Underrepresentation of cancer patients with lower survival in observational patient reported outcome studies - the population-based PROFILES registry

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Background

• Patient-reported outcomes (PROs) are increasingly being used in patient-centered outcome research to support informed health care decisions
• If certain patients are underrepresented in PRO research, the generalizability of the outcomes are likely to be affected

Aim

To assess the generalizability of patient-reported outcome (PRO) research among cancer survivors by comparing socio-demographic and clinical characteristics, and survival of participants and non-participants in cancer survivors invited for questionnaire research through the PROFILES registry.

Methods

• Between 2008 and 2015, cancer survivors (N=14,011) were invited to participate in PROFILES registry studies, of whom 69% (N=9,684) participated
• Cancer types included were colon, rectum, melanoma, basal/squamous cell, endometrial, ovarian, borderline ovarian, prostate, thyroid, Hodgkin lymphoma, non-Hodgkin lymphoma, chronic lymphocytic leukemia, multiple
•Socio-demographic and clinical characteristics and survival data were collected through the Netherlands Cancer Registry and the Dutch municipal personal records database
• Multivariable logistic regression analyses were conducted to assess differences in socio-demographic and clinical characteristics, and cox proportional hazard regression models were conducted to assess differences in survival, between participants and non-participants
•A sensitivity analysis was conducted to estimate the EORTC-QLQ-C30 scores of non-participants using a 'hot-deck' approach (matching participants to non-participants).

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Results

• Participants had a significantly lower mortality compared to non-participants (HR=0.68, P<0.01; **Fig 1**)
•Participants were less often younger than 60 (ORs<0.85, p<0.01) or older than 70 (ORs<0.87, p<0.01), had a higher socio-economic status (OR=1.53, p<0.01), were less often female (OR=0.82, p<0.01), had more often received radiotherapy (OR=1.18, p<0.01), less often no treatment (OR=0.82, p=0.04), had less often comorbidities (OR=0.84, p<0.01) and were less often invited <2 years (OR=0.73, p<0.01) or >3 years (OR=0.88, p<0.01) after diagnosis
• Sensitivity analysis suggests that the health-related quality of life (HRQoL) of participants might be up to 4.3 points higher compared to non-participants (**Fig 2**)

Conclusions

• Cancer survivors not participating in PROs research significantly differ from participants, with respect to socio-demographic and clinical characteristics, and survival
•The HRQoL of non-participants may be systematically lower compared to participants.
• Even in PRO studies with relatively high participation rates, observed outcomes may systematically represent the healthier patient with better outcomes.

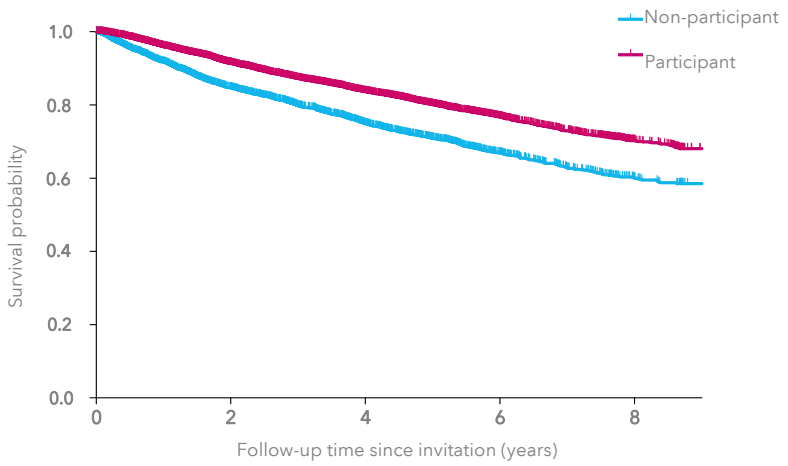

Fig 1: unadjusted survival curves of non-participants versus participants

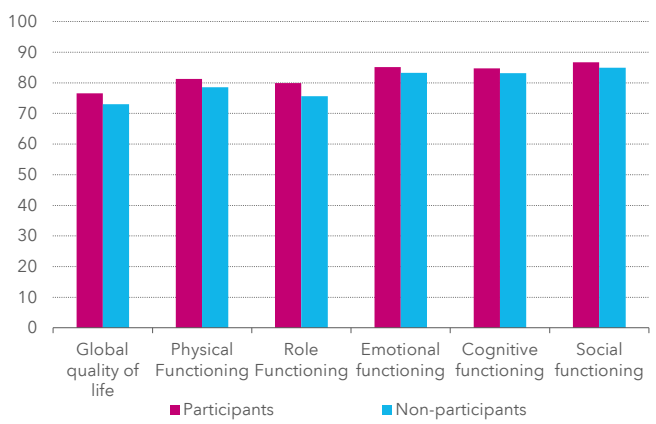

Fig 2: estimated EORTC-QLQ-C30 scores of non-participants versus participants