Different strategies to recruit long-term cancer survivors via population-based cancer registries: response and representativeness

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Background / Study Aim

- Population-based cancer registries may represent a valuable source for cancer survivorship studies.
- However, these registries usually do not routinely collect quality of life and other relevant data addressing cancer survivorship issues.
- Direct recruitment and supplemental data collection by cancer registries is often hampered by data privacy and ethical regulations.
- We assessed response and representativeness of different strategies in recruiting study participants in the context of the CAESAR study, a multiregional study encompassing over 7.000 long-term survivors after breast, colorectal or prostate cancer in 2009-2012.

Study Design

- Population-based, multi-center study
- Involvement of six registries:
  - Schleswig-Holstein
  - Hamburg
  - Bremen
  - Münster
  - Rhineland-Palatinate
  - Saarland

Due to state specific legislation different strategies had to be implemented to contact and recruit study participants:

A) Direct mailing of the questionnaire by the registry without prior notification (one state)

B) Direct mailing of the questionnaire via treating physician (hospital) without prior notification (one state)

C) Notification of survivors by treating physician and asking for informed consent before sending out the questionnaire (two states)

D) Notification of survivors by a study physician (unknown to the patient) and asking for informed consent before sending out the questionnaire (one state)

E) In addition, three previously established cohorts of cancer survivors who had given consent for follow-up recruitment could be included and for whom direct mailing of the questionnaire by the registry without further prior notification was possible (two states)

Results

- 7.012 out of 15.735 eligible cancer survivors filled out the detailed questionnaire and could be successfully recruited (44.6% response overall, Table 1).
- The requirement of notification by a physician and obtaining informed consent prior to mailing (strategy C and D) resulted in response rates between 23,5% and 37,2%.
- Non-cooperation by physicians caused a 33%-49% loss of potential study participants (strategy C).
- Direct mailing of the questionnaire by the registry resulted in an overall response of 43.2% (strategy A) and of 58.2% when the questionnaire was sent by the hospital (strategy B).
- In contrast, 78.6% to 80.5% of all patients from the established cohorts filled out and returned the questionnaire (strategy E).
- Overall, only little differences in the composition of study population and target population were observed (Table 2) but different selection processes within the multistep-recruitment seem to exist (Table 3).

Conclusions

- A two-step approach requiring incorporation of the treating physician and prior informed consent results in a substantial loss of potential participants.
- Direct mailing of the questionnaire in combination with the informed consent form via the hospital doctor represents an economic alternative when direct contact by the registry is not feasible.

Contacting survivors and mailing of questionnaires

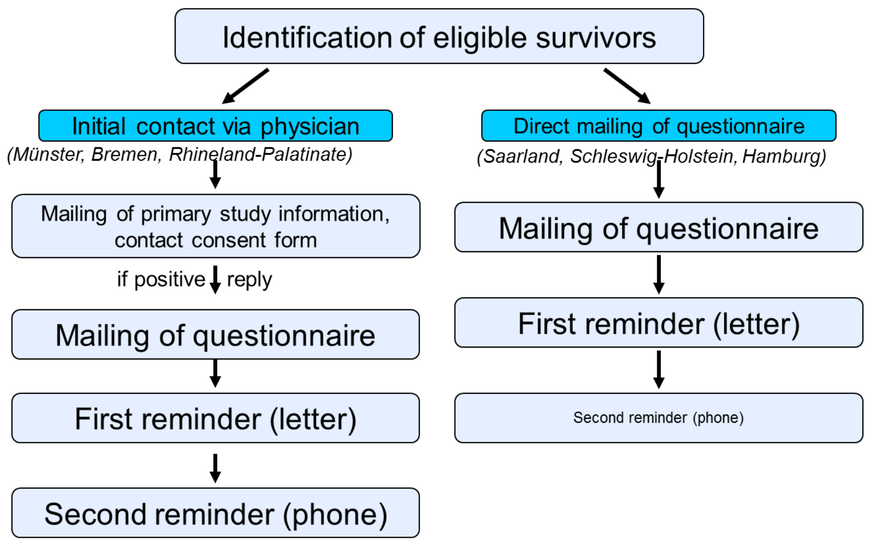

Table 1: Participation by recruitment step

Registry	Recruitment strategy	Eligible	Patients informed by physician	Patients consented to be contacted	Patients being sent a questionnaire	Return of full-length questionnaire
<u>Two step approach</u>						
Bremen (via hospital or registered doctor)	**C**	**2431**	1627/2431 66,9%	764/1627 47,0%	764	664/2431 **27,3%**
Rhineland-Palatinate (via registered doctor)	**C**	**3134**	1604/3134 51,2%	847/1604 52,8%	847	737/3134 **23,5%**
Münster (via study physician)	**D**	**3582**	3582/3582 100,0%	1590/3582 44,4%	1590	1332/3582 **37,2%**
<u>Direct mailing of questionnaire</u>						
Hamburg (via study centre/cancer registry)	**A**	**2185**	---	---	2185	943/2185 **43,2%**
Saarland (I) (via hospital/CCCs)	**B**	**856**	---	---	856	498/856 **58,2%**
Saarland (II) (Verdi cohort)	**E**	**375**	---	---	375	300/375 **80,0%**
Saarland (II) (ESTHER-II cohort)	**E**	**833**	---	---	833	655/833 **78,6%**
Schleswig-Holstein (OVIS cohort)	**E**	**2339**	---	---	2339	1883/2339 **80,5%**
Overall (counts/eligible) **Conditional probability**		**15735**	6813/9147 **74,5%**	3201/6813 **47,0%**	9789/15735 **62,2%**	7012/15735 **44,6%**

Table 2: Comparison of full questionnaire responders versus non responders (all regions)

	Tumor								Overall	
	Breast		Colorectal				Prostate			
	Female		Female		Male		Male			
	Responders	Non responders	Responders	Non responders	Responders	Non responders	Responders	Non responders	Responders	Non responders
Eligible patients										
N	3077	3509	637	1210	895	1315	2403	2689	7012	8723
(row%)	(46,7%)	(53,3%)	(34,5%)	(65,5%)	(40,5%)	(59,5%)	(47,2%)	(52,8%)	(44,6%)	(55,4%)
Age at diagnosis										
Mean	57,1	57,6	61,7	64,1	62,4	63,2	65,4	65,9	61,0	61,9
(SD)	(9,6)	(10,8)	(9,0)	(9,2)	(7,9)	(9,4)	(5,6)	(6,1)	(8,9)	(9,8)
Age at survey										
Mean	65,3	66,2	70,4	72,8	70,6	71,6	72,9	74,0	69,0	70,3
(SD)	(9,6)	(10,9)	(9,1)	(9,6)	(7,9)	(9,5)	(5,8)	(6,3)	(8,9)	(9,9)
Years since diagnosis										
Mean	8,2	8,6	8,7	8,7	8,2	8,4	7,5	8,1	8,0	8,4
(SD)	(2,2)	(2,3)	(2,6)	(2,5)	(2,4)	(2,3)	(1,9)	(2,1)	(2,2)	(2,3)
Stage at diagnosis (col%)										
UICC I	41,3%	39,4%	23,2%	23,1%	24,7%	28,7%	1,9%	2,0%	24,1%	24,0%
UICC II	42,3%	41,7%	27,0%	28,3%	30,3%	29,1%	38,8%	36,8%	38,2%	36,4%
UICC III	7,5%	7,8%	25,7%	25,0%	24,4%	22,7%	21,3%	16,1%	16,0%	15,0%
UICC IV	1,2%	2,0%	3,9%	4,3%	4,4%	4,0%	4,9%	5,1%	3,1%	3,6%
Unknown	7,7%	9,1%	20,1%	19,3%	16,3%	15,5%	33,0%	40,1%	18,6%	21,0%

Table 3: Results of multiple logistic regression to assess potential selection bias due to different recruitment strategies*

	Overall comparison	Sources of potential selection bias				
	Responders versus non-responders	Potential attrition bias in established cohorts	A priori selection of specific hospitals	Physician's willlingness to contact patients	Patients' consent to receive a questionnaire	Patients' willingness to fill out a 30 pages questionnaire
Applies to	Strategy A,B,C,D,E	Strategy E	Strategy B	Strategy C	Strategy C,D	Strategy A,B,C,D,E
Region	All regions	Saarland, Schleswig-Holstein	Saarland	Bremen, Rhineland-Palatinate	Bremen, Rhineland-Palatinate, Münster	All regions
Patients' characteristics	OR 95%-CI	OR 95%-CI	OR 95%-CI	OR 95%-CI	OR 95%-CI	OR 95%-CI
Tumor site						
Breast	**1,00 (ref.)**	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)
Colorectal	**0,64 (0,57-0,72)**	**1,23 (1,01-1,49)**	**0,34 (0,26-0,44)**	**0,80 (0,67-0,96)**	0,95 (0,80-1,11)	**0,80 (0,69-0,93)**
Prostate	**0,84 (0,72-0,99)**	1,23 (0,95-1,60)	---	**0,64 (0,49-0,82)**	1,03 (0,82-1,29)	1,08 (0,86-1,34)
Gender						
Male	**1,00 (ref.)**	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)
Female	**0,80 (0,70-0,91)**	0,87 (0,68-1,11)	**0,65 (0,48-0,88)**	0,91 (0,74-1,11)	**0,78 (0,65-0,93)**	**0,71 (0,59-0,85)**
Age (at survey)						
18-54	**0,73 (0,64-0,82)**	**0,58 (0,50-0,68)**	1,05 (0,83-1,32)	0,91 (0,74-1,12)	0,90 (0,74-1,08)	**0,79 (0,67-0,94)**
55-64	0,94 (0,86-1,04)	0,90 (0,80-1,01)	1,02 (0,83-1,25)	0,89 (0,75-1,04)	1,33 (1,14-1,54)	0,90 (0,79-1,02)
65-74	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)
75-84	**0,63 (0,58-0,68)**	**0,62 (0,56-0,69)**	**0,68 (0,55-0,84)**	0,97 (0,85-1,10)	**0,66 (0,59-0,74)**	**0,71 (0,64-0,79)**
85+	**0,51 (0,38-0,67)**	**0,64** (0,34-1,21)	**0,23** (0,03-1,83)	0,87 (0,48-1,57)	**0,42 (0,29-0,62)**	**0,47 (0,34-0,66)**
Years since diagnosis						
Change per 1 year	**0,94 (0,93-0,96)**	**1,21 (1,17-1,24)**	**1,21 (1,14-1,28)**	**1,08 (1,04-1,12)**	1,00 (0,98-1,02)	**0,92 (0,90-0,94)**
Stage at diagnosis						
UICC I	1,00 (ref.)	**1,00 (ref.)**	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)	1,00 (ref.)
UICC II	1,01 (0,92-1,10)	**0,86 (0,77-0,96)**	**0,77 (0,65-0,93)**	1,08 (0,94-1,25)	0,98 (0,85-1,11)	0,94 (0,83-1,06)
UICC III	1,11 (0,99-1,24)	**0,83 (0,72-0,95)**	0,88 (0,68-1,13)	**1,40 (1,17-1,68)**	1,00 (0,85-1,18)	0,91 (0,78-1,06)
UICC IV	0,87 (0,72-1,05)	**0,45 (0,36-0,57)**	0,78 (0,44-1,40)	**1,54 (1,05-2,26)**	**0,69 (0,53-0,90)**	**0,73 (0,56-0,96)**
Unknonw	0,90 (0,80-1,00)	**0,37 (0,33-0,43)**	**0,37 (0,28-0,50)**	0,89 (0,73-1,07)	**0,81 (0,69-0,95)**	**0,66 (0,57-0,77)**

* ORs are adjusted for all presented variables

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