reviewed 3 research projects which are currently ongoing, and in which the respective researchers had specific questions which they wished to gain feedback from the participants.

All the participants were welcomed in the Opening address by Professor Amanda Mc Cann – Chair, (PVCR) after which each participant was allocated to their designated zoom breakout rooms (*rms 1,2& 3*) with the researcher, scribe and facilitator.

The researchers hosted the 1 hour discussion starting with an initial introduction of themselves and their research, what they hoped to achieve during the discussions with the group of friendly dragons & patient representatives. The format of the discussions were interactive with opportunities for patients and researchers to collaborate.

Feedback was provided to the main room at the end of the break out sessions by volunteer dragons.

This report summarises the events from the Virtual Dragons Den.

The questions posed by researchers are captured as is feedback from participants from each of the breakout rooms.

# Room 1 – Personalised Drug screening for pancreatic cancer

1

## **Problem statement**

- Pancreatic cancer is the 5<sup>th</sup> biggest cause of cancer death in Ireland with low survival rates after 5 years.
- Each tumour is unique, progression of the tumour and response to treatment depends on the patient's cancer cells and their surrounding environment.

2

## **How this research will help cancer patients**

*Defining how tumour structure relates to a patient's tumour cells and their surroundings will allow use of non-invasive imaging techniques to:*

- a) Better assess how effective certain therapies are (eg drug treatment before removal of tumour tissue ( neoadjuvant therapy)*
- b) Provide more accurate assessment of tumour stage at 1<sup>st</sup> diagnosis to allow the most appropriate choice of treatment*

*Developing engineered systems to grow patient tumours in the lab will facilitate screening of several potential drug treatments, thereby helping to identify the best treatment suited to a given patient's cancer*

3

## **Discussion for Dragons consideration**

*Developing this approach for research, the researcher requires access to patient's biopsy samples. The researcher is interested in hearing the Dragon's opinions on specific questions that are important in this research.*

4

## **Value of patient representatives**

- Patients have a unique lived experience of their condition and can provide valuable advice. Although this research is specific to pancreatic cancer, feedback and advice from all cancer patients will be very beneficial and will inform key aspects of the research namely:
  - Obtaining and using patient tissue
  - Insights into the best route to bring patient biopsy- based personalised medicine to the clinic

**Participants at this event came from a variety of backgrounds - from directly and indirectly experiencing cancer to more clinical perspectives. Despite being not pancreatic cancer focussed, questions posed were relevant and of interest to participants facilitating a more holistic feedback and response.**



*Personalised drug screening for pancreatic cancer*

# Room 1 – Personalised Drug screening for pancreatic cancer

## Questions

1. How willing would patients be to provide a tissue biopsy for research purposes?
2. How willing would patients be to undergo an additional fine-needle biopsy for research purposes?
3. What are your thoughts on having tissue grown in the lab for research and drug screening purposes?

## Patient response

A large portion of patients are keen to understand more, and are open to getting involved with cancer research. By providing patients with clarity on the risks and tissue purposes, this would make donation very likely. Patients have key concerns;

- Early awareness of research activity is essential.
- This could be achieved by simply having leaflets/posters within the hospital
- Following diagnosis/consultation, patients could be asked if they would like to hear about relevant research, if yes be provided with information and recruitment details

*This would give patients more time to process both clinical aspects of their illness and idea of participating in research*

*This opportunity to read about research allows patients to make an informed choice, ask questions and decide themselves without pressure from physician*

- More control, for patients
- Meaningful consent

## CHALLENGES

There might be a need to approach the patients before they have a confirmed diagnosis, this may be distressing for patients

Delivery of information/consenting a patient may be concerning

Ensure clarity of information regarding research, less technical information and replace with language that is easy to read and understand

## DRAGON solutions

Thoughtful interactions with patients, ideally clinical research nurse or GP to inform the patient in advance that they may be approached about research

Patients should ensure they speak to a trusted individual, e.g. a clinical nurse or GP, also there should be an opportunity to have additional support of a family member or friend in attendance

Ensure patients fully understand the research, have time to process the information and have an opportunity to ask questions



*Communication of research outcomes following patient participation is very important. It improves the overall experience for patients to know how their actions have benefitted the field of cancer research*

## Room 2 – Home Management of Neutropenia, a side effect of Chemotherapy

1

### **Problem statement**

- Neutropenia is the condition that results from having low levels of neutrophils – a type of white blood cell needed to fight infections.
- Chemotherapy can induce neutropenia which impairs the immune system of patients making them susceptible to infections.
- This condition, called febrile neutropenia (FN) is associated with high body temperature and is an oncologic emergency.
- Patients with febrile neutropenia have to be hospitalised, treated with antibiotics. The mortality rate associated with FN is 21%

2

### **Opportunity to detect early**

- FN is currently diagnosed in hospital through blood tests, patients need rapid treatment to prevent sepsis and death.
- There is no monitoring system currently to detect neutropenia at the time of onset in the home setting.
- NEUTRO-PREDICT is a device currently in development to allow patients to monitor their neutrophils at home.
- The device will enable earlier detection of neutropenia before the onset of fever This will enable treatment to be commenced in an outpatient setting thus reducing cost of hospitalisation, reduce overuse of antibiotics & growth factors and enable scheduled chemotherapy treatment to continue thus maximising treatment outcome.

3

### **Response to previous PVCR Feedback**

- Following on from previous discussions, a mobile application to support the device and its use is being developed
- This APP will provide information and support needed by patients about neutropenia and avoiding infections.
- Other considerations that could be included on the APP are temperature and heart rate to complement the existing blood count measurements used to detect the onset of FN

### **Objectives of collaboration with Dragons Den**

1. To get a better understanding of the usefulness of a near patient, easy to use blood cell counter for patients at risk of developing FN.
2. How effective this device is in managing the side effects of chemotherapy, avoiding risks of developing infections and fever.
3. What features do participants want to see in the device to make it more useful.



Management of neutropenia at home

## Room 2 – Home Management of Neutropenia, a side effect of Chemotherapy

### Questions.

1. What information is available from the hospital about the side effects of chemotherapy particularly risks/ consequences of developing cytopenia and its management?
2. Did patients feel at risk of developing complications due to neutropenia during their treatment?
3. Would patients be interested in a hand- held blood cell monitor to use at home to monitor their own bloods following chemotherapy?

### Patient view of hand held blood cell monitor for home use following chemotherapy.

- General consensus that such a device would be useful.
- It would save time and resources for patients who travel to hospitals without knowing the status of their neutrophils.

### Patient response

- Many of the patients participating in this debate did experience neutropenia post chemotherapy.
- One participant cited poor information/ communication about neutropenia following chemotherapy in the oncology unit. The participant was treated by nursing staff and did not meet the oncologist.
- Other participants cited the impact of having neutropenia in terms of delayed chemo schedules, and the requirement for regular blood tests to check cell counts.
- There is a significant drain on resources for patients having to have regular blood tests, time to attend the oncology clinic, and cost of bloods if accessing GP.
- Some patients were actively treated to prevent neutropenia but still developed neutropenia even 2 years post chemotherapy.



it would be amazing to be able to track neutrophils myself with the device rather than going to the GP or hospital.



For paediatric patients it is stressful travelling to Crumlin. This device will give control to patients, and make it easier



It costs €50 to get bloods tested at the GP post recovery. The blood test should not be cost prohibitive once chemotherapy is complete and patients are discharged



*Neutropenia is a significant issue for patients, most patients cited examples of how neutropenia affected their treatment. A device that can forewarn patients of development of low white cell count (WCC) would be beneficial*

# Room 3 – IMPROVER – Involving Men with Prostate cancer in Engaged Research

1

## **Problem statement**

- Prostate cancer is very common in Ireland affecting one in six men.
- Research is currently ongoing to develop a better way to detect aggressive prostate cancer from a simple urine test (epiCaPture)
- EpiCaPture can catch nearly 90% of aggressive prostate cancer.
- Researchers working on EpiCaPture now wish to engage with end users of this potential new test: men living with prostate cancer and their doctors, ensuring a representative sample in terms of geographic spread and mix of different socio-economic profiles.

2

## **How this research will help cancer patients**

- The researchers wish to learn from end-users about their needs, opinions and feed this into the development of epiCaPture. This will ensure that epiCaPture will make the process of prostate cancer diagnosis as patient friendly as possible.

3

## **Value of the patient perspective**

Feedback from patients provides insights from the patient perspective. This will enable the researchers to build questions that can be posed to the larger cancer community.

The focus of the questions will be to get a perspective from cancer patients on a national scale as to what should be addressed in the field of testing.

This will help bring a test that can address any of the unmet needs and stressors patients encounter on their journey

4

## **Discussions in advance of formal meeting**

Participants had many contributions in advance of formal questions posed by the researcher. Many different experiences shared by participants which suggest a lack of standardisation in the approach used by GP's

## **Discussions before meeting**

- Why do we go straight to biopsy? We should do MRI before biopsy. If epiCaPture and PSA can catch 100% of aggressive prostate cancers, the next step would be to go to MRI, and only then should we go to biopsy.
- What was missing from my cancer journey was 'how do you feel' in spite of amazing treatment.
- I had my PSA tested at 60 by my GP but I had no idea what it meant. I had no idea why I was attending a specialist about other than one of my blood tests was a little abnormal



IMPROVER – Involving Men with Prostate cancer in Engaged Research



# Room 3 – IMPROVER – Involving Men with Prostate cancer in Engaged Research

## Feedback sought from patients

1. How can we improve the experience of testing for the patient while using a urine test?
2. What is the ideal method and manner of informing patients of a test result
3. What is the current timeframe between providing a sample for testing and getting the test result? Would shortening this timeframe change the experience?
4. From experience, are there any areas of the process of testing and diagnosis that could be improved?

## Feedback from patients

There are many areas where the patient experience can be improved upon based on feedback of participants:

- ✓ Long waiting times to get results back
- ✓ Many examples of tests being repeated - prolonging anxiety for patients
- ✓ Lack of explanation of specific procedure/ reasons
- ✓ Uncertainty of moving between different phases of prostate cancer and different treatment schedules
- ✓ Feeling that GP's are not expert enough, over reliance on age profiling so younger patients not considered for Prostate ca in spite of elevated PSA
- ✓ Time spent doing tests before specific prostate cancer testing, patients believe that is is valuable time that is wasted.
- ✓ Little support/ information for patients in the early stages which creates anxiety.

- ✓ Participants believe that there should be an opportunity for the patient to be accompanied by a relative, patients don't always hear feedback from consultants, so a second person would be helpful in relaying back aspects of the conversations.
- ✓ Information should be provided in a way that is understood by patients, although the numbers are important, clear explanations should be provided of the meaning of these numbers and what they mean relative to the progression of the prostate cancer.
- ✓ Lack of holistic approach was cited by patients with co-morbidities, seen by different medical specialities each focused on their specific expertise, no coming together in a holistic way to understand how each condition may impact the other.



my main stressor was the type of treatment I would get, I spent a lot of time researching treatment options, and getting additional opinions



Information about epiCaPture test will be useful, where will it be done,- GP office or Consultant?



The process of diagnosis was more stressful than the treatment. When you have other comorbidities such as diabetes, liaising with different specialists was unsatisfactory.



I have an issue with age profile, spent many months with advanced form of Pr Ca, but GP kept saying my high PSA was prostatitis or a UTI



*Communication of diagnosis and management is an important aspect, lack of proper communication by clinicians and poor understanding by the patient leads to increased anxiety and negative experiences for patients*

# Room 3 – IMPROVER – Involving Men with Prostate cancer in Engaged Research

## Feedback sought from patients

1. In your opinion what would make a significant difference in the stage of being tested ?
  - a. Shorter wait time?
  - b. How the results are presented?

## Other aspects to consider:

Participants provided very useful insights in terms of their experiences of how a Prostate Ca diagnosis was communicated to them.

The wait time seems to be a function of testing. If patients are better informed, if they understand what numbers mean, and if the journey and where they are at is clearly explained, they will better understand the timelines involved and can question deviations from what they are led to understand in terms of such timelines.

## Feedback from patients

There are many areas for improvement in terms of communication. Waiting times are a function of testing, but better explanation at all stages and what to expect are considered important by patients

- ✓ Speak more in layman's terms – there is a lot of 'the number is this, the number is that'
- ✓ There are always other options – even treatments not reimbursed/ available in Ireland but it is important that patients are provided with other alternatives.
- ✓ There is some onus on patients to ask questions to the clinician. If the clinician does not know the needs of the patient, it is difficult for them to respond with specific answers
- ✓ Appears to be a lot of inconsistency among GP's in terms of criteria for diagnosis, some GP's are over-reliant on AGE profile even with high PSA.
- ✓ The process needs to be streamlined, made easier - availability of epiCaPtture with PSA will be a welcome 1<sup>st</sup> step.
- ✓ There should be another family member in the room to listen to the consultant.
- ✓ A system that allows the GP to refuse a request from a patient for a PSA should be changed



'I arrived at the GP's office not knowing what PSA was – questions I had were – do I have cancer? Counciller/ nurse present to answer questions would have been great'



'The most important facet of prostate cancer to get in early and detect early?'



'Things needs to be streamlined and made easier, many men will not push for PSA test, DRE not always done properly. PSA +epiCaPtture together is 1<sup>st</sup> step in improvement, 2<sup>nd</sup> step is MRI.'



'I have no confidence that PSA will detect a development of aggressive cancer. I feel epiCaPtture will provide an avenue/ warning message that will be picked up'.



*Waiting time without knowing what is happening is commonly cited by patients, when patients do not have explanations of terminology, or how it relates to the cancer progression, that is the issue*

# Room 3 – IMPROVER – Involving Men with Prostate cancer in Engaged Research

## Feedback sought from patients

1. Would anyone have any suggestions on methods or routes for reaching the men of the country who are hard to contact? For both the survey and dissemination

## Other Considerations

Participants also expressed the importance of focus on 'living well' beyond treatment, this is where employers are interested. By offering testing, it can be diagnosed earlier which is a good thing

'Medical community need to be on board – perhaps there is perception that PSA tests can lead to overtreatment which is why we don't have screening programmes for prostate cancer'.

## Feedback from patients

Examples can be taken from other screening programmes as to how to reach men who are difficult to contact.

- ✓ Use the exact same format as used for HPV, Breast check, a letter in the post for everyone on the electoral register, notification to go for a test
- ✓ Patients & doctors need to start lobbying for a screening programme- make representation to politicians to get it written into GP guidelines
- ✓ Movement from the ground up – empower men & their families through information- men's sheds, active retirement groups
- ✓ Work with ICS and Marie Keating Foundation to advocate, provide information and encourage men to participate
- ✓ Use of public figures to get the information out there, promote epiCaPture.
- ✓ Target large employers to provide testing/ health insurers offer as upfront investment of provision of the test.
- ✓ Advertisement campaign, improve national awareness. Bring awareness to study and what is being done. Raise male public awareness of prostate cancer



'in Spain PSA can be done at the Pharmacy'.



'In the UK we are looking at how to encourage employers to come forward and offer testing for employees, it seems that employers are interested in this'



'The yearly MOT check up starts at 50-55. Need to tell patients that they can have the epiCaPture test done as part of their check up. Involvement of ICS, Marie Keating Foundation is important here.'



'In UK, PCF has a bigger profile, the logo is very visible. In Ireland it is nowhere. Simon Harris wore the pin this year – no one knew what it was'.



*'Ultimately we need to get men involved and interested in their health'.*