

Challenges of Collecting Health Data and Maintaining Contact with an Aging Study Population

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Selenium and Vitamin E Cancer Prevention Trial (SELECT)

- Primary aim: Assess the effect of selenium and vitamin E alone and in combination on clinical incidence of prostate cancer
- Participants age 50+ randomized and followed for median 5.5 years at one of 400 North American sites
- Supplementation stopped early (October 2008) due to lack of benefit
- Ppts may opt to continue follow-up by the Statistical Center
- Updated analysis (October 2011) showed significant 17% increase in prostate cancer risk in the vitamin E alone arm


SELECT Centralized Follow-up (CFU)

- Annual follow-up by mail
 - Mailed to address where ppt resides during his birth month
 - Separate questionnaires for those with prostate cancer (16pp) and those without prostate cancer (12pp)
 - Ppt may update/add personal contact information
 - First class flat (9" X 12") mailer with familiar SELECT logo
 - Business reply mail (BRM) return envelope

9. High intensity focused ultrasound (HIFU)

No

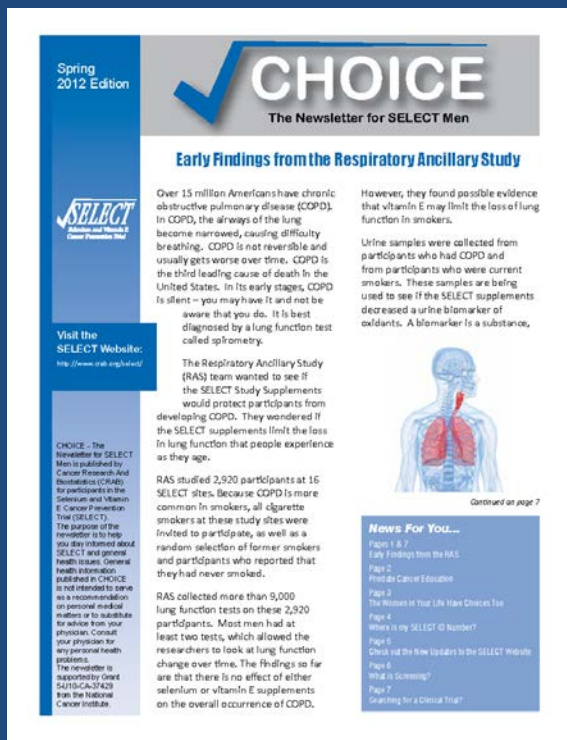
I don't know or I'm not sure

Yes 

9a. Date you had high intensity focused ultrasound: /
mm yyyy

10. Did you receive any other therapies or treatments? If so, please describe them below.

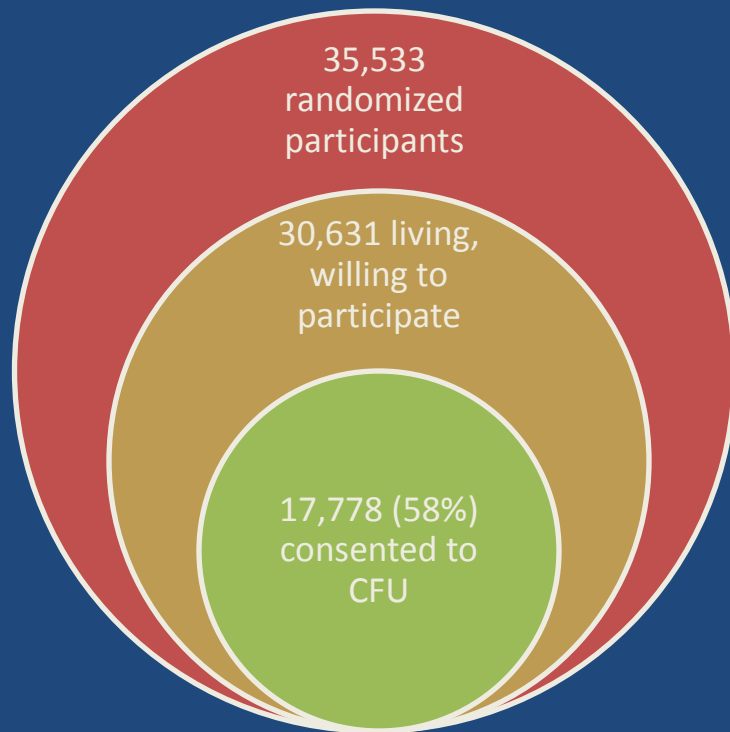
- Newsletters mailed to all ppts twice yearly (spring and fall)
- Retention item (calendar) mailed each year



Other Communication with Participants

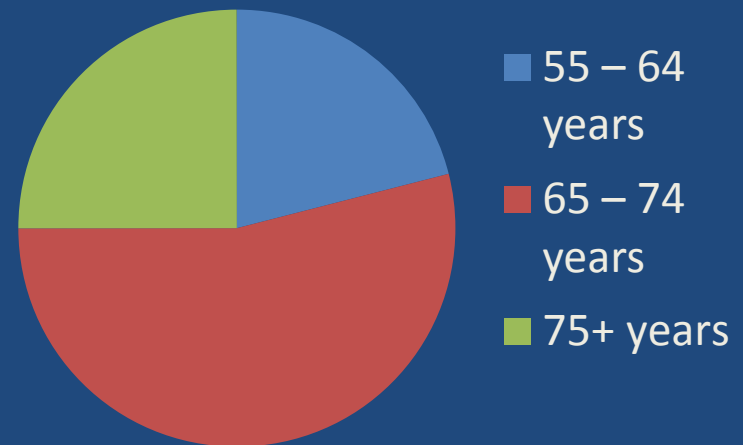
- Letters requesting medical record/tissue releases for study endpoints
- Phone calls and e-mails (~ 4,000 to date)
 - Clarify questionnaire responses
 - Respond to comments written on questionnaires
 - Follow up on reports of study endpoints and other health problems
 - Provide unblinding information

Characteristics of CFU Participants

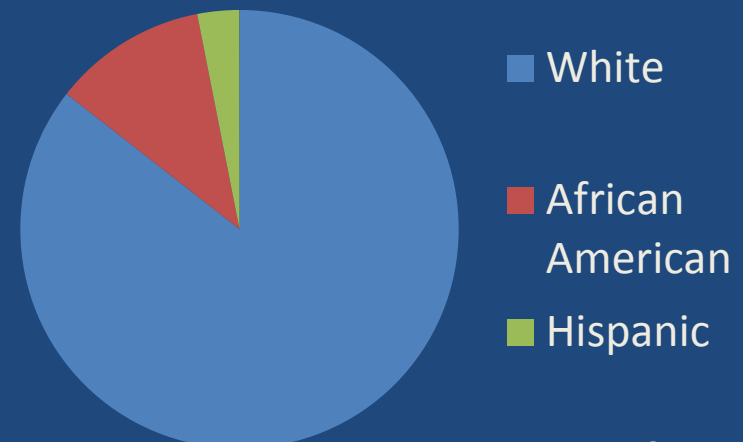


- 96% US (incl. Puerto Rico), 4% Canada
- 98% English, 2% Spanish
- 93% without prostate cancer

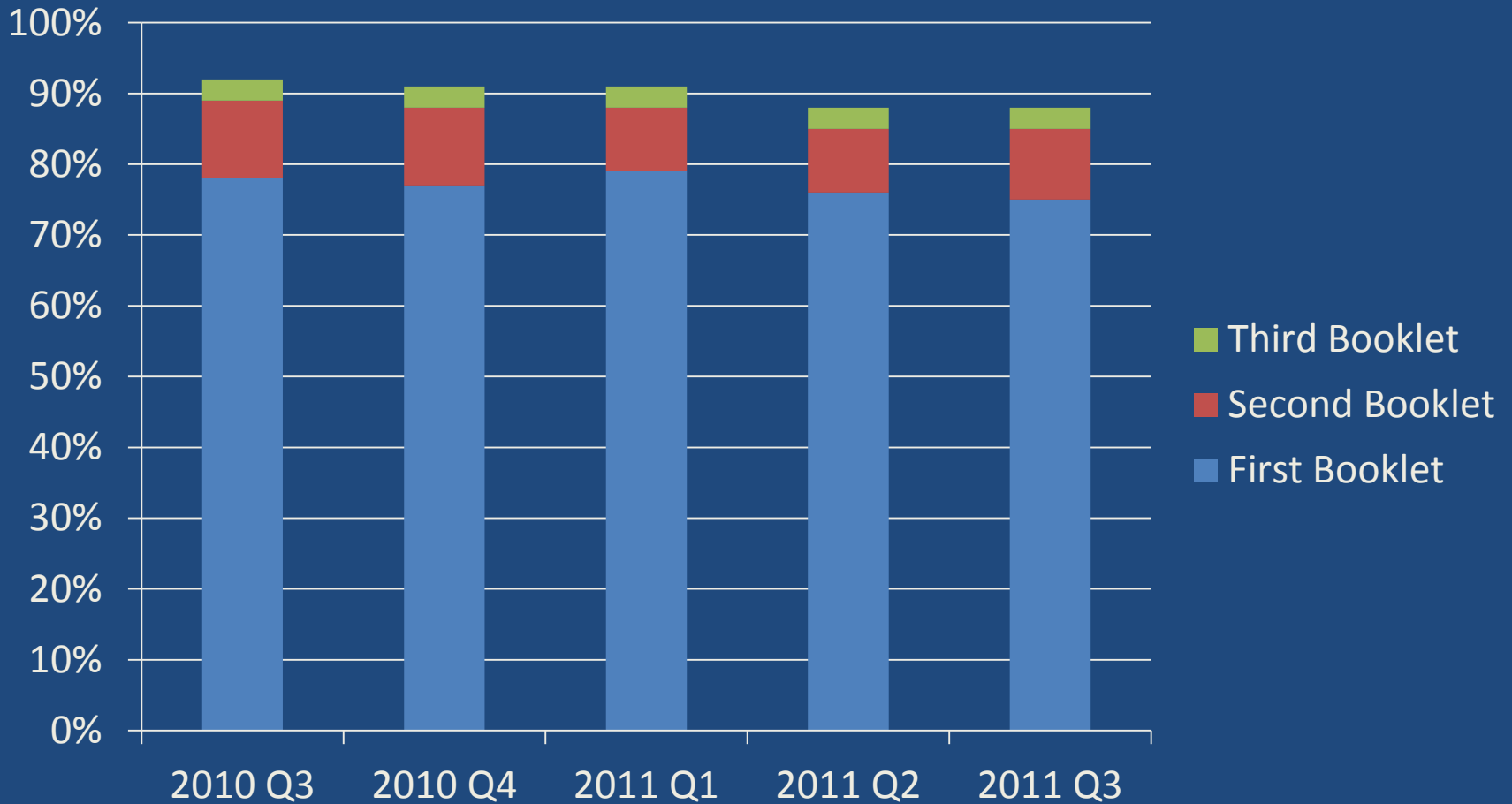
Age



Ethnicity



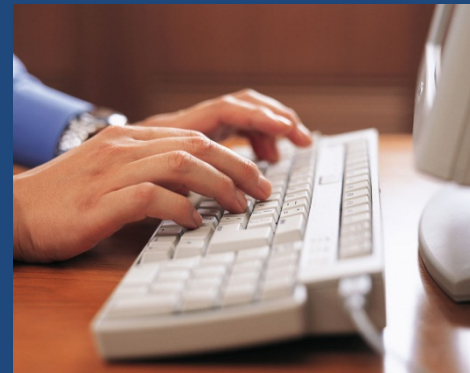
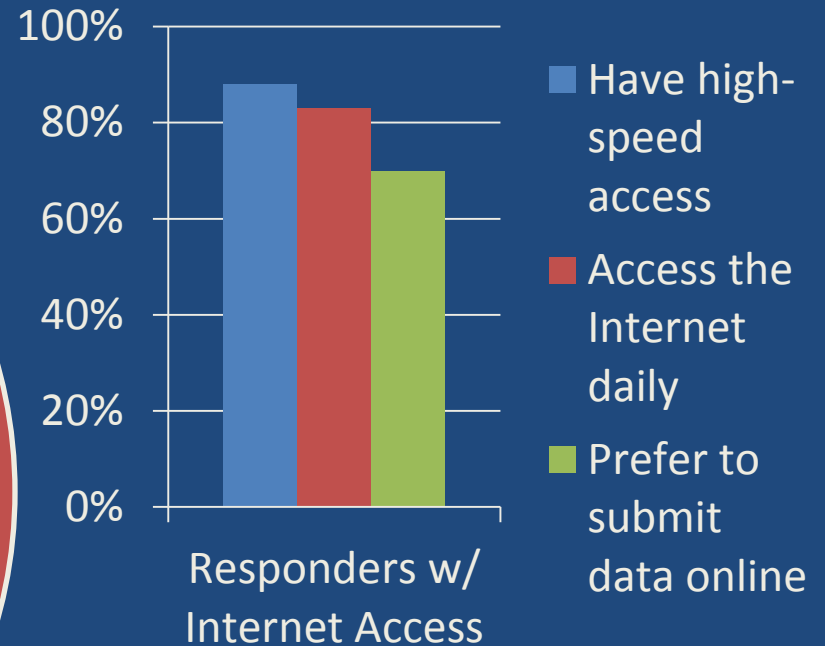
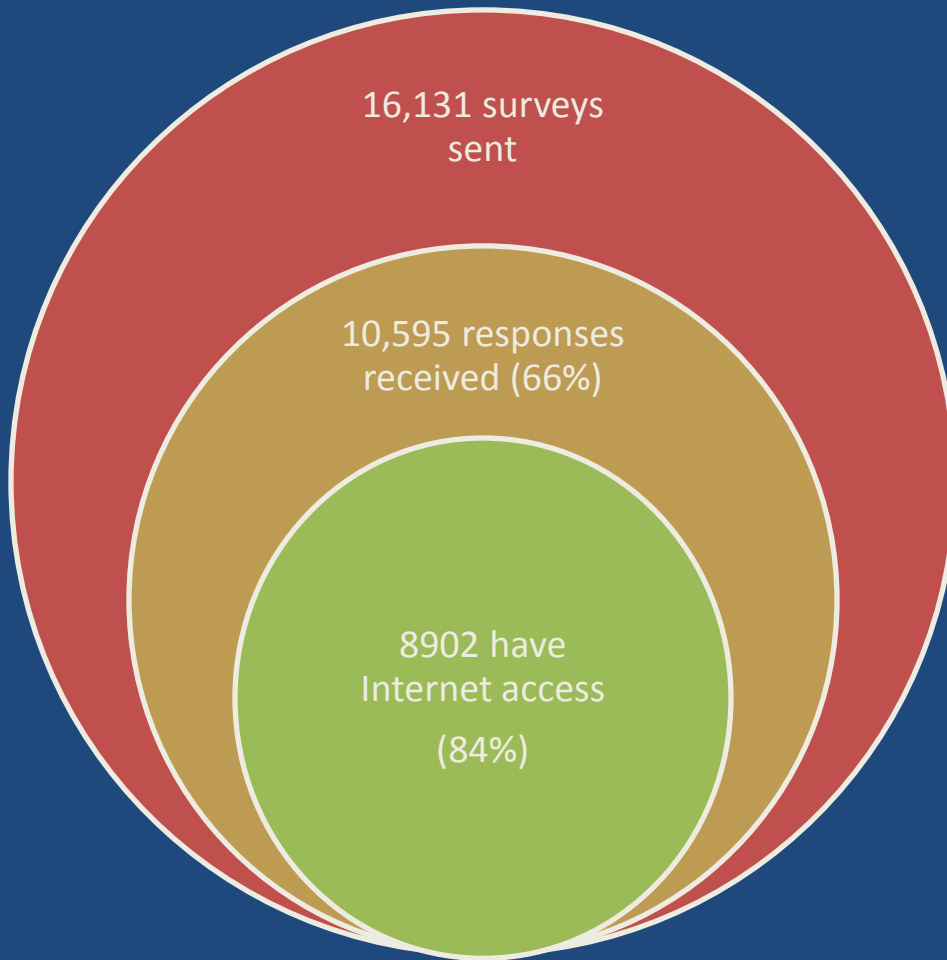
Response Rates to Mailings



Challenges of Data Collection

- Change from site follow-up to mail
- Retirement
- Relocation
 - Permanent move to warmer climate
 - Seasonal relocation
 - Assisted living
- Health problems
- Study fatigue

Survey to Assess Internet Use



On-line Data Entry System (MySELECTData) Released June 2011

- Decrease mailing costs
- Reduce use of paper
- Accommodate mobile population
- Provide access to update contact info 24/7
- Apply data to database immediately



- [Contact Us](#)
- [Privacy Policy](#)
- [FAQ](#)
- [Change Password](#)
- [Log off](#)
- [SELECT Website](#)

Welcome

Welcome to MySELECTData! SELECT participants who agree to continue on SELECT's Centralized Follow-up may use this website to update their personal contact information and health information annually.

If you are a participant on Centralized Follow-up, you will get your SELECT forms in the mail as an Annual Booklet in your birth month. **You have two ways to submit your data to the SELECT Coordinating Center:**

- 1) Complete your booklet using a black pen and mail it to the SELECT Coordinating Center, or
- 2) Login to the MySELECTData secure website to complete your booklet on-line.

If you choose to submit your Annual Booklet online it will be available each year starting in your birth month. The Annual Booklet will be available for up to six months past your birth month. You will be able to update your personal contact information at any time.

How to get started:

You will need your SELECT ID Number to create a password. Your SELECT ID number can be found on correspondence you have received from SELECT. [Contact us](#) if you don't know your SELECT ID Number. By clicking on the Logon button below, you will be asked to create a password if this is your first time using MySELECTData to enter your health or contact information.

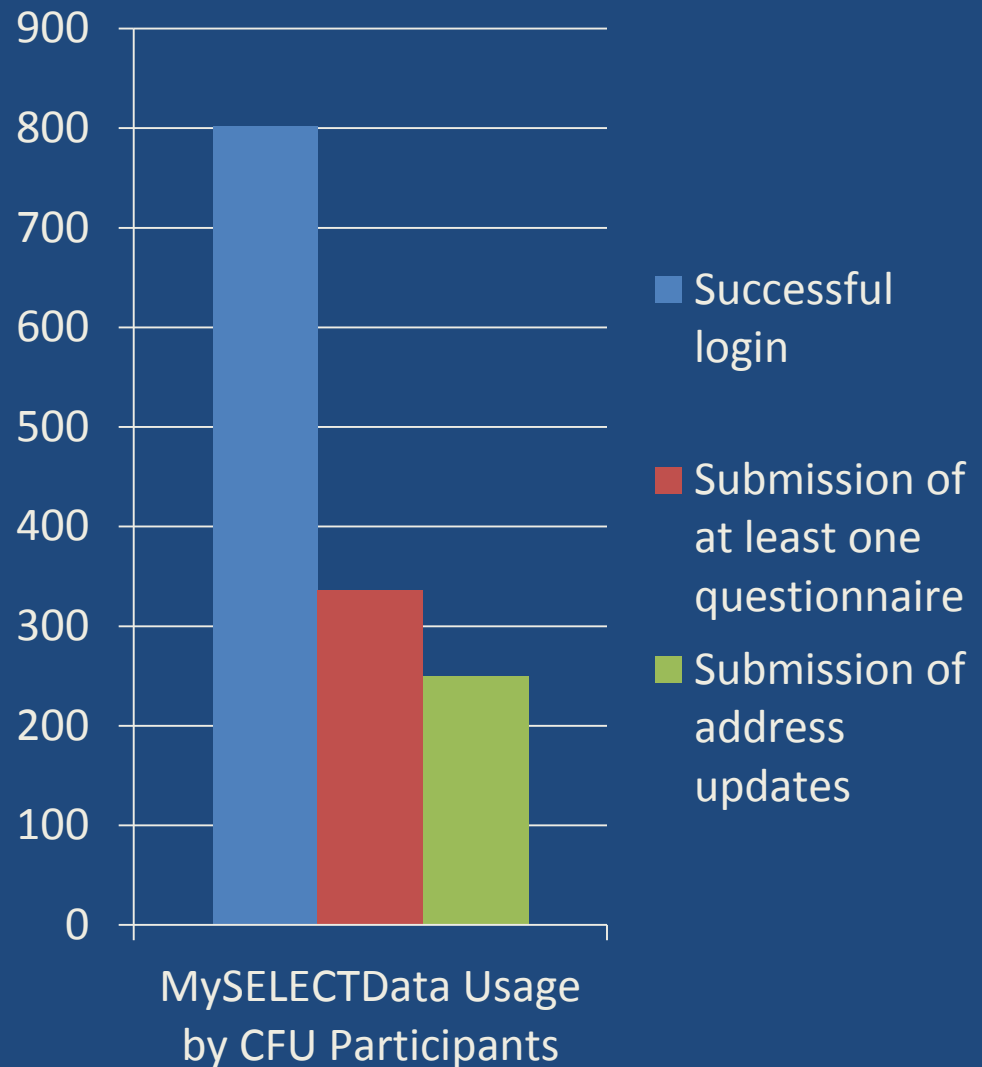
Logon

For technical help and answers to frequently asked questions click on the [FAQs](#) link.

Unauthorized access is prohibited. If you have questions about the security of this site, please read our [privacy policy](#).

One Year Later...

- Of 17,778 ppts registered to CFU:
 - 17,456 active
 - 197 have died
 - 125 have refused or are lost to follow-up
- Of active group, 11,905 (68%) have an e-mail address



Why so little use?

- Complex process for initial logon and password assignment
- Infrequent need to use MySELECTData, thus tendency to forget userid and password
- MySELECTData design text-intensive, small text, minimal graphics: may not look inviting to participants
- No delivery preference system (mail vs Web)
- Easier to fill out booklet than to logon

Other Difficulties in Maintaining Contact

- Undeliverable mail
- No response to repeated questionnaire mailings (10% of total)
- Living situation, comorbidity incl. cognitive impairment

Strategies to Increase Use of MySELECTData

- Send e-mail reminders to ppts who have e-mail addresses: “It’s time to submit your data”
- Allow ppts to choose delivery option (Web or mail) for newsletter and annual questionnaire
- Focus groups by telephone

Proposed Improvements to MySELECTData

- Ease of access
- Functionality
- Expand window for submission of health data
- More frequent content updates to public website to increase number of visits
- Brief surveys about health topics
- Customized feedback based on health questionnaire data

Thank you

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- Jason Harris-Talley
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