Implementing an On-line Tracking System© (OSTS©) for Collaborative Research Projects with Cancer Registries

Laura Holtby | June 22, 2010
NAACR Conference
Introduction

• Cancer registries play an important role in reducing the burden of cancer in North America.
  ✓ cancer control surveillance
  ✓ epidemiologic research
  ✓ evaluation of public health programs
  ✓ assessment of patient care

• Growing recognition of the contribution cancer registries can make to cancer control planning, implementation and resource management.
Background

• Learnings from previous multi-site studies emphasized the need for an online database system to meet the following criteria:
  ✓ Confidentiality is maintained across users
  ✓ Real-time communication tool
  ✓ Central repository for documentation

• Learnings from the 2007–Unmet Needs Pilot study with Manitoba Cancer Registry identified areas to improve:
  ✓ Simplify the recruitment outcomes tracking process.
  ✓ Communication by email/phone time consuming for staff.
  ✓ Difficult to manage overlap in mail-outs with the receipt of completed questionnaires.
The Challenge

For the 2009 – Unmet Needs study conducted with Nova Scotia and Alberta Cancer Registries:

- How could we develop an on-line system to address the following criteria?
  - Ensure participant confidentiality
  - Minimize time and cost on Registry staff for research activities to link Study ID’s for mail-outs.
  - Reduce burden on study participants with real-time documentation in a central location.
  - Maximize efficiency and accuracy of collecting data.
• Development of an Online Tracking System (OSTS)
• System features designed for all project staff
• Feedback from Registry staff about using OSTS
• Future implications of these systems
Online Survey Tracking System (OSTS)

• What is OSTS?

  “It is more than a database....it’s a system!”

• Custom built using ColdFusion MX7 server technology and MySQL4.1 backend database.

• Security Features include: SSL security certificate, Login/password, Daily data backup.
Purpose & Benefits of OSTS

• Maintains confidentiality of study participants
• Compatible with Registry data files
• Allows all users to access the system simultaneously
• Monitors and tracks project progress in real-time
• Provides a central repository for documentation
• Ensures consistent execution of project protocols
• Minimal training required to use the system
OSTS Features

• Message Board
• Data Collection Checklist
• Study ID lists generated in EXCEL
• Update Registry Records
• Participant Tracking documentation
• Real-time participation statistics
Message Board: Real-Time Communication

Survivorship Study 2009

Welcome to the Survivorship Study

Thanks for your involvement with the Survivorship Study!

Please direct inquiries to the project staff listed below:

Stephanie Filsinger
Project Coordinator
519-888-4567 x32278
sfilbin@uwaterloo.ca
Hours: M-F, 8:00am-4:00pm

Laura Holby
Project Manager
519-888-4567 x36337
lholby@uwaterloo.ca
Hours: M-F, 8:30a to 4:30p

If you require technical support, please email: survivorship@healthy.uwaterloo.ca

Administration:

*NO PROJECT SELECTED*
Select the project you would like to work on

SURVIVORSHIP 2009-NS
SURVIVORSHIP 2009-AB

Message Board

Hi Rosalee,
Just wanted to let you know that the shipment for Mailing A has been sent out today.

Please let me know when you receive this shipment.

Have a great day!
Laura (click to edit)

Hi Laura,
We received the shipment today!
We will keep you updated about when the letters are sent out.

Laura (click to edit)
### Checklist for Mailing Cycles

Click on a mail-out cycle below (A-E, X) for further details or to record mail-out information.

<table>
<thead>
<tr>
<th>Mailing Cycle</th>
<th>Prepared By</th>
<th>Couriered to CCS</th>
<th>Tracking #</th>
<th>Mailed to Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Pre-notification Letter</td>
<td>UW &amp; CCS</td>
<td>Oct 6, 2009</td>
<td>00011646</td>
<td>Oct 9, 2009</td>
</tr>
<tr>
<td>B. 1st Questionnaire Package</td>
<td>UW</td>
<td>Oct 14, 2009</td>
<td></td>
<td>Oct 20, 2009</td>
</tr>
<tr>
<td>(1 week after pre-notification letter mailing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. 2nd Questionnaire Package</td>
<td>UW</td>
<td>Nov 6, 2009</td>
<td></td>
<td>Nov 13, 2009</td>
</tr>
<tr>
<td>(2-3 weeks after 1st questionnaire package mailing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. 1st Reminder Letter</td>
<td>UW</td>
<td>Nov 30, 2009</td>
<td></td>
<td>Dec 4, 2009</td>
</tr>
<tr>
<td>(2-3 weeks after 2nd questionnaire package mailing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. Final Reminder Letter and Non-Respondent Questionnaire</td>
<td>UW</td>
<td>Jan 29, 2010</td>
<td></td>
<td>Feb 8, 2010</td>
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<tr>
<td>(2-3 weeks after 2nd reminder package mailing)</td>
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<tr>
<td>X. Replacement Mailing</td>
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<tr>
<td>(As required up to the end of data collection)</td>
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</tr>
</tbody>
</table>
B. 1st Questionnaire Package

1. Generate Labels with Study ID Numbers:
   - Survey (Survivor & Support)
   - Envelope (Survivor Only)
   - Excel File (CCS)

2. Number of packages prepared:
   - Both (S+P): 850
   - Survivor Only: 0
   - Support Only: 0
   - Total: 850

3. Prepared By:
   - UW
   - Sent to CCS: 10/14/2009
   - Tracking #: 

4. Generate List of Surveys Received Late
   - Late Received Excel File (CCS)

5. Number or packages sent:
   - Both (S+P): 821
   - Survivor Only: 0
   - Support Only: 0
   - Total: 821
Participant Tracking: Central Documentation

Survivorship Study 2009

Survey Status for Study ID: S481001B

Participant Role: Survivor

Gender: Female

Initial Cancer Diagnosis: Breast
Age of First Diagnosis:
Have a Support Person: Yes

Survey Mailing Outcomes:

<table>
<thead>
<tr>
<th>Mailing Cycle</th>
<th>Participant Outcome</th>
<th>Outcome Date</th>
<th>Response Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. 1st Questionnaire</td>
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</tbody>
</table>
Update Registry Records

Survivorship Study 2009

Survey Status Summary

Participant Role
Gender

Outcome
Mailing Cycle

All Participants with an Outcome
All Participants with No Outcome

Enter the Study ID preceded by S or P to identify whether the participant is a Survivor "S" or Support Person "P" followed by the appropriate Mailing Cycle letter A-E, X (e.g. S1230001B).

StudyID

Search
Survivor and Support Person: Response Rate Summary
Sunday, June 6, 2010

Survivor Response Rate (ProjectID = 12)

<table>
<thead>
<tr>
<th>Details</th>
<th>Complete</th>
<th>Partially completed</th>
<th>Refused - do not have any needs</th>
<th>Refused - do not have cancer</th>
<th>Refused - language</th>
<th>Refused - not interested</th>
<th>Refused - offended by survey</th>
<th>Refused - other</th>
<th>Refused - reason unknown</th>
<th>Refused - returned blank</th>
<th>Refused - unable to complete</th>
<th>Removed - completed but not received</th>
<th>Removed - deceased</th>
<th>Removed - other</th>
</tr>
</thead>
<tbody>
<tr>
<td>850 Sent</td>
<td>446 (52.5%)</td>
<td>9 (1.1%)</td>
<td>12 (1.4%)</td>
<td>19 (2.2%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>15 (1.8%)</td>
<td>1 (0.1%)</td>
<td>33 (3.9%)</td>
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<tr>
<td>795 Eligible</td>
<td>(93.5%) Percent of total sent</td>
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<tr>
<td>546 responded</td>
<td>(68.7%) Percent of eligible</td>
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</tbody>
</table>
Feedback from Registries

• Improves Collaborative Efforts

“OSTS can benefit a study center by improving collaboration efforts with a registry because of the reduced workload for registries. If the responsibilities of the registry can be minimized they are more likely to be able to participate”.

• Adaptable to meet the needs of Registry staff

“Because the Study Id lists from OSTS could be generated in Excel, this allows the registry to merge these files with their Master list file and perform fast, easy merge mail-out materials.”
• Reduces burden and stress on study participants

“We can immediately track the status of their questionnaires. This reduces stress for study subjects who may feel their questionnaire is lost or in limbo”.

“The late list ensures that a [participant can] be removed from the mail-out. Some [participants] get distressed by reminder letters when they have already returned their questionnaires so this is a great feature of the OSTS”.
Feedback from Registries

• Valuable communication tool
  “[OSTS] reduced the need for phone calls [between registry and research staff] because you could have questions answered and things clarified instantly.”

• User Friendly Resource
  “Sweet Program – User friendly. Excellent resource for recording information on study participants.”
Conclusions

• Using a system like OSTS© can improve collaboration between researchers and registries to enhance relationships, joint initiatives, and mutual learning in the area of cancer control by:

✓ Reducing stress on study participants.
✓ Ensuring the registry can meet their legal obligations for protection of privacy.
✓ Reducing the burden on front line registry staff.
✓ Improving the efficiency & accuracy of collecting data.
✓ Sharing information efficiently between registry and research staff.
As we integrate cancer practice, surveillance and research, such systems to assist with collaboration of Researchers and Registries will become invaluable:

- Needs assessment across the cancer continuum
- Sub-group studies – longitudinal studies, health equity, diverse population
- Population based intervention studies
- Health care utilization studies
Acknowledgements

• Cancer Care Nova Scotia:
  ✓ Maureen MacIntyre, Director Surveillance & Epidemiology Unit
  ✓ Rosalee Walker, Research Assistant
  ✓ Ron Dewar, Surveillance Analyst

• Alberta Health Services:
  ✓ Carol Russell, Provincial Manager, Alberta Cancer Registry
  ✓ Lorraine Cormier, Research Assistant
  ✓ Zhichang Jiang, Surveillance Analyst
Survivorship Research Team

✓ Sharon Campbell, Principal Investigator
✓ Stephanie Filsinger, Study Coordinator
✓ Laura Holtby, Research Manager
✓ Matt Vander Meer, Database Developer
✓ Janice Tiessen, Database Manager
THANK -YOU!

For Further Information about OSTS and the 2009 Unmet Needs Studies in Nova Scotia and Alberta contact:

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