

National Cancer Registry Ireland

Towards Routinely Capturing the Cancer Patient Experience



A consultation with
Patient Voice in Cancer Research

Policy Response

2nd July 2019

Introduction

On the 10th of April 2019 a Patient Voice in Cancer Research (PVCR) workshop was jointly hosted by the National Cancer Registry (NCRI) and PVCR in University College Dublin. The aim of the workshop was to inform cancer survivorship needs assessment research which will be conducted by the NCRI. This research will include a large nationwide survey on the unmet needs of cancer survivors. The results of this research will also help the NCRI develop methods on how to best capture the cancer patient experience on a routine basis. The key talking points and themes from this meeting have been published in an accompanying independent report. This brief report summarises the NCRI policy response to address the issues raised by PVCR.

Key themes

Lack of awareness of the NCRI

There was a consistent message from across PVCR that the NCRI is not well recognised among patients and there is little awareness of their role in cancer data collection, cancer services and research. The NCRI are aware of their limited public profile and accept that it is important that it is enhanced both to successfully undertake a national cancer patient survey and to ensure patients have knowledge of how their data is being used. To address this, the NCRI will commence with a public engagement meeting in Cork on October 8th 2019. Patient groups, patients and public representatives will be invited. The NCRI will explore how public awareness can be raised nationwide on an ongoing basis with the Department of Health.

The NCRI will also endeavour to enhance its service to the patient community by development of resources that are specific to patient needs, in particular the NCRI shall review its website content with a view to making it more useful and accessible to a broader audience. Materials will also be developed to explain who the NCRI is and what its role is.

Routine Patient involvement

During the course of the meeting it was evident that the NCRI require regular patient involvement to support best-practice decision making and research planning. To address this the NCRI will establish a Patient Panel (this panel will be representative of cancer patients in Ireland in terms of age, geography, disease and demography). The NCRI will seek the advice and support of PVCR and other patient led groups in the establishment of this group both in terms of logistics and governance. This group will guide the development, rollout and dissemination of the National Unmet Needs survey to ensure its relevance and to maximise participation and impact. Consideration will be given to how the NCRI can ensure the voices of carers, parents and other family members of cancer patients can be represented in the NCRI. A Patient Panel shall be particularly important in guiding the following:

Language

A common theme from participants at the PVCR was the appropriate use of language with regard to patient involvement and survey activity. In particular the appropriate description of participants (e.g.

patients or survivors) and the phase of their care (e.g. survivorship) was highlighted. The NCRI will consult closely with patients to ensure that language is appropriate and acceptable.

Choice

It was evident that participant participation in surveys should not be treated as a “one size fits all” approach, this relates to the completion of survey forms, participation in further research, receiving outputs and in their involvement in dissemination and communication of research findings.

- This research will be designed to ensure that survey participants can complete a brief survey or more enhanced survey depending upon their willingness to give their time to participate.
- Furthermore, participants will be given the choice to receive reports from the research and participate in further research studies.
- Patients will be invited to work with the research team in interpretation of findings as well as contribute to the communication and distribution of research findings.

The participant role

It was evident that there is both a desire and a need for patients to be involved throughout the research process, from design to analysis and dissemination. The NCRI will commit to involving patients throughout this survey. This will primarily be through the NCRI patient panel who will support research design and interpretation. In particular, patient views will be sought on issues of ensuring patient confidentiality, data security and in ensuring broad access to all patient groups including harder-to-reach groups, including those with disabilities and later-stage disease.

Participants in the survey will also be invited to become involved in the later stages of the research, particularly the distribution of the results. This will be with a view to stimulate public debate around research implications and government policy response.

Research design to maximise patient involvement

The NCRI agree that a methodology should be developed to reflect a broad base of patient groups, particularly those often under-represented in research such as patients from harder to reach groups, adult survivors of childhood cancer, those with rarer cancers, older patients and those with cancer that has spread beyond the initial site (metastatic disease). The NCRI will look into working with the patient panel and the National Adult Literacy Agency (NALA) to develop survey tools that can maximise access and use language that is accessible to those of a broad spectrum of educational backgrounds. We will consider facilitation of survey in other languages. Consideration will also be given to promoting access to those with physical or learning disabilities, however, it is conceded that cost may be a barrier to maximising access to all. Priorities shall be discussed with a patient panel.

While the NCRI will aim to contact patients around 2-3 years after diagnosis, patients will be given the option to consent to defined longitudinal follow-up (further surveys a few years after the initial survey) to monitor ongoing care needs and understand how these needs change over time. It is difficult to ascertain care needs shortly after diagnosis through surveys, as limited registry data is available, and previous studies have suggested that patients are less likely to participate in research during this time. The NCRI shall explore options as to how best to investigate care needs in this phase of the cancer journey.

Patient Participation in surveys and clinician involvement

A mixture of participant views on clinical involvement in screening patients to participate in the survey were presented. While a number of patients felt strongly that no one should be in a position to exclude a patient from the opportunity to participate in this research, others felt that clinical support would be important and may increase the confidence of patients and boost participation

rates. The NCRI shall conduct a more in-depth consultation with patients to determine the best approach.

Conclusion

The NCRI thank the PVCR initiative, Professor Amanda McCann, Ms Elaine Quinn, Irish Cancer Society, and importantly, all members of the public who participated in the PVCR NCRI workshop for their valuable contribution to informing the design of an unmet needs survey in Ireland. Their thoughtful and incisive views will help ensure a successful research plan.

For this research to be successful and to impact service change, ongoing patient involvement is a necessity. The NCRI is committed to frequent and meaningful involvement of patients as partners in this and other research work. The actions above have been embedded in the plans for the proposed unmet needs study and the NCRI would like to work closely with PVCR to establish a model for ongoing patient involvement in the research and core business activity of the NCRI.

Actions for the NCRI to respond to the PVCR feedback

Action	Proposed completion date
Meet with PVCR to work toward establishing a patient panel	Q3 2019
Establish patient panel	Q2 2020
Review NCRI website to improve patient accessibility	Q4 2019
Organise public engagement events to raise awareness of NCRI	Q4 2019
NCRI and Department of Health explore how public recognition of NCRI can be enhanced on an ongoing basis	Q4 2019
In-depth meeting with patients on arrangements 1 st contact in patient surveys	Q3 2019
Amend Unmet needs survey proposal to reflect patient feedback	Completed Q2 2019
Engage with NALA and Patient group to ensure survey design is fit for purpose	Q1 2020