Validity of Self-Reported Mammography in Manitoba

Erich Kliewer

Teresa Mayer

Marion Harrison

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1. Introduction

The utilization of screening mammography is often determined through self-reported information (1-6). Even where organized screening programs exist, self-reported information is often used to define incident and prevalent screens. Studies on the reliability and validity of self-reported mammography suggest that women accurately report if they have ever had a mammogram, but that they tend to underestimate the length of time since their previous mammogram (5, 7-9). Few of the existing studies have examined the accuracy of reporting of population subgroups (e.g. by rural/urban residence, socioeconomic status, birthplace, opportunistic or organized screening attendees), although differences have been reported (7,8,10). We are not aware of any published studies on the validity of self-reported mammograms among Canadian women.

The purpose of this study was to test the validity of self-reported mammography screening among various subgroups of Manitoba women. Self-reported information among a sample of the general population of Manitoba women (National Population Health Survey) and among women attending the Manitoba Breast Screening Program was compared with screening information recorded in Manitoba Health's physician billing files.

2. Methods

2.1 Data sources

In this study self-reported mammography information for women residing in the province of Manitoba was compared to mammography claims from the Manitoba Health Medical Claims database. Two sources of self-reported mammography were used: the 1996/97 National Population Health Survey (NPHS) and the Manitoba Breast Screening Program (MBSP) questionnaire for years 1995-99.

2.1.1 National Population Health Survey

In 1996/97 the second round of the NPHS was administered by Statistics Canada to a large sample of residents of Canada using a multi-stage cluster design to choose respondents. The NPHS was composed of two sections: (1) a general or household survey asked of all household members; and (2) a health section, in which only one family member age 13 years or more was selected. Data used in this report comes from those individuals who answered the health portion of the survey. First Nations communities and persons residing on Canadian Force Bases were not included in the sample for the NPHS.

For the 1996/97 NPHS, the Manitoba Government paid to increase the Manitoba sample size to enable more detailed research. The survey was completed by 11,431 residents of Manitoba, of which 3,573 were women aged 40 years and over. Only women 40 years of age and older were asked if they had had a mammogram. For our analyses we used the "share" data files which contain information for individual respondents. The NPHS asked respondents if they were willing to have their data linked to health records for research purposes and a special share file was created for individuals who agreed to have their questionnaires linked to health records for

research.¹ This file contains the Personal Health Identification Number (PHIN). Many respondents supplied a PHIN, but for those respondents who provided a Manitoba Health Services Insurance Plan (MHSIP) Registration Number or incorrect PHIN, the PHIN was determined by linking the NPHS file to the Manitoba Health Population Registry. Probabilistic linkage, based on name, birth date, sex and in some cases MHSIP Registration Number was used.

Of the 3,573 women aged 40 and over, 3,465 stated that their data could be linked for research purposes. Only 3,233 of these women had a successful match to a PHIN. Furthermore, only 3,167 women had valid (yes or no) responses to the question, "Have you ever had a mammogram, that is, a breast x-ray?" Women who did not answer the question (not stated or refused) were excluded from the study. In order to reduce the number of false-positives arising in our comparison with the physician claims data, only women who lived in Manitoba for five consecutive years before the NPHS interview were kept in the study. This reduced the total number of women in the survey to 3,121. This final sample size is 87.3% of all NPHS respondents who were women aged 40 and over and residents of Manitoba. Tables 1 has the frequency distributions of the characteristics of the women who were kept in the study and those who were excluded.

Age was calculated at the time of the last NPHS interview date, using Manitoba Health Population Registry birth date. Urban/Rural status was determined from the NPHS variable "GE36DURB". Urban includes Winnipeg and Brandon and all other areas were considered to be rural. Aboriginal ethnic origin indicates whether the respondent stated that their ethnic or cultural group was either (1) North American Indian, (2) Métis or (3) Inuit/Eskimo and race indicates whether the respondent stated that their geoples of North America or (3) North American Indian, Métis or Inuit/Eskimo.

Compared to the women included in the study, among the excluded women there was (Table 1):

- a greater percentage of women aged 70 and over but a lower percentage of 60-69 year old women
- a lower percentage of married women but a greater percentage of widowed
- a lower percentage of Canadian-born
- a greater percentage of women who spoke English and another language
- a lower percentage of women who had at a minimum graduated from high school

AM66-LNK 1 Yes 2 No

¹ The wording in the NPHS on linking survey data with administrative data is as follows:

LINK-INT

We are seeking your permission to link information collected during this interview with provincial health information. This would include information on past and continuing use of services such as visits to hospitals, clinics, doctor's offices or other services provided by the province. Do we have your permission?

- a greater percentage with income not stated but a lower percentage of women who earned \$30,000 or more
- a greater percentage of women with occupation 'not applicable'

		Inclu	ıded	Excluded		
Characte	pristics	Ν	%	Ν	%	
Age (years)	40-49	840	26.9	110	24.3	
	50-59	681	21.8	100	22.1	
	60-69	645	20.7	67	14.8	
	70+	955	30.6	175	38.7	
Region of residence	Rural	1,277	40.9	169	37.4	
	Urban	1,844	59.1	283	62.6	
Marital status	Single	148	4.7	33	7.3	
	Widow	912	29.2	156	34.5	
	Divorced/separated	262	8.4	45	10.0	
	Married/common-law/partner	1,791	57.4	214	47.4	
	Missing	8	0.3	4	0.9	
Country of birth	Canada	2,793	89.5	381	84.3	
	Not Canada	327	10.5	67	14.8	
	Unknown	1	0.0	4	0.9	
Ethnicity	Aboriginal	122	3.9	19	4.2	
	Non-Aboriginal	2,999	96.1	433	95.8	
Race	Native	102	3.3	16	3.5	
	Non-Native	3,018	96.7	434	96.0	
	Missing	1	0.0	2	0.4	
Languages spoken	English & Other	1,066	34.2	197	43.6	
	English only	2,039	65.3	249	55.1	
	No English	15	0.5	6	1.3	
	Not stated	1	0.0			
Education	Some high school or less	1,342	43.0	219	48.5	
	High school grad/degree/diploma	1,761	56.4	212	46.9	
	Missing	18	0.6	21	4.7	
Family income	No income or < \$30,000	1,420	45.5	200	44.3	
	\$30,000 or more	1,197	38.4	116	25.7	
	Not stated	504	16.2	136	30.1	
Occupation	Admin/science/arts/religion	526	16.9	68	15.0	
	Clerical/sales/services	609	19.5	71	15.7	
	Farming/fishing/forestry	56	1.8	4	0.9	
	Processing/construct/crafts	77	2.5	12	2.7	
	Not applicable	1,830	58.6	290	64.2	
	Not stated	23	0.7	7	1.6	

Table 1. Characteristics of women in the NPHS who were included and excluded in the analyses

Women who indicated that they had had a mammogram were asked, "When was the last time?" Valid responses were "less than 6 months ago, 6 months to less than one year ago, 1 year to less than 2 years ago, 2 years to less than 5 years ago, and 5 or more year ago, 7 For the analyses

than 2 years ago, 2 years to less than 5 years ago, and 5 or more years ago." For the analyses, women who responded "less than 6 months ago" and "6 months to less than one year ago" were aggregated to "less than one year ago." For these analyses looking at time since last mammogram, 10 additional women were excluded because they had a response of "don't know."

2.1.2 Manitoba Breast Screening Program

All women who attend The MBSP are given a self-administered questionnaire to obtain information on demographics, risk factors for breast cancer and relevant medical history. First time screeners are asked, "How many years ago was your last mammogram?" Possible answers are "less than 1", "between 1 and 2", "between 2 and 3", "between 3 and 4", "between 4 and 5", "more than 5" and "never had one." Women with invalid responses (missing, spoiled or no response) to this question were removed from the study. Prevalent screeners were asked, "Since your last screening visit have you had a mammogram?" Possible answers were "Yes" or "No".

The number of first time screeners in the years 1995 to 1999 was 59,616. Among these women, 277 had invalid, missing or spoiled responses to the question on self-reported mammogram. Of the 59,339 remaining women, 7 women did not successfully link to the MHPR file (PHIN could not be validated). A further 1,133 women did not live in Manitoba in the five consecutive years before the date of their MBSP screen and were excluded from the study. After these exclusions, 58,199 (97.6%) women were kept in the analyses. The characteristics of the incident screeners included and excluded from the analyses are shown in Table 2.

The amount of demographic and socioeconomic information that was available in the MBSP was limited. Age was calculated at the time of the MBSP screen date. Date of birth is provided by Manitoba Health from the population registry and verified when an appointment is made. Although in Tables 2 and 3 we identified the number of women under 50 years of age and over 69 years of age, they have been excluded from the remainder of the analyses. Urban/rural residence was based on the women's postal code at the time of the MBSP screen. Women were asked at their first screen what their highest level of education was, as well as their ethnic background.

Compared to the women included in the study, among the excluded women there was:

- a greater percentage of women of Asian ethnicity but a lower percentage of women of Western and Eastern European ethnicity
- a greater percentage of women with 'Missing' education but a lower percentage with less than high school education
- a greater percentage of women who had their mammogram in 1999 and a lower percentage who had it in 1997

Characteristics		Inclu	ded	Excluded		
		Ν	%	Ν	%	
Age (years)	$< 50^{1}$	716	1.2	34	2.3	
	50-59	35,008	58.5	909	61.7	
	60-69	23,191	38.8	508	34.5	
	70+ ¹	902	1.5	22	1.5	
Region of residence	Rural	23,911	41.1	530	37.4	
	Urban	34,218	58.8	882	62.2	
	Missing	70	0.1	5	0.4	
Ethnic background	Canadian	3,754	6.5	101	7.1	
	Aboriginal	1,839	3.2	30	2.1	
	Asian	1,665	2.9	180	12.7	
	British	19,406	33.3	462	32.6	
	French	4,667	8.0	86	6.1	
	Western European	9,993	17.2	158	11.2	
	North European	2,278	3.9	43	3.0	
	Eastern European	9,351	16.1	154	10.9	
	South European	1,202	2.1	21	1.5	
	Other European	1,032	1.8	18	1.3	
	Other	653	1.1	40	2.8	
	Missing	2,359	4.1	124	8.8	
Education	Some high school or less	24,917	42.8	521	36.8	
	High school graduation	20,985	36.1	481	33.9	
	Degree or diploma	11,771	20.2	326	23.0	
	Missing	526	0.9	89	6.3	
Year	1995	2,567	4.4	60	4.2	
	1996	12,619	21.7	293	20.7	
	1997	16,633	28.6	328	23.2	
	1998	13,709	23.6	364	25.7	
	1999	12,671	21.8	372	26.3	

Table 2. Characteristics of incident screeners in the MBSP who were included and excluded in the analyses

1. Excluded for all analyses except that by age

There were 25,313 prevalent screeners in the years 1995 to 1999. A total of 355 women were excluded from the study. Of these, 207 were excluded because they lived in Manitoba for less than 5 consecutive years before their screen; 131 were excluded because the interval mammogram response was missing or spoiled; 17 were excluded because there was no record of a MBSP screen mammogram on the medical claims. The characteristics of the prevalent screeners that were included and excluded from the study are shown in Table 3. Education and ethnic background were obtained from the first-visit questionnaire. All other characteristics were from the prevalent screen survey.

Compared to the women included in the study, among the excluded prevalent screeners there was:

- a greater percentage of women with a degree or diploma
- a lower percentage of women who were screened in 1999

Table 3.	Characteristics	of prevalent	screeners	in the	MBSP	who	were	included	and	excluded	d in
the analy	yses										

Characteristics	Inc	luded	E	Excluded		
		N	%	N	%	
Age (years)	50-59	12,372	48.9	190	53.5	
	60-69	12,941	51.1	165	46.5	
Region of residence	Rural	10,126	40.0	157	44.2	
	Urban	15,159	59.9	197	55.5	
	Missing	28	0.1	1	0.3	
Ethnic background	Canadian	1,389	5.5	21	5.9	
	Aboriginal	466	1.8	8	2.3	
	Asian	505	2.0	17	4.8	
	British	9,468	37.4	146	41.1	
	French	1,969	7.8	19	5.4	
	Western European	4,176	16.5	54	15.2	
	North European	1,108	4.4	21	5.9	
	Eastern European	4,082	16.1	43	12.1	
	South European	459	1.8	2	0.6	
	Other European	446	1.8	5	1.4	
	Other	303	1.2	4	1.1	
	Missing	942	3.7	15	4.2	
Education	Some high school or less	10,437	41.2	129	36.3	
	High school graduation	9,870	39.0	136	38.3	
	Degree or diploma	4,818	19.0	87	24.5	
	Missing	188	0.7	3	0.9	
Year	1995			1	0.3	
	1996	142	0.6	7	2.0	
	1997	1,964	7.8	43	12.1	
	1998	8,953	35.4	142	40.0	
	1999	14,237	56.3	162	45.6	
Visit number	2	23,093	91.2	320	94.7	
	3	2,132	8.4	18	5.3	
	4	83	0.3			
	5	5	0.0			

2.1.3 Medical Claims

All physician claims for reimbursement of medical care in Manitoba are submitted to the single payer agency, MHSIP. All but a minority of physician services are provided on a fee-for-service basis. Many medical services provided in nursing stations on remote First Nations communities are not recorded, which will understate utilization of physician services in these areas. Medical claims include a billing tariff code that indicates any procedures performed and an ICD-9-CM

code (to three digits) for one diagnosis and the date of service. For this project, all medical claims (physician and radiology billings) for mammography for all women in the province were retrieved from April 1984 to March 1999. Mammography claims were identified using five tariff codes: 7098 (bilateral mammogram), 7099 (unilateral mammogram), 7110 (unilateral xeroxmammography), 7111 (bilateral xeroxmammography) and 7104 (Manitoba Breast Screening program mammogram). Xeroxmammography is a now outdated process and was more prevalent before 1990.

For women who had a medical claims record with a mammogram tariff code, the most recent mammogram prior to the NPHS interview date was used to calculate the time from the survey date to the medical claims mammogram date. For the MBSP study, the date of the MBSP screen was used as the survey date.

Evidence of mammography on the Medical Claims files was considered to be the "gold standard." One limitation to the claims data is that it does not capture services occurring outside the fee for service system (e.g. those done in-hospital). Although this is believed to be a very small number relative to the total number of mammograms, it needs to be verified.

2.1.4 Manitoba Health Population Registry

The Manitoba Health Population Registry (MHPR), which contains the registration information for all individuals who are eligible for Manitoba medical insurance, was used to identify women who had migrated into the province subsequent to 1985 and for whom we may, therefore, not have complete information on their physician claims. The MHPR was also used to verify PHIN on both surveys.

2.2 Linkage process

The NPHS, MBSP and medical files all contained the PHIN. Therefore, a straight-forward deterministic linkage was undertaken to merge the NPHS and MBSP files to the medical claims.

2.3 Analyses

Analyses on agreement between the responses in the NPHS and MBSP to information in the medical claims file was undertaken for "ever had a mammogram" and for "time since last mammogram". The claims data were considered to be the "gold standard".

In order to determine the validity of self-reported "ever had a mammogram", concordance, sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and the kappa statistic were calculated. The methods for calculating these measures are described below. The analyses for "ever had a mammogram" were stratified according to various demographic and socioeconomic characteristics.

Figure 1. Self-report mammography compared to mammography from medical claims.



Concordance = ((a + d) / (a + b + c + d)) * 100Sensitivity = (a / (a + c)) * 100Specificity = (d / (b + d)) * 100Positive Predictive Value = (a / (a + b)) * 100Negative Predictive Value = (d / (c + d)) * 100

The Kappa statistic is a measure of nonrandom agreement between two measurements of the same categorical variable. Although the Kappa statistic is generally not used when there is a 'gold standard', we have reported it. Agreement for the kappa statistic is considered poor if it is less than 0.00, slight if it is 0.00-0.20, fair if it is 0.21-0.40, moderate if it 0.41-0.60, substantial if it is 0.61-0.80, and almost perfect if it is 0.81-1.00 (11).

Time since last mammogram was grouped into the following categories:

- Less than one year ago
- One year to less than two years ago
- Two years to less than five years ago
- Five or more years ago

Overall agreement was examined in two different ways. First, concordance was calculated for all women included in the study, i.e. women with mammograms and women without mammograms. Women with self-report and medical claims in the same time period were considered in concurrence. Also, women who stated they never had a mammogram and the medical claims also indicated that no mammogram had been done since at least 1984 were considered in concurrence. Concordance was then calculated by adding all women who had exact matches (self-report and medical claims time were the same) and dividing by the total number of women. (Figure 2). Another concordance percentage was calculated by determining whether a claims mammogram fell one year before or after the self-reported mammogram.

a
7

			Medical claims		
Self-report	<1 year ago	1-<2 years	2-<5 years	5+ years	Never
<1 year	\mathbf{x}_1				
1-2 years		X ₂			
2-5 years			X3		
5+ years				\mathbf{X}_4	
Never					X 5

Figure 2. Concordance for time since last mammogram.

Concordance = $((x_1 + x_2 + x_3 + x_4 + x_5) / \text{total number of women}) * 100$

3. Results

3.1 Ever had a mammogram

Sections 3.1.1-3.1.9 provide the results on the validity of self-report of ever having a mammogram. For the MBSP sample the tables refer to incident screeners. Prevalent screeners are discussed in Section 3.2

3.1.1 Total

A similar pattern with respect to the various validity measures was evident for both the NPHS and MBSP women (Tables 4, 5). Overall, the concordance was high in the NPHS (86.6%) and MBSP (91.2%). In both groups of women, the percentages for sensitivity and negative predictive values were in the high 90s, whereas specificity (NPHS 75.3%; MBSP 70.2%) and the positive predictive values (NPHS 79.3%; MBSP 89.5%) tended to be lower (Tables 4, 5). Thus, almost all women who had had a mammogram accurately stated that they had had one, however, a substantial proportion of women stated that they had had a mammogram although the claims data indicated that they had not had one. These patterns occurred fairly consistently across each demographic and socioeconomic strata that were examined (see following sections). Warnecke et al. reviewed a number of studies of the validity of self-reported mammography (12). The results of these studies, and a more recent one (7) were similar to ours, in that most found that the sensitivity of self-report was over 90% and that the sensitivity was considerably higher than the specificity. Few studies have reported on the NPV, but those who have, have found it to be over 90%, which is in keeping with our results (4, 6, 10, 13).

	Cla	aims							
NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Yes	1,503	393	1,896	86.6	98.3	75.3	79.3	97.9	0.73
No	26	1,199	1,225						
Total	1,529	1,592	3,121						

Table 4. Self-reported mammography in the NPHS compared to medical claims mammograms

Of women who reported that they had had a mammogram, 20.7% of the NPHS women and 10.1% of the MBSP women had not had one according to the medical claims. Some of this may be attributed to women having a mammogram in a hospital (which would not be captured in the

medical claims files) or out-of-province. While women who did not live in the province for five consecutive years prior to their mammogram were excluded from the analyses, women who moved into the province more than five years ago may have accurately reported a prior mammogram that was performed in their previous province/country of residence.

	Cla	ims							
MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Yes	41,634	4,880	46,514	91.2	99.5	70.2	89.5	98.2	0.76
No	216	11,469	11,685						
Total	41,850	16,349	58,199						

Table 5. Self-reported mammography in the MBSP compared to medical claims mammograms

With the exception of specificity, all of the measures of validity were higher among the MBSP women than among the NPHS women. Generally, this also occurred when the analyses were stratified by demographic and socioeconomic characteristics. However, in making comparisons between the NPHS and the MBSP women it needs to be noted that the NPHS women were a fairly representative sample of Manitoba women (other than Aboriginal women), whereas the MBSP women were those who attended the screening program and therefore may not be as representative. Furthermore, the NPHS sample, unlike the MBSP sample, included a substantial proportion of women less than 50 years of age and over 69 years of age.

3.1.2 Age

Generally, in both the NPHS and MBSP sample, women who were 70 years of age and over had the lowest score on the validity measures (Tables 6, 7). However, there were exceptions. For example, among the women in the NPHS, specificity was lowest for those aged 50-59. Women in the MBSP sample tended to score higher than those in the NPHS sample, although this pattern was not as consistent among women aged 60-69.

1 00		Claima				
by age g	roup					
Table 6.	Self-reported	mammography in the	e NPHS compared	to medical	claims mar	nmograms,

Age		Cl	aims							
group	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
40-49	Yes	343	98	441	87.6	98.2	80.0	77.7	98.5	0.75
	No	6	393	399						
50-59	Yes	456	67	523	89.6	99.1	69.7	87.2	97.5	0.74
	No	4	154	158						
60-69	Yes	387	68	455	89.0	99.2	73.3	85.1	98.4	0.76
	No	3	187	190						
70+	Yes	317	160	477	81.9	96.1	74.4	66.5	97.3	0.64
	No	13	465	478						
Total		1,529	1,592	3,121						

Age		Cla	ims							
Group	MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
<50	Yes	407	56	463	91.8	99.3	81.7	87.9	98.8	0.83
	No	3	250	253						
50-59	Yes	25,170	2,763	27,933	91.8	99.5	71.6	90.1	98.3	0.78
	No	123	6,952	7,075						
60-69	Yes	16,464	2,117	18,581	90.5	99.4	68.1	88.6	98.0	0.74
	No	93	4,517	4,610						
70+	Yes	554	102	656	88.3	99.3	70.4	84.5	98.4	0.74
	No	4	242	246						
Total		42,818	16,999	59,817						

Table 7. Self-reported mammography in the MBSP compared to medical claims mammograms, by age group

3.1.3 Region of residence

In the NPHS, women who lived in urban areas did not report their mammogram status as accurately as those who live in rural areas (Tables 8, 9). In the MBSP, however, the pattern was not as clear, as concordance, the PPV and the Kappa were higher among urban women. Some of the differences may have to do with the way urban and rural were defined in the two samples. In the NPHS urban areas were defined as "those continuously built-up areas having a population concentration of 1,000 or more and a population density of 400 or more per square kilometer based on the previous census." For the MBSP sample we determined urban residence based on postal code. The NPHS documentation noted that their "definition of urban/rural may not correspond to the areas which Canada Post identifies as urban or rural postal codes."

Table 8. Self-reported mammography in the NPHS compared to medical claims mammograms, by region of residence

		Cla	ims							
Residence	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Rural	Yes	626	146	772	87.8	98.4	77.2	81.1	98.0	0.76
	No	10	495	505						
Urban	Yes	877	247	1,124	85.7	98.2	74.0	78.0	97.8	0.72
	No	16	704	720						
Total		1,529	1,592	3,121						

Table 9. Self-reported mammography in the MBSP compared to medical claims mammograms, by region of residence

		Cla	ims							
Residence	MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Rural	Yes	14,258	2,855	17,113	87.8	99.5	70.2	83.3	99.0	0.73
	No	65	6,733	6,798						
Urban	Yes	27,330	2,014	29,344	93.7	99.5	70.1	93.1	96.9	0.78
	No	150	4,724	4,874						
Total		41,803	16,326	58,129						

3.1.4 Marital status

Divorced or separated women consistently had the highest percentages on the validity measures (Table 10). Widowed women tended to have the lowest validity of self-reported mammograms.

Marital		Cla	ims							
Status	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Married /	Yes	968	209	1,177	87.7	98.8	74.2	82.2	98.1	0.75
Partner	No	12	602	614						
Single	Yes	54	21	75	85.1	98.2	77.4	72.0	98.6	0.70
	No	1	72	73						
Widowed	Yes	346	137	483	83.7	96.7	75.3	71.6	97.2	0.68
	No	12	417	429						
Divorced /	Yes	131	24	155	90.5	99.2	81.5	84.5	99.1	0.81
separated	No	1	106	107						
Total		1,525	1,588	3,113						

Table 10. Self-reported mammography in the NPHS compared to medical claims mammograms, by marital status

3.1.5 Birthplace and ethnicity

All of the validity measures were higher for native-born Canadians than the foreign-born (Table 11). The differences were particularly evident for sensitivity and the negative predictive value, indicating that a greater proportion of the foreign-born stated that they had not had a mammogram when in fact they had. It should be noted that the number of immigrant women who stated that they had had a mammogram but for whom that could not be verified in the medical claims file, may be slightly inflated. We excluded from the analyses any woman who had not been a resident of Manitoba for the 5 years prior to her MBSP mammogram. It may well be that some of these immigrant women had had a mammogram in their home country more than five years ago and they would fall into our false positive category.

able 11. Self-reported mammography in the NPHS compared to medical claims mammograms, y country of birth

		Cla	ims							
Birthplace	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Canada	Yes	1,359	349	1,708	87.0	99.0	75.4	79.6	98.7	0.74
	No	14	1,071	1,085						
Other	Yes	144	44	188	82.9	92.3	74.3	76.6	91.4	0.67
	No	12	127	139						
Total		1,529	1,591	3,120						

As noted in Section 2.1.1 Aboriginal status was determined in the NPHS in two questions; one asked about ethnicity and the other about race. Regardless of how Aboriginal status was defined, the concordance, Kappa and PPV were lower among Aboriginal than non-Aboriginals (Tables 12, 13). On the other hand, the sensitivity and NPV were slightly higher among the Aboriginal

women. It should be noted, however, that the number of Aboriginal women included in the NPHS sample was small, as the survey only included those living outside of First Nations communities. A somewhat different pattern was observed in the MBSP, where, with the exception of specificity, the Aboriginal women scored lower on the validity measures than non-Aboriginal women (Table 14).

Table 12. Self-reported mammography in the NPHS compared to medical claims mammograms, by ethnicity

		Cla	ims							
Ethnicity	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Aboriginal	Yes	33	22	55	82.0	100.0	75.3	60.0	100.0	0.62
	No	0	67	67						
Non-	Yes	1,470	371	1,841	86.8	98.3	75.3	80.0	97.8	0.74
Aborigina	l No	26	1,132	1,158						
Total		1,529	1,592	3,121						

Table 13. Self-reported mammography in the NPHS compared to medical claims mammograms, by race

		Cla	ims							
Race	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Native	Yes	25	21	46	79.4	100.0	72.7	54.4	100.0	0.57
	No	0	56	56						
Non-	Yes	1,478	372	1,850	86.8	98.3	75.4	80.0	97.8	0.74
Native	No	26	1,142	1,168						
Total		1,529	1,591	3,120						

Table 14. Self-reported mammography in the MBSP compared to medical claims mammograms, by Aboriginal ethnic background

		Clai	ms							
Aboriginal	MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Aboriginal	Yes	781	214	995	86.8	96.5	79.2	78.5	96.7	0.74
	No	28	816	844						
Non-	Yes	39,249	4,473	43,722	91.4	99.6	69.3	89.8	98.3	0.76
Aboriginal	No	172	10,107	10,279						
Total		40,230	15,610	55,840						

In the MBSP, there was no consistency in the validity measures across the various ethnic groups (Table 15). Aboriginals had the lowest concordance (86.8%) and PPV (78.5%), while Other Europeans had the highest, 96.1% and 96.2% respectively. Women of Asian ethnicity had the highest specificity (85.7%) and Kappa (0.83), but the lowest sensitivity (96.3%) and NPV (93.6%). Women of British ethnicity had the lowest specificity (63.6%) and Kappa (0.71). Northern Europeans had the highest sensitivity (99.9%) and NPV (99.6), although there was not a great deal of variability between ethnic groups for these four measures.

There have not been previous studies that have had ethnic breakdowns similar to those in the NPHS or MBSP. Lawrence et al. examined the validity of self-reported mammograms among European Americans and Mexican Americans (11). They found the sensitivity to be lower among the Mexican Americans but that there was no difference in specificity. Hiatt et al. also found that sensitivity was lower among Hispanics than non-Hispanics, but that specificity was significantly higher among Hispanics (14).

		Cla	ims							
Ethnicity	MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Canadian	Yes	2,559	380	2,939	89.5	99.5	67.9	87.1	98.4	0.74
	No	13	802	815						
Aboriginal	Yes	781	214	995	86.8	96.5	79.2	78.5	96.7	0.74
	No	28	816	844						
British	Yes	14,204	1,885	16,089	90.1	99.8	63.6	88.3	99.1	0.71
	No	31	3,286	3,317						
French	Yes	3,498	372	3,870	91.8	99.6	67.8	90.4	98.4	0.75
	No	13	784	797						
N. Europe	Yes	1,617	193	1,810	91.4	99.9	70.7	89.3	99.6	0.77
	No	2	466	468						
W. Europe	Yes	7,325	723	8,048	92.5	99.6	72.6	91.0	98.4	0.79
	No	31	1,914	1,945						
E. Europe	Yes	6,810	655	7,465	92.8	99.7	74.0	91.2	98.9	0.80
	No	21	1,865	1,886						
S. Europe	Yes	881	93	974	91.4	98.8	70.0	90.5	95.2	0.75
	No	11	217	228						
Other Eur	Yes	908	36	944	96.1	99.6	70.0	96.2	95.5	0.79
	No	4	84	88						
Asian	Yes	982	92	1,074	92.2	96.3	85.7	91.4	93.6	0.83
	No	38	553	591						
Other	Yes	465	44	509	92.0	98.3	75.6	91.4	94.4	0.79
	No	8	136	144						
Total		40,230	15,610	55,840						

Table 15. Self-reported mammography in the MBSP compared to medical claims mammograms, by ethnic background

3.1.6 Language spoken

In the NPHS sample there were very few women who did not speak English, thus the reliability of the results for these women is low (Table 16). There were only minor differences in the validity measures between women who spoke only English and those who spoke English as well as another language.

		Cla	ims							
Language	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
English	Yes	978	264	1,242	86.4	98.7	74.8	78.7	98.4	0.73
only	No	13	784	797						
English &	Yes	522	127	649	86.9	97.6	76.1	80.4	96.9	0.74
other	No	13	404	417						
No English	Yes	3	2	5	86.7	100.0	83.3	60.0	100.0	0.67
	No	0	10	10						
Total		1,529	1,591	3,120						

Table 16. Self-reported mammography in the NPHS compared to medical claims mammograms, by language(s) spoken

3.1.7 Education level

Although the differences tended to be small, women who had not graduated from secondary school tended to score lower on the validity measures than those who had. The exceptions to this were the NPV among the NPHS sample (Table 17) and the specificity and Kappa among the MBSP women (Table 18). In the MBSP sample the specificity was considerably lower among women with more education.

Table 17. Self-reported mammography in the NPHS compared to medical claims mammograms, by education level

Education		Clai	ims							
level	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
< high	Yes	583	192	775	84.9	98.1	74.3	75.2	98.1	0.70
school grad	No	11	556	567						
High schoo	lYes	916	199	1,115	87.9	98.4	76.0	82.2	97.7	0.75
grad+1	No	15	631	646						
Total		1,525	1,578	3,103						

1. High school graduate / degree / diploma

Table 18. Self-reported mammography in the MBSP compared to medical claims mammograms, by education level

Education		Cla	ims							
level	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
< high	Yes	16,168	2,294	18,462	90.2	99.1	73.3	87.6	97.6	0.77
school grad	No	153	6,302	6,455						
High schoo	l Yes	25,128	2,549	27,677	92.1	99.8	66.4	90.8	99.0	0.75
grad+1	No	51	5,028	5,079						
Total		25,179	7,577	32,756						

1. High school graduate / degree / diploma

Since the MBSP sample included a large number of women, we disaggregated women with at least a high school diploma into 'high school graduation' and 'degree or diploma'. The trends in

the various validity measures were fairly consistent, although the differences tended to be small (Table 19). Concordance, sensitivity, PPV and NPV increased with increasing education, but the reverse was true for specificity and Kappa.

Education		Clain	ns							
level	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
< secondary	/ Yes	16,168	2,294	18,462	90.2	99.1	73.3	87.6	97.6	0.77
graduation	No	153	6,302	6,455						
High school	l Yes	15,941	1,678	17,619	91.8	99.8	66.5	90.5	98.9	0.75
graduation	No	37	3,329	3,366						
Degree or	Yes	9,187	871	10,058	92.5	99.9	66.1	91.3	99.2	0.75
diploma	No	14	1,699	1,713						
Total		41,500	16,173	57,673						

Table 19. Self-reported mammography in the MBSP compared to medical claims mammograms, by education level

3.1.8 Occupation

Although the differences were small, of those women with an occupation, validity of self-reported mammogram tended to be lowest for those women who worked in farming, fishing or forestry (Table 20). The only exception was for specificity where they and women in processing, construction and crafts had the highest values.

Table 20. Self-reported mammography in the NPHS compared to medical claims mammograms, by occupation

		Cla	ims							
Occupation	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Admin ¹	Yes	284	60	344	88.2	99.3	75.0	82.6	98.9	0.76
	No	2	180	182						
Clerical ²	Yes	320	70	390	87.9	98.8	75.4	82.1	98.2	0.75
Farming ³	No	4	215	219						
Farming ³	Yes	25	6	31	87.5	96.2	80.0	80.7	96.0	0.75
	No	1	24	25						
Processing ⁴	Yes	35	8	43	88.3	97.2	80.5	81.4	97.1	0.77
	No	1	33	34						
Not	Yes	829	247	1,076	85.5	97.9	74.9	77.0	97.6	0.71
applicable	No	18	736	754						
Total		1,519	1,579	3,098						

1.Administration/science/arts/religion 2. Clerical/sales/services 3. Farming/fishing/forestry

4. Processing/construction/crafts

3.1.9 Income

With the exception of specificity, the values on the validity measures were lower for low income women (Table 21).

		Cla	ims							
Income	NPHS	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
No income,	Yes	576	195	771	85.2	97.5	76.5	74.7	97.7	0.71
<\$30,000	No	15	634	649						
>=\$30,000	Yes	675	128	803	88.6	98.7	75.1	84.1	97.7	0.76
	No	9	385	394						
Not stated	Yes	252	70	322	85.7	99.2	72.0	78.3	98.9	0.71
	No	2	180	182						
Total		1,529	1,592	3,121						

Table 21. Self-reported mammography in the NPHS compared to medical claims mammograms, by Income

Some studies have examined the accuracy of self-reported mammograms among education, employment and income groups (4, 13). They have generally found little differences across various socioeconomic status groups. In this study the differences in concordance and the overall kappa were small. The largest differences occurred in specificity, which was lower among those with lower education and lower income.

3.1.10 Timing of last mammogram

The distribution of the self-reported date of last mammogram compared to the date recorded in the medical claims is shown in Table 22 for the NPHS sample and in Table 23 for the MBSP sample. The overall concordance on both groups was similar (NPHS 70.9%; MBSP 67.6%). If concordance was calculated by assuming agreement if the physician claims file mammogram was one year before or after the self-reported mammogram, the concordance increased to 84.3% in the NPHS and 83.6% in the MBSP.

					Ν	Medical C	Claims				
	<1 year ago		1-<2	years	2-<5	years	s 5+ years		None		Total
NPHS	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%	
<1 year	594	70.1 ¹	132	15.6	31	3.7	19	2.2	71	8.4	847
1-2 years	40	9.6	181	43.6	123	29.6	16	3.9	55	13.3	415
2-5 years	7	1.9	40	11.0	142	39.0	56	15.4	119	32.7	364
5+ years	0	-	5	1.9	23	8.8	88	38.8	144	55.4	260
Never	4	0.1	7	0.6	3	0.2	12	1.0	1,199	97.9	1,225
Total	645	20.7	365	11.7	322	10.4	191	6.1	1,588	51.0	3,111

Table 22. Distribution of date of self-reported mammogram in the NPHS compared to the date in the medical claims

1. Row percentage

Concordance = 70.9%

Concordance "within one year" of mammogram claims = 84.2%

For the NPHS women, the percent agreement between the self-reported date and the date in the medical claims decreased with increasing time since last mammogram. Of women who stated they had had a mammogram within the last year, 70.1% were confirmed in the medical claims file. This decreased substantially to 43.6% for women who reported they had had a mammogram 1-2 years ago. For women who reported their mammogram was 2 or more years ago the agreement was 39%. For women in the MBSP sample there was not a clear trend in the accuracy of self-report with time since last mammogram. Only 38.6% of women who reported they had had a mammogram in the last year were confirmed in the medical claims. The highest agreement was for women who had a mammogram between 2-5 years ago (66.1%).

	Medical Claims											
	<1 year ago		1-<2 years		2-<5 years		5+ years		None		Total	
MBSP	Ν	%	Ν	%	Ν	%	Ν	%	Ν	%		
<1 year	160	38.6 ¹	180	43.5	41	9.9	9	2.2	24	5.8	414	
1-2 years	977	5.5	10,243	58.2	5,721	32.5	272	1.5	409	2.3	17,622	
2-5 years	109	0.5	2,541	11.8	14,192	66.1	2,764	12.9	1,871	8.7	21,477	
5+ years	19	0.3	78	1.1	1,077	15.4	3,282	46.9	2,545	36.4	7,001	
Never	16	0.1	20	0.2	76	0.7	112	1.0	11,461	98.1	11,685	
Total	1,281	2.2	13,062	22.4	21,107	36.3	6,439	11.1	16,310	28.0	58,199	

Table 23. Distribution of date of self-reported mammogram in the MBSP compared to the date in the medical claims

1. Row percentage

Concordance = 67.6%

Concordance "within one year" of mammogram claims = 83.6%

It is not clear why the pattern of agreement was different for the NPHS women than for the MBSP women, particularly for women who reported they had had a mammogram in the last year. Of the 180 MBSP women who stated they had had a mammogram less than a year ago but in fact had had it between 1 and 2 years ago, 61 had had their mammogram 13 months ago and 107 had had it 13-15 months ago. If the time since last mammogram categories is collapsed to less than two years ago, then there was 82.1% agreement among these women, which is similar to the NPHS (85.7%).

One reason for the discrepancy between the MBSP and the medical claims is that women may knowingly state their last mammogram was more than a year ago, when in fact their last mammogram was within the past 12 months. Women who participate in the MBSP receive a letter of invitation that states "If you have not had a mammogram in the past 12 months... please phone to make an appointment." Thus, women may report that their previous mammogram was more than a year ago in order to be eligible to attend the MBSP.

In both groups women tended to over estimate how recently they had had their mammogram. Among NPHS women who inaccurately reported the date of the mammogram (n=907), 84.5% said they had had a mammogram more recently than indicated by the medical claims. Among the MBSP women this phenomenon was not as large, but still substantial (73.4%). Similar findings have been reported in other studies (5, 7-9).

3.2 MBSP prevalent screeners

As noted in 2.1.2, the MBSP data allowed for the separation of incident and prevalent screeners. The scores on several of the validity measures varied considerably between prevalent screeners (Table 24) and incident screeners (Table 4). The sensitivity was much lower among prevalent screeners (61.1%) than incident screeners (99.5%), while the reverse was true for specificity (prevalent screeners 99.2%, incident screeners 70.2%). Thus a greater proportion of prevalent screeners than incident screeners stated they had not had a mammogram when in fact they had one according to the medical claims. In contrast, a greater proportion of incident screeners than prevalent screeners stated they had had a mammogram when in fact the claims did not show that they had had one. We repeated the analysis where self-reported mammogram was flagged as "yes" if medical claims recorded last mammogram was done within three (Table 25) and six months (Table 26) after the prior screen. Although the sensitivity improved, it remained substantially lower than that in the incident screeners.

Table 24. Self-report mammography in the MBSP compared to medical claims mammograms, prevalent screeners

	Cla	aims							
MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Yes	1,047	192	1,239	96.6	61.1	99.2	84.4	97.2	0.69
No	667	23,407	24,074						
Total	1,714	23,599	25,313						

Table 25. Self-report mammography in the MBSP compared to medical claims mammograms, prevalent screeners.¹

	Cla	aims							
MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa
Yes	1,338	192	1,239	97.8	78.1	99.2	87.5	98.4	0.81
No	367	23,407	24,074						
Total	1,714	23,599	25,313						

1. Self-report was flagged as "yes" if medical claims recorded last mammogram was done within three months after the prior screen.

Table 26. Self-report mammography in the MBSP compared to medical claims mammograms, prevalent screeners.¹

	Cla	Claims									
MBSP	Yes	No	Total	Concord	Sens	Spec	PPV	NPV	Kappa		
Yes	1,398	192	1,239	98.0	81.6	99.2	87.9	98.7	0.84		
No	316	23,407	24,074								
Total	1,714	23,599	25,313								

1. Self-report was flagged as "yes" if medical claims recorded last mammogram was done within six months after the prior screen.

Self-report by prevalent screeners in the MBSP has never been analyzed in detail. These results have shown that there are inconsistencies in the interpretation of questions by both women and

MBSP staff. Women are asked if they have had a mammogram since their last visit to determine if they are still eligible to be screened. Mammograms done in follow-up to a screening abnormality were considered by some staff to be part of the screening episode and were not recorded as an interval mammogram. Some women also identified their last screen as an interval screen and because the questionnaire is self-administered, these mistakes were not always identified by staff.

4. Discussion and Conclusions

This study has examined the validity of self-reported mammography by comparing self-reported information in the NPHS and MBSP with data recorded in Manitoba Health's physician claims files. By having a population-based 'gold standard' it was possible to measure validity more accurately than many of the previous validity studies.

The results of this study indicate that while overall concordance between self-reported mammogram and the medical claims file was good, and the sensitivity and the NPV were high, specificity and the PPV were low. Thus, women who had a mammogram tended to accurately report that they had had one, but a fairly large proportion of women who had not had a mammogram, stated that they had had one. The low specificity and PPV may be partially attributed to the limitations of this study, which are described below.

Although the physician claims data were considered to be the "gold standard' there are limitations with this data source; mammograms that are done in hospital or out of province are not included. The proportion is thought to be small but needs to be quantified.

It is unlikely that many women had a mammogram outside of Manitoba while they were residents of Manitoba. However, women who moved to the Manitoba, may well have had a mammogram in their prior province/country of residence. We attempted to limit the impact of migrant women by only including women who had been residents of Manitoba for at least five years. Ideally the analyses would have included only women who had been residents of Manitoba for a longer period of time. Manitoba Health is currently in the process of extending their population registry back to 1970. When that is complete we could determine how many women in the NPHS and MBSP sample were migrants to Manitoba and what impact excluding only the most recent migrants from our analyses had on the results.

We only obtained mammogram information going back to 1984, as that is the time period for which the physician claims data were readily available. Thus, in our analyses we may have inaccurately classified women who had their last mammogram prior to 1984, as not having had one. The physician claims database is also being extended back to 1970 by Manitoba Health. When that is completed, we will be able to determine how many women had there first mammogram between 1970 and 1983.

Although we believe the number of women involved in the above limitations of our study are small, they would have primarily resulted in an inflation of the number of women in our 'b' cell of Figure 1, that is, in the number of women who stated they had had a mammogram, but that could not be validated in the physician claims data (false-positives). This would have contributed

to the low specificity and PPV found in this study. However, as previously noted, Warnecke et al. in their review found that specificity was lower than sensitivity in most studies (12).

The overall results we found for the validity of self-reported mammogram tended to be fairly consistent across the various demographic and socioeconomic groups examined. However, we only undertook univariate analyses of validity and did not do any test for statistical significance. Future research should take advantage of the large number of women in the NPHS and MBSP sample and undertake multivariate analyses to identify the profile of women who do not accurately self-report their mammogram history.

Although women tended to accurately report whether they had ever had a mammogram, their recall of the date of the last mammogram was not as good. In both the NPHS and MBSP sample, women tended to underestimate the time since their last mammogram. Again, multivariate analyses could be undertaken to determine the characteristics of women who inaccurately report the timing of their last mammogram.

The results of the validity of self-reported mammogram among MBSP prevalent screeners were different from those of the incident screeners, in that the prevalent screeners had lower sensitivity but higher specificity. This is most likely a result of problems with the self-administered questionnaire and should be improved with modifications to the questionnaire.

5. References

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