

**Data Workgroup  
October 21, 2008**

**I. Attendance**

Member	Present	Member	Present	Member	Present
Marlys Knell	X	Goldie Burnham		Julie Johnson	
Jacy Clarke		Michael Fishbein		Kay Dosch	
Willeen Druley		Judy Paradies	X	Mary Reiner	
Liyan Xu		Adeola J		Michelle West	
Anna Orlvoa		Corey Smith		Tinka Duran	
Lillian Tom-Orme	X	Tracy Baum		Leah Frerichs	
June Ryan	X	Cheri Hample		Shinobu Watanabe-Galloway	X

Guests:

Melissa Jim (IHS/CDC)  
Kate Hansen (UNMC)  
Nicole VanOsdel (UNMC)

**II. Agenda**

1. Critique of three Fact Sheet drafts
2. Critique of Breast Cancer
3. YRFS and other state survey access issues; RPMS data quality
4. IHS mortality data linkage update (Melissa Jim)

**III. Fact Sheet**

Shinobu Watanabe-Galloway presented three new Fact Sheets: (1) Cancer Incidence/Mortality, (2) Screening, and (3) Risk Factors.

- ❖ New fact sheets were developed for community members. They are more colorful and use larger print than previous version. The front side contains quiz and the other side display data in graphs and tables.
- ❖ Workgroup members and guests liked the new fact sheets.
- ❖ Workgroup members and guest reviewed each of three fact sheets and gave suggestions for changes – e.g., rephrasing and rewording to make some of statements more easily understood and read, inclusion of NPCCCP contact info at the bottom, changing incidence/mortality tables into graphs, inclusion of quit line number.
- ❖ For providers and public health professionals, similar fact sheets will be developed but without quiz. These fact sheets will be also laminated and include useful / simple facts about cancer.

**IV. Breast Cancer Presentation**

Shinobu developed a presentation about breast cancer burden, screening and risk factors for Macy's women's health event.

- ❖ Workgroup members and guests made suggestions for changes

**V. YRFS and other state surveys; RPMS data**

- ❖ Some survey data conducted by state health/education department or AATCHB cannot be accessed
- ❖ For example, to get the data from tobacco surveys conducted by AATCHB, we need permission from each tribe participated
- ❖ Shinobu contacted South Dakota and North Dakota Department of Education to obtain YRFS results. SD Dpt of Education informed that it is the department policy not to release the YRFS data. It is not clear why the data cannot be released. She will consult with Adeola to decide

how to proceed. Shinobu was also unable to obtain the data from ND. Marlys will contact ND Dpt of Ed staff to follow up.

- ❖ Northern Plains Tribal Epi Center (NPTEC) is working with Aberdeen IHS to access/use RPMS data. (To actually examine RPMS data, NPTEC needs to get an approval from each tribe)
- ❖ Lillian found limited use of RPMS data because of inaccurate and incomplete data. It appears that RPMS data quality varies across different service unit. There is still a lot of unknowns with RPMS data. The pilot study (gap analysis at Macy) will help us better understand the RPMS data quality and use of RPMS for cancer research/programming.

#### **V. Mortality data linkage project**

- ❖ Melissa Jim gave an update on the linkage project