

# THE PATIENT VOICE

in CANCER RESEARCH

*Placing survivorship at the heart  
of the cancer research agenda*

PATIENT ENGAGEMENT EVENT

April 13<sup>th</sup> 2016

University College Dublin

DISCUSSION FINDINGS

*Organised by UCD Medicine Research, UCD Conway Institute, Systems Biology Ireland & BREAST-PREDICT  
In conjunction with Relay for Life UCD & the Irish Cancer Society*



## **EXECUTIVE SUMMARY**

Cancer survivors pinpoint problems with the current service.

Clinicians in Ireland do not provide cancer survivors and their families with time appropriate information about their disease, rarely if ever tell them about relevant clinical trials underway in the country and fail to ask them to donate tissue samples for research.

Cancer patients are not always aware of social services which they could use during their treatment and very often find they have little support when the acute phase of their treatment is concluded.

The burden of treatment is higher for patients living outside the main cities, who may require one person to drive them to hospital and another to care for their family.

These points emerged from discussions among over 100 cancer survivors and their families at a meeting organised by the UCD Conway Institute in April, 2016.

Patients and their families said they want doctors and nurses to remember that cancer patients need different information at different times. Some want all information at the time of diagnosis while others are too overwhelmed to take it in at that stage. Information needs also vary according to the patient profile, age, the nature of the disease and the stage at which it is diagnosed.

Many patients would wish to participate in clinical trials but thought they were only taking place in the United States and said that protocols should be introduced to ensure that information on relevant clinical trials in Ireland are provided to each patient before treatment is initiated.

Patients would be only too happy to provide tissue samples for research and suggested that consent forms for tissue donation should be integrated with the forms signed before the start of surgery.

They also felt that there should be a re-balancing of the Irish research portfolio to reflect the entire cancer journey from prevention to treatment to survival from what is fast becoming a chronic disease.

## **KEY RECOMMENDATIONS**

### INFORMATION

- More and better information should be delivered in a time appropriate and personalised way that takes accounts of the patient's specific circumstances.
- Print information should remain an important source of information.
- Clinicians should identify reputable internet sites for patients.
- Information should be provided on social services available for patients.
- Better information on cancer should be provided to the public.

### SUPPORTS

- Account should be taken of the burden of treatment for patients living away from the main treatment centres.
- Clinicians should focus on quality of life and coping strategies for living with cancer as well as treatment.
- Support should be provided for patients who have finished their acute treatment.

### CLINICAL TRIALS

- Protocols should be introduced to ensure patients are aware of all relevant clinical trials.
- Where consultants are not aware of a possible treatment plan they should portray a way forward where patient and clinician would work together.

### RESEARCH

- A research culture should be incorporated into the treatment model.
- Protocols should be developed to seek consent from patients for the donation of tissue samples.
- Patients would be happy to participate in research and to develop research strategies.
- The Irish research portfolio should be rebalanced to reflect the entire cancer journey from diagnosis through treatment to survival.

## PATIENT INFORMATION

Patients and their families said the information on cancer was out there, but patients were not getting it. The problem was in accessing appropriate information and finding someone to deliver it at the correct time, as different patients wanted information at different times.



It was felt that the way in which information was delivered and the time at which it was delivered was important.

Some people felt that detailed information should be provided at the time of diagnosis, with an opportunity to look back on it later with the help of a health professional.

*“We are not always given answers by medics.”*

*“When the consultant told me I had cancer, I lost him after that first sentence.”*

*“Some people don’t want to know anything when they get a diagnosis, while others want to know a massive amount, it is very individually based. The oncologist or care nurse should be making patients aware that there is plenty of information out there and they can get it when they need it.”*

It was agreed that when a person was diagnosed there was fundamental information which they required to help them cope with the journey which followed.

*“We should have person centred care, an understanding of the patient as an individual and come up with a treatment plan they can follow and which empowers them and supports them.”*

They said that the information provided was often of a general nature and patients were left to their own devices in finding the specific information which they required and it could be difficult for them to work out which internet sites could be trusted.



*“The information necessary may be quite different depending on your age – for example it can be different if you are 30 or have had the menopause,. It can be very difficult if you don’t fit into a particular profile.”*

*“The information can be overwhelming. How do you manage it? If you “Google” your diagnosis the information that comes up can be quite intimidating. All the information is there, but not necessarily in one particular website. Then there can be a generation gap, with some people preferring to get their information on paper rather than the internet.”*

It was suggested that patients and their families should be provided with detailed information which they could read later if that was what they wished.

*“It’s a good idea to give you leaflets at diagnosis, then you can take them away and read them afterwards.”*

One patient said her doctor recommended a website and knowing that it was a reliable one was very important. However, those present warned that not everybody could access the internet.

*“We may be wrong in assuming that everybody has access to a computer and the internet. Many don’t have access to a basic desktop and not everyone has*

*3G and we should remember this with so much work being done with mobile phones and apps. There is a question of resources being required here.”*

*“At the time of diagnosis it is hard to take all the information in and clinicians may need to provide information which is appropriate to the individuals. If the consultant feels there is no treatment out there for the condition I think he or she should tell the patient that they are not aware of treatments but together they would move forwards.”*

*“There is a total lack of support for melanoma patients. I knew nothing about the labs here until today. We use a Facebook page and I get all my information from the UK and the US networks.”*

## **Clinical Trials**

Participants said they were amazed at the number of clinical trials underway in this country. There was agreement that patients should be informed about clinical trials which were underway, but some divergence about when this information should be provided. Some participants thought all information should be provided at the time of diagnosis, while others felt that patients might be overwhelmed at this time while dealing with their diagnosis and they should be told later.

*“I thought trials were an American thing. I associate them with America because probably that is where I have learned through the media that they are being carried out. I never thought of it as an option in the 17 years I have been ill.”*

Of ten people at one table, only one was aware that trials were underway in UCD – and that because he used to work there. It was agreed that the tours of UCD Conway Institute had changed this perception.

Participants were very enthusiastic about the day and appreciative of the information it provided about clinical trials in UCD and would like to see similar events organised in the future.

*“Today has been a really good day. The patient support group with which I am involved would be very happy to be a part of research”*

*“I am proud seeing what is going on here and hopeful also. I think what is going on here should be communicated to people.”*

*“We should try and get research culture into the treatment mode.”*

*“I felt I should participate in research because others did it for me years ago. The project was well delivered and explained to me by a doctor and that made a difference.”*



Some participants felt that there could be a time issue around when information on clinical trials was provided. They said if patients heard about clinical trials many did so only when they had finished their treatment and it was too late for them to consider participation. Consultants who were not part of clinical trials might not mention them. They felt there should be a protocol whereby information on clinical trials would be delivered to every patient by his or her consultant at the time of their diagnosis.

*“Maybe it should be introduced in the gap between diagnosis and treatment.”*

*“Consultants could say ‘We recommend this as the best treatment for you, but there are also clinical trials out there.’”*

*“We know there are consultants around the country who are not involved in clinical trials and they are not telling their patients about trials and perhaps they don’t know about the trials. It should be standard that consultants let patients know that there are clinical trials ongoing and they could contact the people running them if they wish.”*

The need for additional resources in this area was identified. The comment was made clinical nurses spent a lot of time providing patients with information on their cancers and there were probably insufficient clinical nurses to hone in on clinical trials and disseminate this information to patients, especially if the trials were not in their hospitals. Another participant felt that, at a later time after diagnosis, specialist nurses could give patients details of current clinical trials relevant to their diagnosis and treatment.



## **PATIENT EXPERIENCE**

### **Support services**

Location was also important in terms of support. If patients lived in certain parts of the country, they said it could be difficult to get support services during and after treatment. The Gary Kelly Support Centre in Drogheda was mentioned as an example of a community based facility which could make a huge difference to patients' lives.

The Marie Keating Foundation was also mentioned as a service which participants found really beneficial in providing information but again there was better access to this in Dublin.

*"I have been ill for 17 years and these kind of information and support services were never mentioned to me.*

*"Lots of acute hospitals focus on treatment and not quality of life."*

*"What you really need is for somebody to sit with you and say 'I have heard what you said.'"*

*"What you need is a liaison person to take you aside, empathise with you and ask if there is anything you need immediately."*

*"I was given lots of information and each week I went back it changed, so I was having to make decisions and decide on treatment I would have and it was very hard. I found the support centres gave me further information at diagnosis and post diagnosis. You need to sit down and talk to somebody who knows about it, give yourself time to cry then find out and make your own decisions."*

One of the points which emerged from the discussion was the need for better support at discharge when patients emerged from the healthcare system

"You have been getting constant care and attention and then you go home and sit down and there's nobody around and you wonder how to cope without everything around you. There should be at least an acknowledgement from the

acute setting that you will go home and be on your own and they will try and support you.”

*“When you are diagnosed, you are assigned a cancer nurse. But afterwards when you have finished your treatment you don’t know if you are still allowed to ‘phone that nurse for the next 10 years.”*

*“Your cancer nurse may leave and what do you then if you need to speak to somebody when you have finished your treatment.”*

*“People live longer. Cancer is becoming more like a chronic disease. People often have ‘invisible’ symptoms- you can look perfectly fine but you need to manage from day to day. It is difficult especially if you have other medical conditions.”*



### **Location - Rural/Urban Disparity**

The problems of patients who had to travel long distances for treatment was raised. It was pointed out that this could add 2 – 3 hours a day and was an extra burden for people already burdened. It might necessitate family members taking days off work and for many people there was also the practicalities of child care or school runs while undergoing treatment, for example.

One participant said that if patients had a medical card they could get reduced fees at crèches while having treatment. “Again this is a question of information. When I was having treatment I needed help from two people, one for me and one for the children and I didn’t know about the reduced crèche fees until afterwards.”

## RESEARCH

It was suggested that there should be a re-balancing of the portfolio of research.

*“We would like research in treatment, but increasingly there are needs in prevention, treatment, post treatment and survivorship. We would like a portfolio reflecting the whole cancer journey. There are specific questions around how people can prevent getting cancer, prevent a recurrence or prevent it in their children. There is a lack of information for rare illness and rarer variances. Nurses could become more involved as they were at the interface with patients.”*

There were a number of suggestions about the need for coping strategies for living with cancer following the acute phase of treatment and discussion about family involvement and bringing information into the community perhaps through a transition year programme. “I would like to see more attention paid to the chronic aspects of cancer, which is something which hopefully will become more and more important.

It was also felt that there was a need to educate the public – the 2 in 3 who did not get cancer.

*“I wasn’t aware of cancer research being undertaken in UCD.”*

### **Actively Shaping Research Strategy**

Participants were very open to helping shape research strategy.

*“Patients and the public expect that research will be funded and supported in the way it should be. They are willing to participate in studies, to have their samples used and they want to sit at the table with researchers and make decisions on studies to be done and how they will be done and when protocols are done we want to be involved at a strategic level.”*

*“What is really interesting to a researcher may not be so interesting to a patient.”*

It was mentioned that in this area timing again was important psychologically.

*“You might want to be post-treatment and settled into your new reality. Some people might say ‘I never want to hear about cancer again. It’s in my past.’ There is a broad spectrum of opinion there.”*

It was also suggested that it would be a good idea if people could drop research suggestions into support centres. Generally, it appeared that people felt it a good idea to be involved as time allowed and depending on where they were in their cancer journey.



## Tissue samples

It was generally agreed that the provision of tissue samples was an excellent idea. The view of participants was very positive about donating tissue, with permission to retain and use it for as long as it could be useful for research.

People were taken aback by the fact that they were never asked to donate tissue samples and there was an overwhelming ‘yes’ to the idea of providing tissue for as long as it was useful.

It was suggested that the equivalent of an organ donor card should be made available – possibly on the Irish Cancer Society website - where patients could give permission for the use of tissue.

It was also suggested that arrangements should be made for consent to be presumed and that people could opt out rather than opting in. There was a

feeling that people would be surprised that one consent form did not cover everything

*“Everything should be integrated. Patients should own their own information and bring it with them in a user friendly way.”*

*“Most people would want their samples used. Perhaps they would not be in the best space to make decisions when first diagnosed”*

*“If we could provide tissue now, then it could be used by researchers in 5 – 10 years.”*

*“When you are signing a consent form for surgery, you could sign another one for pathology.”*



## **APPENDIX 1: QUESTIONS**

### **PATIENT INFORMATION**

1. Do you believe there is easy access to information and/or data on clinical trials in this country?
2. Is the available cancer literature pitched appropriately?
3. Has the information available through the internet been useful in relation to your diagnosis and journey since that time?
4. Which apps have you found most helpful in relation to your diagnosis and subsequent journey since your diagnosis?

### **PATIENT SUPPORT**

5. Do you think overall cancer care and the patient experience depends on where you live in Ireland?
6. What supports would have helped you once your treatment was completed?
7. Did you get the supports you needed when you were initially diagnosed and what/was/would have been particularly useful?

### **PATIENT INVOLVEMENT IN RESEARCH**

8. Is there one area of research that you believe should be funded? What is the one question with regard to cancer that you would like to know the answer to?
9. Were you aware of cancer research being undertaken in UCD before your visit today?
10. Have you been asked to donate samples for research? If you would agree to donate, would you be willing to give open/blanket consent for the use of your samples?
11. Would you be interested/willing/able to spend some time on shaping research, in other words not participating in a study, or being asked for a sample, but having an active role in shaping research strategies?

## **APPENDIX 2: FACILITATORS**

### **MCs**

Marie Ennis O'Connor (patient advocate)

Claire O'Connell (freelance journalist)

### **Table Facilitators**

Robert O'Connor (Irish Cancer Society)

Eibhlin Mulroe (CEO ICORG)

Sharon O'Toole (St James' Hospital)

Claire Kelly (oncology nurse)

Patrick Slevin (INSIGHT)

Anne Cody (Health Research Board)

Elaine Kelly (patient advocate)

Derick Mitchel (CEO, IPPOSI)