

Collaborating with Cancer Registries to Conduct Survivorship Research Studies

Sharon Campbell | June 24, 2010
North American Association of Cancer Registries



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UNMET NEEDS STUDY: PURPOSE

Goal Provide evidence to guide health care decisions, resource allocation for increasing number of survivors

Study Purpose:

Develop and Validate Unmet Needs Survey
Identify Prevalence and Predictors of High Unmet Needs



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WHAT ARE UNMET NEEDS?

Definition

- Problem or concern for which a person is unable to get the help they need to resolve the problem.
- Distinguish between:
 - problems which a person experiences and
 - problems they wish help in managing.
- Informs action to be taken or resources to be provided, in order to attain optimal well-being.



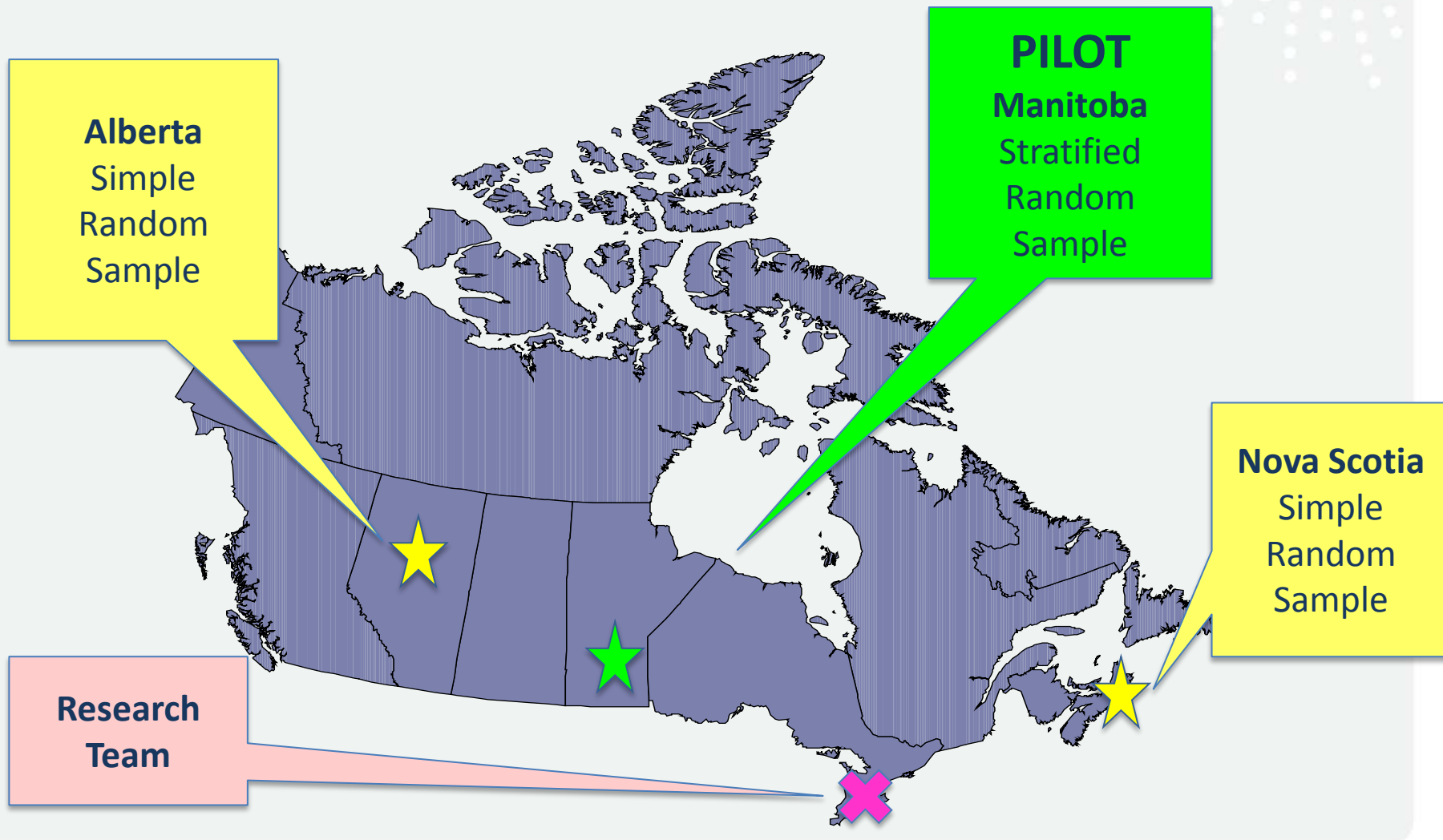
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COLLABORATED WITH THREE PROVINCIAL CANCER REGISTRIES



STUDY DESIGN

Random sample of survivors 12 to 60 months post diagnosis

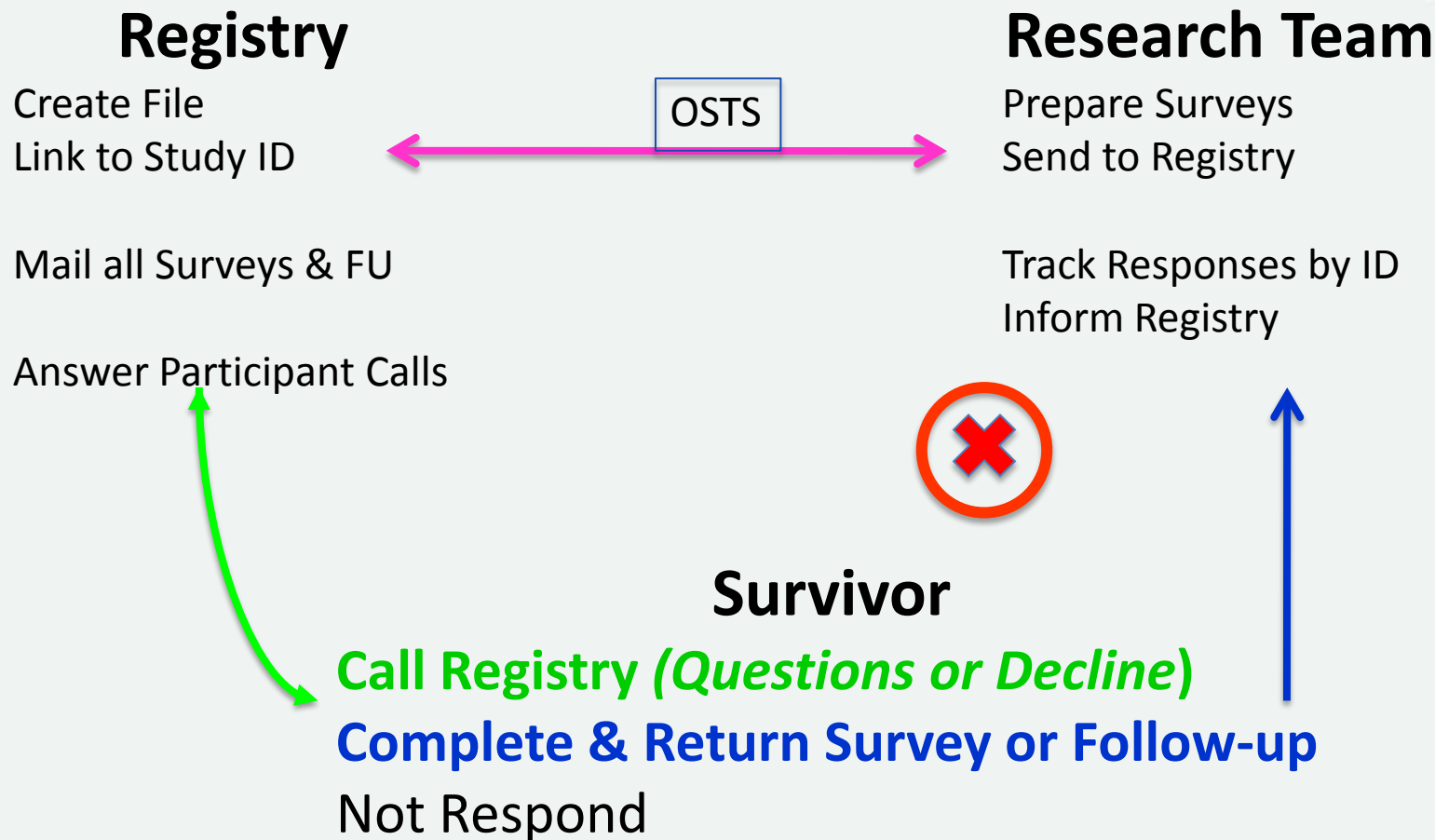
Mailed, self-administrated survey with follow-up

Unmet Needs, Cancer History, Health Care Utilization, Support, Demographics, *Quality of Life (NS, AB)*

ELIGIBILITY CRITERIA

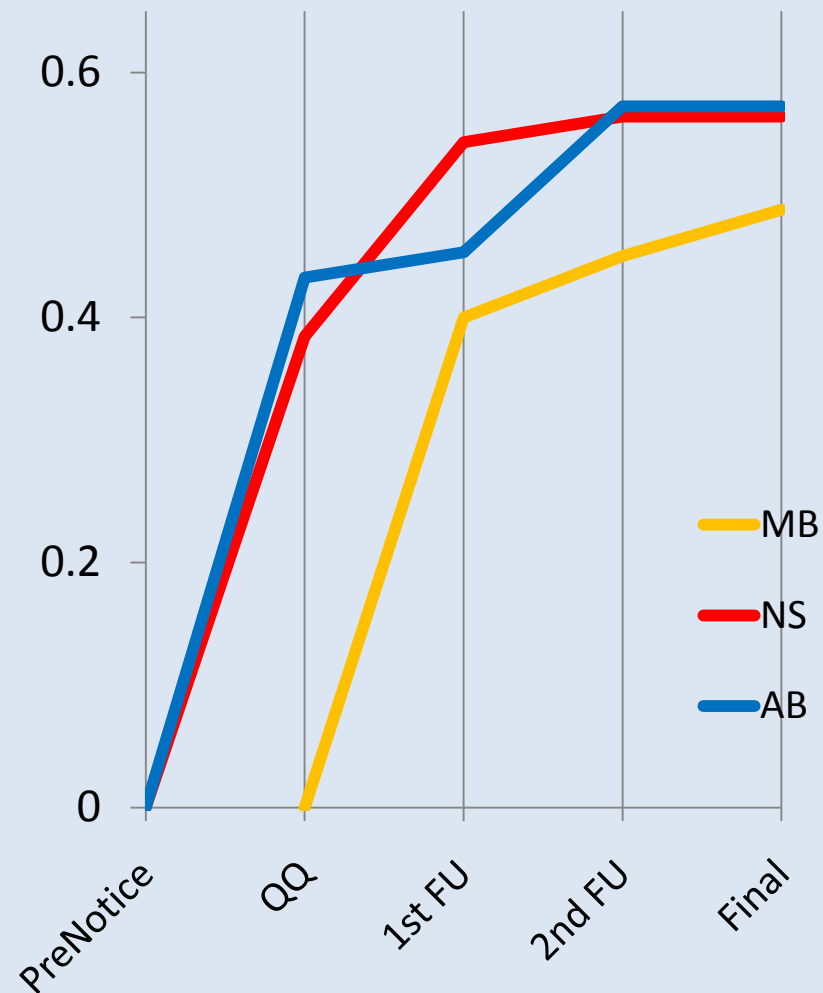
- 12 to 60 months since first diagnosis
- Currently alive
- Age 19 plus at diagnosis
 - NS: < 84 at dx
- Histologically confirmed
 - Exclude NMSC, in-situ, (*MB – neurologic*)
- Not declined research participation before

DATA COLLECTION PROCEDURES



RECRUITMENT PROTOCOL & COMPLETION RATE

| STEPS | MB | NS | AB |
|---------------------------|---------------|--------|-----------|
| Pre-notification letter | NO | YES | YES |
| Info Letter & Survey | First Contact | Quest | Quest |
| 1 st Follow-up | Quest | Quest | Post-Card |
| 2 nd Follow-up | Letter | Letter | Quest |
| Non-Respondent | NO | YES | YES |
| | | | |

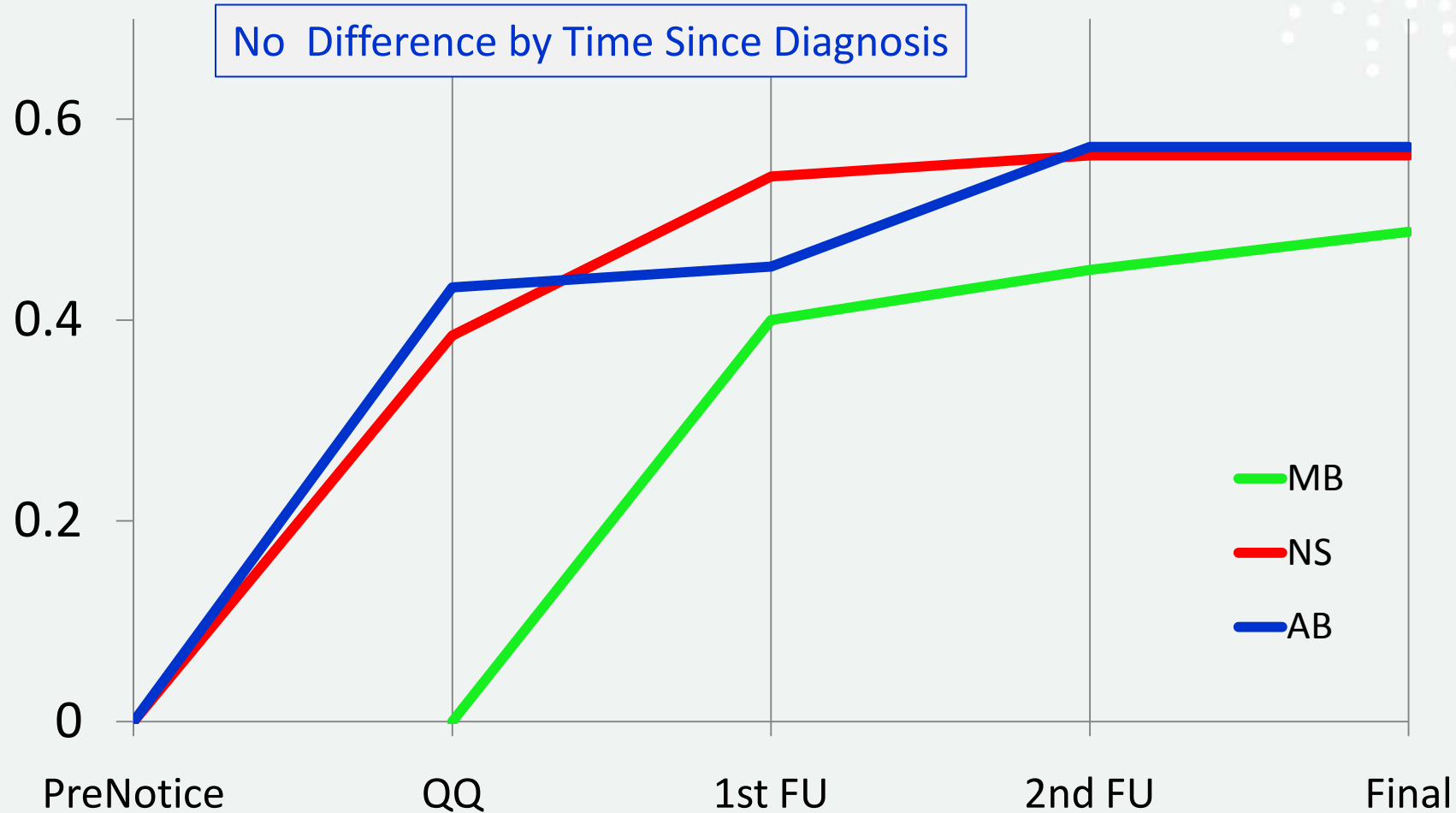


RECRUITMENT PROTOCOL

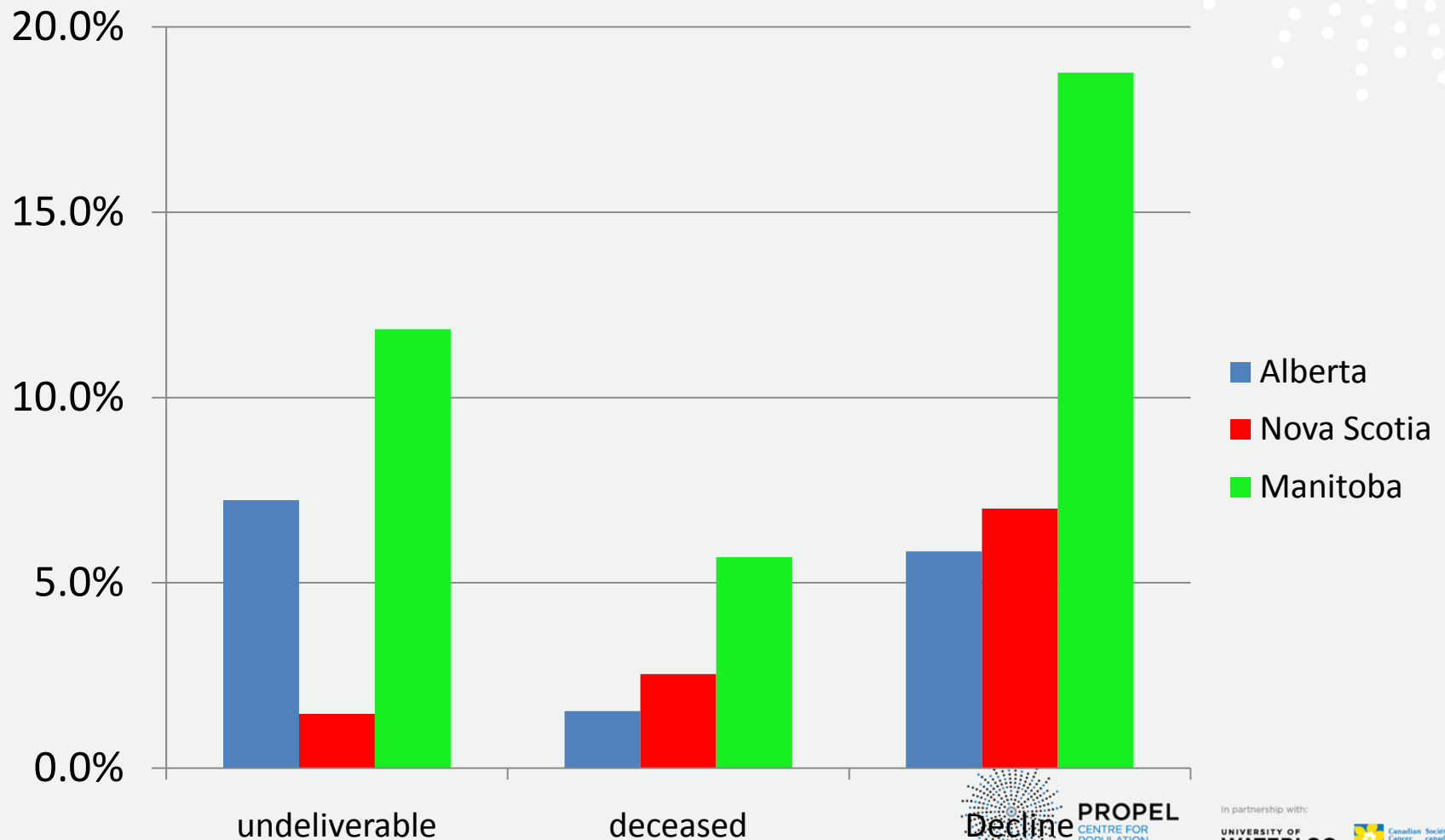
Varied by province to test best RR

| STEPS | MB | NS | AB |
|---------------------------|---------------|--------|-----------|
| Pre-notification letter | NO | YES | YES |
| Info Letter & Survey | First Contact | Quest | Quest |
| 1 st Follow-up | Quest | Quest | Post-Card |
| 2 nd Follow-up | Letter | Letter | Quest |
| Non-Respondent | NO | YES | YES |
| | | | |
| % Eligible | 70.5 | 84.5 | 82.8 |
| % Return | 49.0% | 64.6 | 63.0 |
| % Complete | 48.8 | 56.4 | 57.8 |
| | | | |

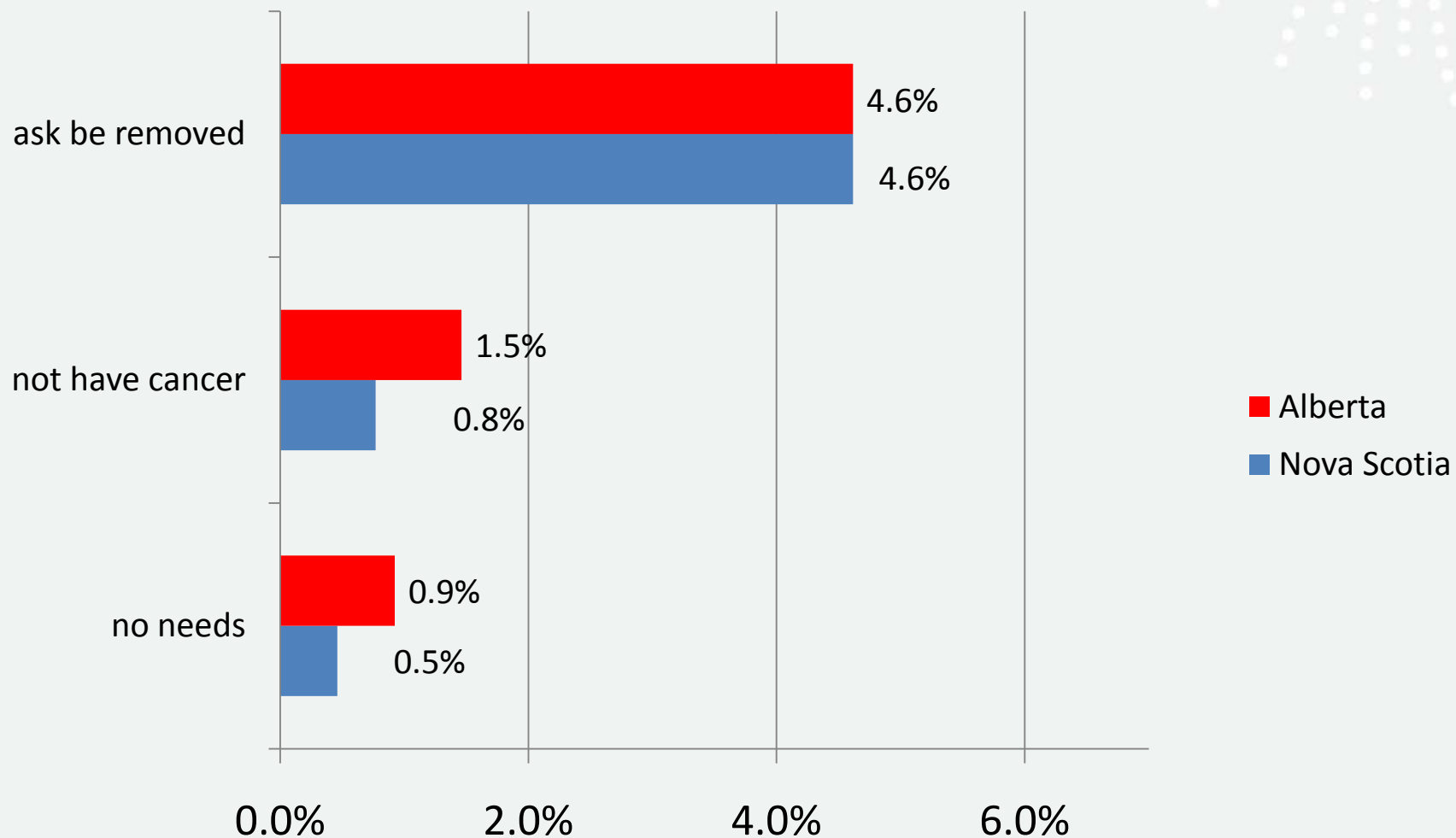
CUMULATIVE COMPLETION RATES



REASON FOR INELIGIBILITY



DECLINED PARTICIPATION:



REPRESENTATIVENESS

(preliminary)

Selection Criteria

% Female

Age 60 + at
Diagnosis

% Urban

Type of Cancer

Time since
Diagnosis

No Differences Between
Universe of Eligible Cases
, Random Sample or Completed
surveys



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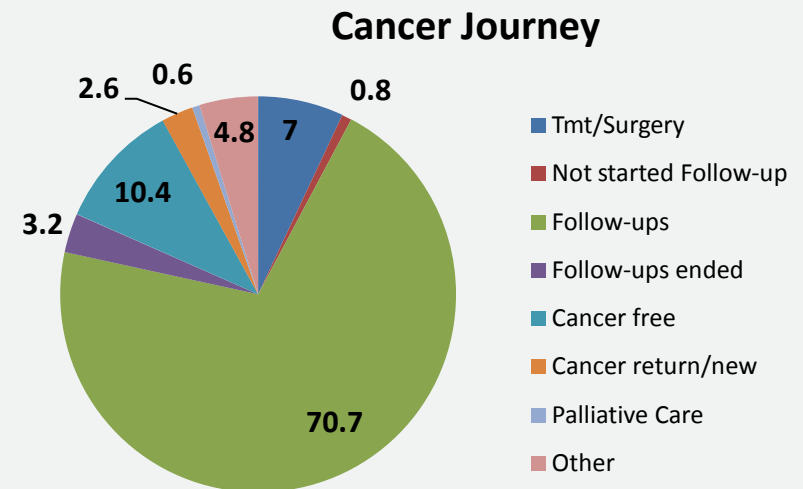
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RESULTS – Disease Variables

- Small % reported a recurrence or spread of their cancer (5.9%) or a new primary cancer (6.5 %), or both (8.2%).
- Interestingly, 10.4% of survivors felt they were cancer free.



RESULTS – PREVALENCE UNMET NEEDS

NO UNMET NEEDS (*Manitoba*)

- 148 (26.9%) of 550 survivors did not have any unmet needs at all in the last month (n=138) or had only one low unmet need (n=10).
- % of survivors with no unmet needs may be higher because many non-respondents called registry to say they were not participating because they had no unmet needs.



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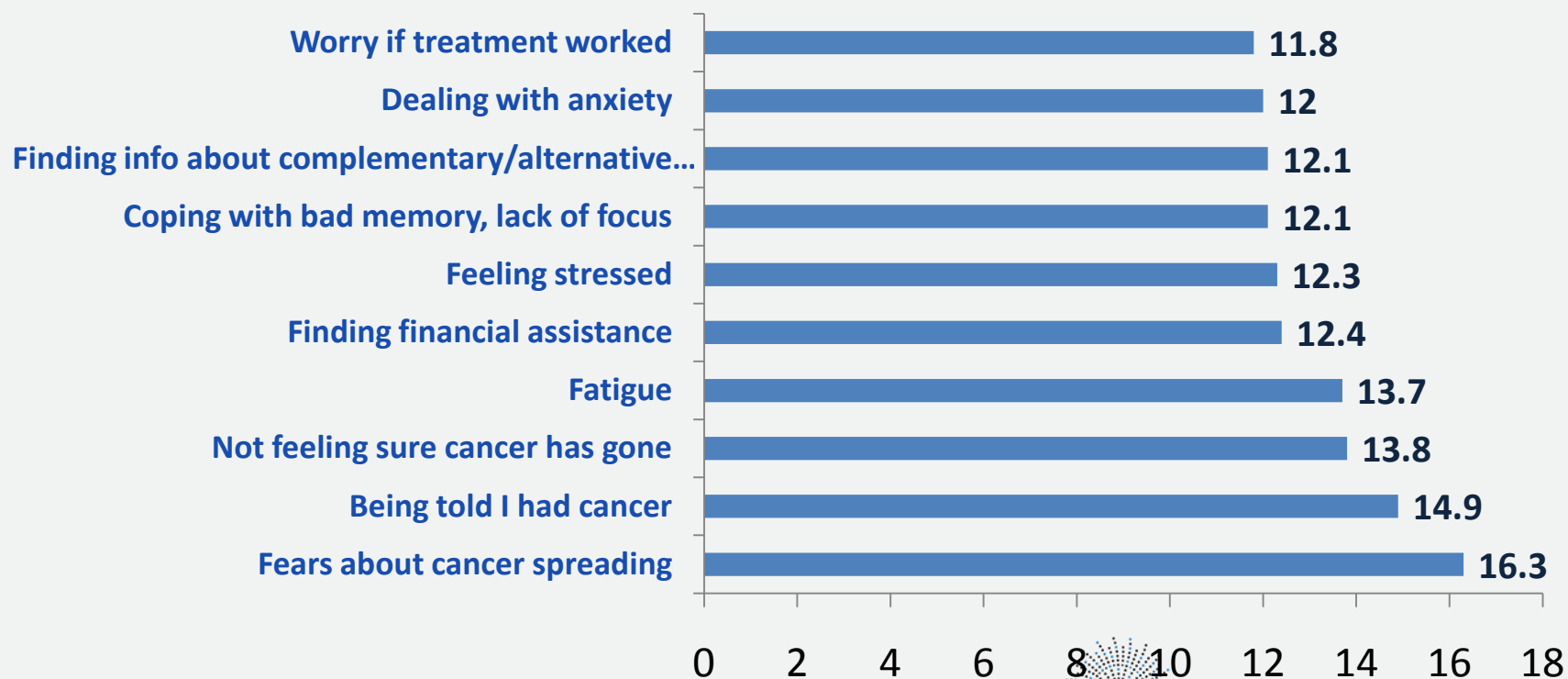
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RESULTS – Top 10 Unmet Needs

Top 10 Unmet Needs (Manitoba)



WORKING TOGETHER: Priorities

Researchers

- Representative sample
- High Response and Completion Rates
- Data Quality
- Time and Cost

Cancer Registry

- Patient Confidentiality*
- Patient Reactions
- Physician Reactions
- Data Quality
- Workload, Time and Cost

* NAACCR Workshop 2002

BENEFITS OF COLLABORATION

Researchers:

Population based cancer registries provide
almost complete sampling frame of survivors

Higher external validity

Registries:

Extend use of surveillance data to improve
survivors' health, quality of life

Potential to increase registry resources



ACKNOWLEDGEMENTS

RESEARCH TEAM

Provincial Cancer Registries

Manitoba

Donna Turner
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Huminara Khair

Nova Scotia

Maureen McIntrye
Rosalee Walker
Ron Dewar

Alberta

Carol Russel
Lorraine Cormier
Jhichang Jiang

University of Waterloo

Sharon Campbell
Stephanie Filsinger
Laura Holtby
Matt van De Meer
Matt Grey

Principal Investigator
Research Coordinator
Research Manager
Database Developer
Database Manager



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Canadian Cancer Society
Société canadienne
du cancer

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The Propel Centre for Population Health Impact™
is a partnership between the Canadian Cancer
Society and the University of Waterloo (UW).

For further information contact:

Stephanie Filsinger, Research Manager

Email: slfilsin@uwaterloo.ca