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Abstract

Healthcare today requires that information is accurate, reliable and timely. Large amounts of data are collected every single day in the provision of care. The consumers of healthcare, who include the public, are increasingly aware of the availability of the multitude of data collections and are eager to harness the information to provide the best evidenced care for patients. Cancer registries, for example, collect information relating to cancer incidence and produce reports on cancer incidence and survival statistics. They are principally used nationally and internationally as powerful information sources to direct planning for cancer services. They are not traditionally concerned with providing information about cancer and cancer prevention to the public at large.

The question the research sought to answer, through the lens of the National Cancer Registry of Ireland, was how can the relevance of patient registries be increased for the public? Answering this question required an analysis of patient registries in general and cancer registries in particular. It was clear from this analysis that there is significant potential to increase the value and relevance to the public of information in patient registries. This led to a consideration of the role which information can play in patient empowerment and hence also the importance of health literacy to ensure that the information being provided can be understood. A representative sample of key stakeholders were interviewed to identify the opportunities for increasing the relevance of data collection such as registries to the public. The results were analysed according to the themes identified.

As the research used the National Cancer Registry of Ireland (NCRI) as the lens through which to consider the research question, the recommendations developed in order to increase the relevance of patient registries to the public were targeted at the NCRI. Based on the international review and the interviews with stakeholders, three key recommendations were identified, namely to include members of the public on the advisory council of the NCRI, run an information campaign aimed at the public to raise awareness of the role and content of the NCRI, and to make the registry more health literacy friendly.

Cancer registries are a valuable information source of information and can be used to further enhance the engagement of the public into supporting their own health and wellbeing. The

research identified a need for recognising the requirement for the evolution of the NCRI through a set of recommendations that are evidence based. It was concluded that empowerment of the patient and health literacy are central to increasing the relevance of cancer registries for the public.