**ABSTRACT**

**BACKGROUND**

The Utah Cancer Registry (UCR) conducts statewide cancer surveillance as part of the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) Program. The UCR plays an integral role in population-based cancer research, due in part to its success in contacting patients who are eligible for research studies. The UCR uses an “opt-in” approach to research recruitment. Utah cancer survivors must agree to allow researchers to contact them. Survivors who request no registry contact remove themselves from future contact by the UCR. Variations in research findings are generalizable. The potential impact of “do not contact” patients on sample representativeness and generalizability is examined.

**OBJECTIVES**

- Examine the characteristics of cancer patients who have requested never to be contacted by the UCR.
- Conduct a sub-analysis of cancer survivors contacted for study recruitment, comparing two groups:
  - Those who requested no future registry contact
  - Those who agreed or simply refused to allow researchers to contact them for a specific study

**METHODS**

A sub-analysis was conducted on cancer survivors contacted to participate in a study within the last 15 years. Cancer survivors who, during study recruitment, actively requested no future contact by the UCR, or who were not contacted or refused to be contacted by the researcher, were included in the sub-analysis. We examined demographics and tumor characteristics. We also examined median lag time between date of diagnosis and date of request of no further contact or agreement refusal to allow researcher contact.

**RESULTS**

- Since UCR’s inception in 1966, 626 patients (0.26% of Utah’s population) elected to do not contact and were not to be contacted by the UCR.
- A sub-analysis of patients contacted to participate in research studies found that 58% of the 2,825 patients contacted (70%) requested no future contact by the UCR.
- Similar to all Utah cases, a majority of patients requesting no UCR contact were non-Hispanic white women, patients living in an urban area, or patients diagnosed with a low-stage tumor.
- The number of cancer patients requesting no UCR contact has been gradually increasing during the last two decades. A majority of “do not contact” patients were diagnosed and requested no registry contact within the last 10 years.

**CONCLUSION**

- Selection bias may not be a major issue in Utah. Patients requesting no UCR contact are largely representative of Utah’s population. Utah cancer survivors remain open to participating in future research.
- Patients cited concerns about privacy or lack of knowledge about the UCR or that cancer was a reportable disease in Utah.

**LIMITATIONS**

- Prior to 2011, the data when a patient requested no contact was not collected in the main cancer database. This limited time analysis to a subsample of patients contacted for studies.
- Not all cancer patients are aware of the UCR or have been contacted by the UCR. Cancer patients requesting no registry contact may be less representative of all cancer cases funded for research.
- Although numerous studies with varied eligibility requirements have recruited cancer cases using the UCR, the last 15 years, the sub-analysis is limited by the eligibility requirements of each study and may not be representative of all Utah cancer cases.

**REFERENCES**