

# RECRUITMENT OF AN ETHNICALLY DIVERSE POPULATION OF CHILDHOOD CANCER SURVIVORS: A SINGLE INSTITUTION EXPERIENCE

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## Background

Cook Children's Hematology-Oncology Center was granted provisional membership in the Childhood Cancer Survivor Study (CCSS) in 2010. The institutional commitment is to recruit five-year survivors of childhood cancer diagnosed from 1987-1999, eligible for the CCSS Expanded Cohort. Due to institutional IRB concerns over patient privacy, Cook Children's requested an opportunity to contact, and obtain HIPAA authorization for release of protected health information to CCSS, directly from its identified eligible participants, as opposed to the standard, centralized recruitment process conducted on behalf of other CCSS institutions. Cook staff initially identified 554 potentially eligible participants and contacted participants using approved methodology, performed by two dedicated staff over 21 months.

## Methods

Contact methods included mailings (brochures/postcards with Dr. Bowman's photograph), face-to-face contact, phone calls from primary oncology providers, utilization of public websites (relative obituaries, appraisal and voting districts) and viewing open social media profiles. Direct access to medical records allowed for multiple options to communicate with survivors. Completion of HIPAA authorization by telephone was approved by the Cook IRB. Survivors verbally indicated interest in participation on two separate occasions before providing HIPAA authorization via telephone.

## Results

From the original 554 potential participants, 20 (3.6%) were found ineligible. As of January 23, 2013, a total of 386 participants or 72.3% of the 534 eligible survivors provided authorization, 49 (9.2%) did not respond, and 24 (4.5%) refused participation. Demographics of recruited participants included equal numbers of males (n=195) and females (n=191); 306 (79.3%) Caucasian, 56 (14.5%) Hispanic, 20 (5.2%) African-Americans, 3 (0.7%) Asian, and 1 (~1%) Other.

	HIPAA Authorizations Received by Method			
	Total	Caucasian	Hispanic	Other
Mailing with Follow up Call	240 (62.0%)	192	34	14
Mailing alone	78 (20.0%)	69	6	3
Signed during Appointment or Meeting	56 (14.5%)	36	14	6
Telephone HIPAA completion	11 (3.0%)	10	0	1
Faxed HIPAA	1 (0.5%)	0	1	0

Eligible Survivors by Race				
	Eligible Survivors	Provided HIPAA Authorization (%)	Refused Participation (%)	Non-responsive (%)
Caucasian	400	306 (76.5%)	19 (4.8%)	34 (8.5%)
Hispanic	88	56 (63.6%)	4 (4.5%)	5 (5.7%)
African-American	39	20 (51.3%)	0	9 (23.1%)
Asian	6	3 (50%)	1 (16.7%)	1 (16.7%)
Other	1	1 (100%)	0	0

### Conclusions

Despite IRB restrictions on recruitment and limited staff, our institution was successful in our recruitment efforts. Application of techniques that engaged survivors on a personal level enhanced participation.