A Secure Website for Participant Submission of Follow-up Data

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Selenium and Vitamin E Cancer Prevention Trial (SELECT) (SWOG S0000)

• Primary aim: Assess the effect of selenium and vitamin E alone and in combination on clinical incidence of prostate cancer
• Median on-treatment follow-up: 5 years
• Supplementation stopped early (October 2008) due to lack of benefit
• Participants may continue follow-up by the Statistical Center
SELECT Transition

During Intervention                      Post Intervention
427 sites                                1 site
35,533 participants                      17,520 participants
2 visits/year                            Annual mailings
2 pills/day                              No pills
SELECT Centralized Follow-up (CFU)

- Annual follow-up by mail
  - Separate questionnaires for those with prostate cancer and those without prostate cancer
  - First class flat (9” X 12”) mailer
  - Business reply mail (BRM) return envelope
- Health questionnaire and contact information updated annually
Challenges of CFU

• Statistical Center did not have personal contact information

• Older adults are mobile
  – 3.1% of US males over age 65 lived in a different home in 2009 than they did in 2008 (US Census 2009)
  • 1.4% of SELECT CFU participants changed city of residence in first 8 months of CFU
  – 5.6% of SELECT participants moved to a new Study Site during SELECT
Why Offer an On-line System?

• Decrease mailing costs
  – Multi-page questionnaires are expensive
  – Participants live outside the U.S.
  – Return postage from Canadian addresses
• Accommodate mobile participants
• Provide access to update contact info 24/7
• Reduce use of paper
• Apply to database immediately
SELECT CFU Participant Internet Survey

• Survey sent to 16,131 participants
• Responses received from 10,595 (66%)
• Wired
  – 84% have access to a computer with Internet capability
  Of those:
  – 88% have high-speed access
  – 83% access the Internet daily
  – 70% prefer to submit data on-line
Timeline

• Specifications: Dec 2010 – Feb 2011
• Development and testing: Feb-Apr 2011
• User acceptance testing (staff and participants): Apr-May 2011
• Release: May 19, 2011
• Announcement of website in participant newsletter: May 23, 2011
SELECT News

Introducing MySELECTData

Participants who use computers know we have a SELECT website, http://www.crab.org/select, which you can access anytime to get current news about SELECT, find CHOICE newsletters, articles on SELECT and our contact information. That’s something old, and now we have added something new.

The SELECT website now contains a new link on the home page called MySELECTData. This link will take you to a secured area on the website where you can update your personal contact information and health information instead of completing the Annual Booklet that is mailed to all participants once a year. When you receive your Annual Booklet you will 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) Log in to the SELECT website at http://www.crab.org/select/ and click on MySELECTData to complete your booklet online.

In order to use MySELECTData, you will need to know your SELECT ID Number and you will be asked to create a password. There are clear instructions and Frequently Asked Questions to help you. You will only be able to see your own contact and health information based on your SELECT ID Number. You may log in to MySELECTData anytime to confirm and update your personal contact information. You may submit your Annual Booklet once a year beginning in your birth month. Once you complete your Annual Booklet and click the Submit button, your data will be at the SELECT Coordinating Center for review. You will have six months after your birth month to complete your Annual Booklet. If you have changes to your health after you submit your Annual Booklet you will be able to provide that information when your next Annual Booklet is available the following year. You will see more articles with examples of MySELECTData in this newsletter. We hope having this option to submit contact and health information to the Coordinating Center will be helpful especially those participants who...
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.
Welcome, SELECT ID Number 901363

You can access your SELECT data from this page. You can review and update your Contact Information at any time. Your Annual Booklet will be available for you to complete each year starting in your birth month. It will be available for up to six months past your birth month.

If you have changes to your health after you submit the Annual Booklet, you will be able to provide that information when your next Annual Booklet is available. We recommend you scroll through the Contact Information and the Annual Booklet without entering any data so you can see what type of information you need to have available when you are ready to enter your data. Then enter your data and remember to click on the “Save Changes” button when you are finished. If you want to complete a hard copy instead of entering your data online, please use the Annual Booklet that was mailed to you.

**IMPORTANT NOTE:** If you are logged on to MySELECTData for four hours or longer without clicking the “Save Changes” or “Send my data” button, you will be logged off automatically. If you make changes to the data without clicking on “Save Changes” or “Send my data” the changes you made will not be saved. You can log in at another time and start again.

**Contact Information** – Click the Contact Information link to the left to view or update at anytime.

Use this link to review or update your contact Information. You may have moved, added a winter home address, or want to update Information for your other contacts of friends or family. This information allows us to stay in contact with you or to find you through your other contacts if we need to tell you about changes in the study.

**Annual Booklet** – Click the Annual Booklet link to the left to complete your Annual Booklet.

The Annual Booklet contains questions about your health. You should have received an Annual Booklet in the mail so you can use this to see what type of questions you will be asked. You can complete your Contact Information and the Annual Booklet using the links above OR complete the Annual Booklet you received in the mail. Please complete either the mailed copy or the online version, but not both. If we do not receive your completed Annual Booklet online or by mail within three months from your birth month, you will receive another booklet in the mail.
Participant Contact Information For Centralized Follow-Up

For: SELECT ID Number: 961363

The SELECT Coordinating Center will use information you provide on this form to contact you for research related to SELECT. We will use other contacts you provide only if we are unable to get in touch with you. You do not have to answer questions that you do not want to answer. Please review and update this information every year or whenever you have changes to your contact information.

Section A: Your name, address and phone number.

1. Full legal name
   - Prefix: Mr.
   - First: John
   - Middle: a
   - Last: Smith
   - Family title: Mr.

2. Name you want on study correspondence (if different from above)
   - First: 
   - Last: 

3. Cell phone #: (123) 456-7890

4. E-mail address: select@crab.org

5. Primary mailing address
   - Street Address 1: 123 Main Street
   - Street Address 2: 
For: SELECT ID Number: 941363

1. Since September 30, 2009, did a health care provider check your PSA?
   - No
   - I don't know or I'm not sure
   - Yes

   1a. If you know the date of the test, please provide the date of your most recent PSA test:
   ___ / ___
   mm / yyyy

   1b. If you know your PSA number, please provide your most recent number: __________ ng/ml

   1c. If you do not know the PSA number from your most recent test, did your health care provider tell you it was
   (Mark only one):
   - High
   - Somewhat high
   - Normal
   - Undetectable or zero
   - I don't know or I'm not sure

2. Since September 30, 2009, did you have any treatments for your prostate cancer?
   - Yes
   - I don't know or I'm not sure
   - No
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Implementation Issues

• Staff support to handle technical questions
• Participants’ ability to follow instructions
• Duplication of submitting on-line data and mailing annual form
• Amount of use by participants
• Spanish translation of website
• Availability on PDAs and smartphones
• Cost effectiveness
Thank you

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