Irish Cancer Society Research

Appendix 1: Key Research Questions and Deliverables

Key research questions

Researchers should respond to the research questions specifically in relation to the following groups of people:

- People aged 65+.
- People living with a physical disability.
- People living with an intellectual disability.

The Irish Cancer Society is interested in learning about the experiences of people who have been diagnosed with cancer, as well as the perspectives of healthcare providers. We would like for these experiences to be analysed in the context of the current set-up and performance of services available in Ireland, and against current knowledge of the importance of early detection. Researchers should also consider good/best practice examples of timely access to diagnostics and mechanisms for raising awareness amongst the general population. Responses to the research objectives should refer to the diversity amongst the public and patients, survivors and their families, e.g. by cancer types, age at diagnosis, gender, whether a person has a disability or requires specific accommodations when seeking access to healthcare, as well as other factors. The successful applicant should conduct research to respond to the following questions.

General

- What is the current context in terms of incidence, stage at diagnosis, survival, etc.?
- What are the benefits of early diagnosis?
- What are the financial, health and social, etc. costs associated with late and with early diagnosis?

- What are the financial, health and social, etc. benefits associated with timely access to diagnostics?
- What is the current performance against waiting list times and National Cancer Strategy key performance indicators which support early detection of cancer?

Public Perceptions

- What are the main barriers and enablers (e.g. service-level, personal, circumstantial, etc.) reported by the specified-groups or their carers (who may or may not be affected by cancer) associated with accessing diagnostic services?
    - How were these barriers overcome?
    - Are any of the enablers transferrable and sustainable?
- What do the public believe is needed to overcome identified barriers?
- Do people in the specified-groups, or their carers, feel they have enough information on signs and symptoms of cancer to know when to seek medical attention? Did people diagnosed with cancer in the specified-groups, or their carers, feel they had enough information on signs and symptoms of cancer to seek medical attention? What is the initial point of contact for health concerns or to access health information? E.g. community resources, pharmacist, internet, GP, Irish Cancer Society information, etc.
- How many times have people with a subsequent cancer diagnosis in the specified-groups had to attend a GP before getting a referral to cancer diagnostics?
- Diversity of impact: Which groups are particularly affected by lack of timely access to diagnostics services (e.g. by socio-economic group, type of cancer, age, disability, need for specific accommodations, gender, household composition, county/region, etc.)? Such impact can include emotional, financial, social, etc.

System level – healthcare practitioners and allied health professionals
Healthcare practitioners and allied health professionals include a range of roles for the purposes of this study, including but not limited to, GPs, nurses, non-consultant hospital doctors, consultant doctors, advanced nurse practitioners, radiologists (diagnostic imaging professionals), dentists, etc.

- What are the barriers and enablers to access to diagnostics in general and in particular for the specified-groups as reported by general practitioners and other healthcare practitioners?
    - How can the reported barriers be overcome?
    - How can the reported enablers be replicated and sustained?
    - What are the emotional, financial, social, etc. impacts of such barriers on healthcare professionals and allied health professionals?
- What works well in terms of a) identifying the need for diagnostics, b) ensuring access to diagnostic services for patients?
- What does not work well in terms of a) identifying the need for diagnostics, b) ensuring access to diagnostic services for patients?

The research should consider what is already known about early detection, perceptions and attitudes towards access to healthcare services, health service data, etc., and further build upon existing knowledge. The successful research team should consider that the Irish Cancer Society would like to take a solutions-focused approach towards addressing the findings from the research to use in our advocacy and other work to support the specified-groups on their cancer journey.

> ***Solutions***
> * What are the solutions (based on existing or potential solutions) in ensuring greater access to timely diagnostics for the specified-groups?
> * What practices exist in Ireland or elsewhere which are conducive to early/timely detection amongst the specified-groups, e.g. focusing on initiatives for the public and/or innovations or initiatives implemented within healthcare services?
> * What supports are required (at community level, primary care level, hospital level, regional level, etc.) to enhance and improve access to health services, and by extension access to timely diagnostics, for the specified-groups?
>
> ***Lessons learned***
> * To support Irish Cancer Society cancer information, cancer awareness and advocacy activities, we would like to further our understanding of public needs in terms of timely access to diagnostics for the specified-groups. For example, are there areas where people need additional information before seeing a GP?
> * To support Irish Cancer Society advocacy activities, what do the specified-groups, their carers, and health care practitioners feel can be changed and how?

Deliverables and project activities

Phase	Description	Type	Timeline
Inception	A kick off meeting to discuss the project, timeline, methods, data sources, and subsequent report priorities.	Activity	TBC
	Inception report outlining final methodological approach, updated work plan (and timeline) and deliverables against which the project will be managed, etc., including an annex with a research and analysis framework	Deliverable 1	TBC
Continuous communication	Fortnightly phone calls with the Society on project progress and contract deliverables	Activity	TBC

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Implementation	Implementation of research activities	Activity	TBC
Reporting	Mid-point meeting including presentation of findings to date, and discussion of work conducted to date, as well as how the work will be finalised	Deliverable 2	TBC
	End of research meeting including presentation of findings, and discussion of reporting structure	Deliverable 3a	TBC
	Draft report	Deliverable 3b	TBC
	Final report	Deliverable 3c	TBC

Please note: that the above dates, activities and deliverables are subject to change at the discretion of the Irish Cancer Society.