National Cancer Registry of Ireland

Patient Voice in Cancer Research

Patient Workshop & Discussion Groups

10th April 2019

Darmah Market Research

CONTENTS

SLIDE NUMBER

1. EXECUTIVE SUMMARY

The National Cancer Strategy 2017-2026 sets out the vision for delivery of cancer services in Ireland.

Central to the strategy is that services be in place to better serve the needs of cancer patients. Future support services can be **enhanced through a better understanding of patient needs**. The future challenge will be to serve the growing numbers of cancer patients with needs based services. The present issue is how to recognise and evaluate their ‘unmet’ / ‘unidentified’ needs.

In this regard, National Cancer Registry Ireland (NCRI) held a workshop with a PVCR patient forum as a **precursor to a more extensive research programme with a target size of 10,000 patients**. The aim in the extensive research programme will be to listen to cancer patients seek to understand their experiences, help reveal unmet needs and better understand the types of supports and services that can benefit them.

The **PVCR Patient Workshop was undertaken as a planning initiativ**e. Hence it allowed the NCRI consult patients and thus better inform the design and methodology for use in the subsequent extensive research programme. The NCRI in planning for an extensive research programme needs to understand:

- How best to recruit high numbers of patients for the research;
- How to contact the patients and what might be the most appropriate channel to reach patients;
- How best to capture areas of unmet needs
- How to keep patients engaged during the research programme;
- What aspects may pose sensitivities for patients / patients and how to manage such sensitivities;
- How best to facilitate differences and preference across a large diverse group that may represent patients.

A successful NCRI needs high levels of patient participation and involvement. The workshop provided the NCRI with clear feedback, namely:

- Patients were unaware of the existence of the National Cancer Registry; A key action for the NCRI will be responding to the challenge that **patient awareness of the NCRI is low**. A programme to activate the NCRI brand and purpose will need to be prioritized. This needs to happen before there is a big call for patients to become involved.
- Patients believe access/invitation to the research programme should be universal where patients can choose to opt in or opt out;
- Most Patients are not in favour of a screening selection mechanism administered by the doctor or the healthcare professional, however there were some views that the input of the managing clinician would be beneficial.

1. EXECUTIVE SUMMARY

- Patients welcomed the opportunity to be involved in both the research and the consultation process;
- Patients considered their views and experiences to be important and issues such as unmet needs, which change over time, should be further explored;
- Patients were positive to the idea of being represented on a potential 'governance forum' such as steering committee which may review results when establishing recommendations / actions plans;
- Patients were also positive to the role of 'patient ambassadors' and how such a role may be active in the cascading of research findings across the patient / survivor community;
- Patients were supportive of contributing to future studies and on-going engagement with the NCRI in patient/survivor follow on work;
- NCRI recognition that situations can change and that patients would have the freedom to opt out at any point;
- Patients were empowered at the idea of being a central stakeholder in the development of recommendations and being part of an extensive research consultation programme;
- Practical matters, such as patient confidentiality, need to be managed properly;
- The avoidance of mistakes, such as erroneous mailing lists, was considered a priority for patients;
- The research programme should represent a broad range of patient types and not just a narrow sample of cases. This needs to be reflected in the patient recruitment process
- The research method needs to be multi-dimensional in nature, so that patients can choose how they participate, whether it be through surveys, focus groups or qualitative interviews. Patients expressed that interviews be conducted in a supportive environment involving appropiately trained interviewers.

2. Context and background

This document sets out summary findings from a workshop held at the Conway Institute in UCD on 10th April 2019. The workshop carried out on behalf of the National Cancer Registry Ireland (NCRI) engaged cancer patients to discuss and inform the plans and approach for engaging /reaching out to a large base of 10,000 cancer patients.

The workshop participants were divided into 8 tables with approximately 10 at a table who discussed a specific question. In total 6 questions were discussed with 2 of the questions debated/discussed twice.

Each table discussion was supported by a table facilitator and a table scribe, with the facilitator tasked with managing the discussion among the participants around the table while the scribe documented the responses. The structure of the workshop allowed for a 1 hour discussion at each table on their respective question. This 1 hour table discussion was followed by 1 hour of feedback where the Chair of proceedings asked each of the tables to report / summarise the views expressed. The feedback was provided by the table facilitator. Hence the workshop spanned 2 hours, 1 hour of table discussion followed by 1 hour of table feedback.

The six themes/questions considered were:

1) How best to contact study participants
2) Handling the survey and patient information through the use of 3rd party companies to support the survey
3) How best to measure cancer patient ‘unmet’ needs
4) The survey design and content
5) Analysing the survey results and disseminating the findings to patients and key stakeholders
6) Patient engagement with the NCRI going

2. Context and background

The workshop provided the NCRI with an **understanding of the importance of patient participation**, reasons why patients wish to participate and how their participation can inform the needs to be considered in the large survey. Additionally the **NCRI heard about patient concerns** in areas such as data privacy, patient choice, attitude to consent, patient involvement in the dissemination of results, patient attitudes to survey tools / survey forms / online surveys / focus groups.

Based on the findings from the workshop the NCRI now has clarity on:

- The most appropriate approach to contacting / selecting / inviting patients to participate in the extensive research study;
- The acceptance of a professional 3rd party mailing company as a partner with the NCRI in conducting the research from patient contact to collation of findings;
- The importance of a reputation and trust on the part of the NCRI and any third party company that is used;
- Most significantly, the NCRI is not a recognised organisation, there is poor awareness of the organisation , they don't appear to have a profile, this was a recurrent theme throughout the workshop.
- Thus the NCRI needs to promote itself in advance of any survey to ensure such a survey has strong recognition among patients;
- The workshop provided clear understanding on the views, preferences and concerns of patients.

In summary the workshop found patients to be broadly supportive of the need for research and positively disposed to participating in studies both now and in the future. They expressed a view to have **choice** and be given the **option to opt in or opt out of survey work or NCRI communications**. Although many patients expressed the view that they are not in favour of doctors deciding on which patients should be invited or selected for surveys, some patients did acknowledge that the input of the managing clinician In recruitment of patients would be important. The main issue for patients is that their data is not compromised and procedures on data protection and confidentiality are fit for purpose.

If the NCRI is to be successful in achieving its mission and purpose, strong consideration needs to be given to the findings outlined above.

3. Key themes / findings

1. NCRI is not well known to patients;
2. NCRI needs to build profile and awareness among patients;
3. Patients welcome the opportunity to participate in research;
4. Patients wish to have the choice regarding participation in research, many are not in favour of a system where doctors might make the decision on which patients to select for the research ;
5. Patients wish to be involved throughout the research cycle, be active in establishing any findings and have a role on the dissemination of findings / recommendations;
6. Patients welcome the idea of there being patient ambassadors or ‘lead patients’ who can represent patients on steering committees and governance forums;
7. Patients emphasise the need for the proper policy and procedures which ensure issues such as data privacy, patient consent, patient confidentiality are not breeched;
8. A 3rd Party mailing company would be expected to comply with such policies and procedures;
9. A variety of methods should be used so that a wide range of patients can be included in the research;
10. The research programme should cover a range of patient experiences, a range of patient journeys and different patients such as metastatic , prostate cancer and lesser known cancers, cancer of unknown primary.
11. Patients are happy to form an on-going relationship with the NCRI and be involved in future studies;
12. However patients should have the right to choose to opt out if they so wish at ANY point in the future.

4. Summary of key findings

Patient recruitment

Patients have universal access

The choice is with the patient

Patients can opt in or opt out

Opposed to doctors managing the selection of patients

Contact strategy / engagement considerations

Maintain patient confidentiality

Avoid mistakes on communications

Put in place policy & guidelines

No objection to the use of a 3rd party mailing company

Policy to manage data privacy / consent

Patient attitudes

Happy to participate

involved beyond the initial phase

Involved in developing the findings

Favour the idea of patient ambassadors

Patients sit on ‘steering committees’

Use a range of methods

On-line questionnaire

Paper based questionnaire

Focus group discussions

Face – to – face interviews

Telephone interviews

Future involvement / subsequent studies

Patients happy for on-going engagement

Recognise patient situation can change

Patients should have freedom to opt out

Patients have many unmet needs and involvement with NCRI will allow them to articulate these needs

Inclusive

Avoid a narrow sample set

Ensure a wide range of patients participate

Terminology needs to be inclusive

Metastatic, prostate, rare cancers.

Build awareness of the NCRI

4. Summary of key findings

NCRI is an unknown organisation

The lack of awareness of the NCRI was a constant theme throughout the workshop.

The message that the NCRI is an unknown organisation was unprompted, and emerged in several different discussions and contexts eg :

- Participant views about the NCRI contacting them directly - no awareness of NCRI
- Questions regarding where survey/ responses goes back to - no awareness of NCRI
- The importance of their data, who has their data - no awareness of NCRI
- In terms of future involvement with NCRI – no awareness of NCRI

Given the lack of awareness of the NCRI among the participants, it will be necessary for the NCRI to consider the views of the participants.
The NCRI may need to address certain aspects to become a 'proactive' body with a high profile and visibility , one that patients can immediately identify with, want to engage with in the knowledge that they may be helping future cancer patients.

5. *Themes discussions at the workshop*

IN-DEPTH FOCUS GROUP DISCUSSIONS

No awareness of the National Cancer Registry

NCRI needs to increase their profile

- One of the themes to emerge early in the discussion among tables was the lack of awareness of the NCRI .
- Participants were not aware of the presence of the NCRI, they do not know what they do, what information/ data they collect and what is done with this data. The issue of no patient specific materials /information on the NCRI website was also raised.
- This lack of awareness may be problematic should the NCRI carry out a Patient survey involving 10,000 cancer patients in Ireland. If potential participants are not aware of the agency who are conducting this research, it is likely that the survey may not get the required participation.
- In terms of patient engagement with the NCRI, it was clear throughout the meeting that the NCRI firstly needs to raise their profile, they need to outline their purpose , and their wish to collaborate with patients. Promotion of the value/benefit in undertaking a national survey would follow from this , promotion of the patient survey might be akin to the Central Statistics Office promoting the National Census of the population. Therefore it is considered necessary for the NCRI to run some campaigns across different media forms, e.g. radio, print, TV. These promotional messages should highlight the value in a national organisation such as the NCRI working with patients to establish facts and finds insights that can help plan future support models and services that better meet patient needs.
- Participants felt it is imperative that patients are involved with the NCRI going forward in order to inform decisions of the NCRI. As such they are happy for ongoing engagement in the future. If patients are fully aware of the NCRI, they can choose to contact them at any time

Patients want the choice to participate

Appropriate contact strategy / how best to contact patients for participation

- Patients prefer to be part of an inclusive process with the choice to opt in or opt out. Patients favour this over the idea of a system where the doctor screens patients for inclusion in a survey. Many patients were not supportive of the suggestion that the doctor might pre-select patients to participate in a survey, other feedback suggested that the input of the managing clinician would be helpful to ensure there was the required response to the survey. There was consensus that a survey should be open to all patients.
- Patients feel empowered by having the choice to participate in a survey. Patients did not believe it was reasonable to exclude people from the survey based on a level of disability or age.
- Patients are quite happy to be contacted directly by the NCRI and happy to receive an invitation to participate from the NCRI. Given the lack of awareness of the NCRI, it would be important that this issue be addressed in advance of commencement of a survey.
- Also the manner in which the patients are contacted needs to be treated with some sensitivity, for example there needs to be some consideration to the name / stamp on the envelope and some discretion as to what identification appears on the envelope. It was considered that the Irish Cancer Society might be an appropriate entity on an envelope, it is a well known organisation. It is considered important to have an official logo/stamp on a letter as it denotes a level of importance / officialdom.
- The view was there was no necessity for the Doctor's name to be on the invitation. The preference was that the letter / invitation be issued in a more anonymous manner.
- The most important thing for a patient is that the details on the letter be correct and there should not be any mistakes. Hence any information on the patient should be correct with no indication that patient information can be compromised on the basis that information has mistakes. Patients are indifferent as to whether they are addressed by title, forename or surname. The key message being that the letter / invitation be free of mistakes.

Patients want to be kept informed of the process,

Method of engagement

- Patients were not opposed to the NCRI using a 3rd party specialist mailing company firm to manage the field work associated with undertaking a large survey of the proposed scale. Diligent processes , adherence to high standards in terms of patient information, patient confidentiality and data protection are key criteria in selecting a 3rd party .
- The view was that patients should be contacted from within Ireland and by a company based in Ireland.
- Patients highlighted the need for clear guidelines to be followed and careful steps taken to ensure no patient information is compromised. Hence it is appropriate that the NCRI drafts and develops a specification / terms of engagement which a 3rd party would be expected to comply.
- Thus the NCRI would need to evaluate a 3rd party provider on the basis of demonstrating credentials and assurances that high standards of data privacy/data protection can be maintained.
- It was considered important that patients would have clarity on the process and the steps as part of the survey. Patients would need to understand the purpose of the survey, the steps being taken post submission of the survey and the timelines from issue of the survey invitation through to the dissemination of results. Hence any correspondence would need to provide such transparency.
- There was some debate as to the merits of splitting the communication with patients into 2 steps. In the first instance all patients could be notified about the plan to undertake a survey and asked if they wished to participate or not. The second communication would then see the NCRI issue the survey to those who choose to participate. In this way some sensitive concerns might be avoided such as sending a survey to wrong patients.
- It was suggested that an awareness campaign be run in parallel with the survey or in advance of the survey. Patients believed it was necessary to raise knowledge and awareness on the role and activity of the NCRI.
- It is very important that the NCRI and partner companies have a high level of trustworthiness.

Importance to understand patient needs at each stage

How best to measure/capture unmet needs

- Patients acknowledge the value in better understanding their needs.
- There is a recognition that needs change throughout the patient journey, the needs post diagnosis in the early treatment stage differ to those in later treatment and post treatment.
- All patients are negatively impacted financially. Self employed people are particularly challenged, other considerations are childcare costs, car parking, lunch/ food. People returning to work having had cancer also experience difficulties and challenges for example in dealing with insurance companies.
- Post treatment , patients experience side effects such as fatigue, stiffness of joints, dietary issues, fertility, menopausal symptoms, psycho-social issues. These often occur after patients are discharged, sometimes there is little acknowledgement of existence of these side effects which impact patients. Support mechanisms sometimes do not exist for these patients.
- In the early treatment phases, the sense is the patient should have greater involvement in their care plan, their treatment pathway. During this stage, access to tests and diagnostics is seen as very important, as information and knowledge can better inform treatment plans.
- Patients were open to the idea of participating in focus groups. The patients saw the focus group as a forum where needs could be explored with discussion helping to reveal ‘unmet’ needs. Face to face interviews, telephone interviews are also good, a key requirement for a interviewer is to show empathy and understanding when conducting interviews with patients.
- Patients pointed to the role of existing networks and how these could be leveraged to help reveal needs.
- Qualitative research such as focus groups, telephone interviews , face to face discussions, needs to involve patients across different geographies/regions, include different patients profiles , stages of cancer, be inclusive and patients consider it important that language used is appropriate.

Conducting the survey .

Survey design and content

- Initial discussion would suggest that common themes for coverage might include: advice on exercise; dietary guidance; counselling services; financial planning; managing stress; coping with anxiety; access to information; support on speaking to healthcare professionals; understanding the medical language / assistance with medical terminology; return to work; reduced work; side-effects; self assured approach at medical appointments; satisfaction with medical appointments; help in the home; childcare needs; etc.
- There was not a definitive view that a questionnaire should be a certain length. However it was suggested that if the survey was completed on-line then it should be possible to partially complete with the functionality to save and return later to finish the survey, once all parts are complete do the final submission.
- A suggestion was that a "helpline telephone" number should be on the survey which would allow the option to speak to an advisor. Hence this would serve as a "staff assisted" support in the case of a patient completing the survey who might seek assistance.
- The view was older person may prefer to complete the survey on paper, while younger persons may choose the online option.
- If the survey is completed online there would need to be a process for patients to submit email details to the NCRI. The NCRI would need to ensure data security controls are robust and information is secure.
- The use of an information sheet as part of supporting document to accompany the survey was seen as beneficial. Patients held the position that information should be transparent and it is better if participants know how the information will be used, the timelines involved and how the results will be disseminated as well as the value / impact of the survey work.

Patients as partners

Dissemination of survey results

- Patients strongly express the view that they need to be kept abreast of the survey findings and their participation be acknowledged in having access to the survey findings and visibility that their participation has been used as an input which will inform a programme / future strategy.
- The patients should be offered a choice regarding their preferred form of communications be it letter, post, email, online link, symposium, network event, mobile app, a members login area on website for participants, etc.
- Patients may be interested in receiving published reports / journal articles.
- Patients should not be at a loss financially from being involved in the study.
- Patients should have access to progress updates at time intervals and there should be communications as to the next steps.
- An option may be to use a cohort of patients to cascade findings through their support networks. Hence some patients could act as lead patients or ambassadors in helping coordinate the cascade of findings across patient groupings/patient networks. This may serve as a good conduit between patients and the NCRI. The role of a lead patient or patient ambassador would be voluntary and the patient's choice.
- Patients welcomed the idea of being involved in the knowledge transfer to healthcare professionals / health stakeholders e.g. Department of Health and HSE. Patients are happy to have a role in supporting the transfer of knowledge and bringing a patient voice to the forum. Essentially the survey gathers the insight from patients and as such represents the perspective of patients. Thus some representatives of the patients (ambassadors) could support the message delivery to key stakeholders engaged in service delivery i.e. HSE , Department of Health.
- Patient representatives could be part of a steering committee working on the results / survey findings or be part of an expert panel supporting the dissemination of results.

Ongoing engagement with NCRI

On-going patient engagement with the NCRI

- Generally participants were of the view that patients must be involved with the NCRI, their involvement can provide important information from the patients perspective in a broad range of areas.
- The NCRI may consider different approaches in order to include difference preferences across patients, and differences depending on the stage on the patient journey. Hence many forms of media can be used to foster patient engagement such as traditional mail shots, traditional newsletter materials, social media, mobile media, online links, online surveys, information clinics, mobile pop-up stands, seminars, posters at GP clinics, etc. Treatment centres were considered suitable as patients are waiting for their treatments, so they would read any information that they believe would be of benefit to them.
- The NCRI needs to consider the different situations that might stimulate patients to engage with the NCRI and therefore needs to consider designing a long-term patient engagement strategy, for example how often is appropriate for patient contact, what media form is appropriate, how should the type of message / type of content influence the choice of media used, what message content should underpin an engagement model.
- While the NCRI needs to know what it requires from patients, the NCRI needs to establish what patients want from the NCRI, for example patients may want information, patients may want access to support, patients may want advice or guidance.
- The frequency of engagement is important and the NCRI needs to take a long-term view and have a model where it can engage with patients over the life cycle and ensure it covers patients 1 year post treatment, 2 years post treatment, 3 years post treatments, etc.
- Patient panels are considered valuable. The benefit being that patients has lived the experience on the cancer journey and have the insights into the challenges experienced.