Participation Rates and Characteristics of Participants and Non-Participants in Cancer Patient Contact Studies in New York State

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Background

- Cancer research studies involving patient contact often use cancer registries to identify eligible patients, with a goal of recruiting a representative sample
- Low rates of participation may decrease the representativeness of the sample, introduce selection bias, and limit generalizability of study results
- We examined participation rates and characteristics of participants and non-participants for six recent patient contact studies conducted in New York State (NYS)

Methods

- Analyses included patients who were sent an initial study mailing for one of six patient contact studies before November 1, 2021
- We conducted descriptive analyses to examine the percent of patients who consented to further contact or participated in each study
- We used chi-square and Fisher's exact tests to compare demographic characteristics of participants and non-participants in each study
- All analyses were conducted using SAS 9.4

Table 1. Patient Contact Studies Included in Analyses

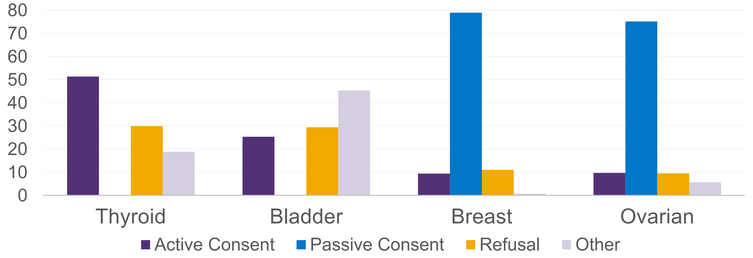
Cancer Type	Diagnosis Years	Physician Consent	Patient Consent	Study Procedures
Thyroid	2011-21	Passive	Active	Telephone interview
Bladder	2018-19	Passive	Active	Intervention, biospecimen
Breast (female)	2019-20	Passive	Passive	Surveys, biospecimen
Ovarian	2019-20	Passive	Passive	Survey, optional biospecimen
Prostate	2020-21	None	Survey Completion	Survey, optional HIPAA form
Prostate	2016	None	Survey Completion	Survey, optional biospecimen

Note: Passive consent provides the opportunity to decline further contact about a study; active consent requires assent to further contact about a study.

Results

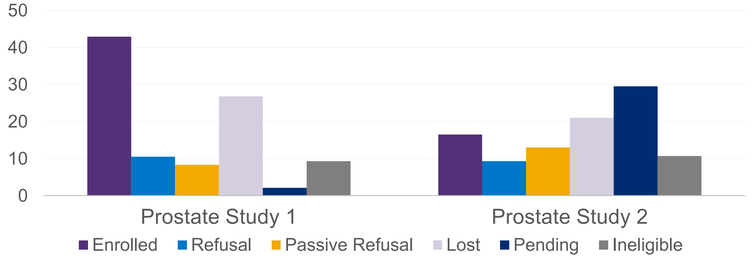
- For studies requiring active patient consent, 25.3% of patients agreed to further contact for an intervention study vs. 51.3% for a study involving a telephone interview only
- For studies requiring passive patient consent, 9-10% of patients assented to further contact and 75-79% passively consented after four weeks
- For two prostate cancer studies involving direct enrollment by survey completion, 42.9% and 16.5% participated in each study as of February 2022

Figure 1. Participation Rates for Studies Requesting Patient Consent for Further Contact



Note: "Other" category includes patients who are ineligible, unable to be located, or pending.

Figure 2. Participation Rates for Studies Involving Direct Enrollment of Patients



Results

- There were statistically significant differences between participants and non-participants in age at diagnosis, race, and region/county at diagnosis for one or more patient contact studies
  - Thyroid cancer patients who consented to further contact were more likely to be White and less likely to be Asian, Black, or other/unknown race (P<0.001); no differences were observed for diagnosis year, sex, or age category
  - Bladder cancer patients who consented to further contact were more likely to be ages 60-69 or 70-79 and less likely to be <60 or ≥80 years of age (P=0.02); no differences were observed for race/ethnicity, diagnosis year, or sex
  - Breast cancer patients who actively consented were more likely to live outside of New York City (NYC) (P<0.001), while patients who refused further contact were more likely to be 60-69 or ≥70 years of age (P=0.002); no differences were observed for race or diagnosis year
  - Ovarian cancer patients who actively consented were more likely to be White (P=0.009) and live outside of NYC (P=0.002); no differences were observed for diagnosis year or age category
  - In one prostate cancer study participants were more likely to be White, and in both prostate cancer studies participants were more likely to live outside of NYC (all P<0.001); no differences were observed for ethnicity or age category

Conclusion

- In recent patient contact studies conducted by the NYS Cancer Registry, participation rates varied by study design and contact procedures
  - The overall study response rate is unknown for the non-enrollment studies
- Patient self-selection may lead to a study sample that differs from the underlying population, including with respect to age, race, and region of NYS

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