

# Awareness and Use of Maternal Serum Screening Among Women From the St. John's Region of Newfoundland and Labrador

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## Abstract

**Objectives:** To examine the awareness and use of maternal serum screening (MSS) among women from the St. John's region of Newfoundland and Labrador.

**Method:** We surveyed 300 women who had recently given birth. Our main outcomes were whether the woman had heard of MSS (prior to the study) and whether she had MSS during her pregnancy.

**Results:** Among the 200 respondents (response rate 66.7%), 139 (69.5%) had heard of MSS and 53 (26.5%) had MSS (38.1% of those who had heard of it). A larger proportion of women over 35 years (59.0%) had heard of MSS than younger women (31.5%) ( $P = 0.001$ ). Among those who had heard of MSS, a larger proportion of women who had MSS (96.2%) than those who did not have MSS (72.1%) discussed the test with their physician ( $P < 0.001$ ); 54.9% of the women who discussed MSS with their physicians decided not to have MSS. Most discussions regarding MSS (82.6%) lasted 10 minutes or less; discussion length was not related to use of MSS.

**Conclusion:** Almost two thirds of women surveyed were aware of MSS, and roughly one quarter had MSS. These findings confirm that most physicians offer MSS to their patients and suggest that patient preference accounts for the low use of MSS in the province.

Understanding why women do not have MSS may lead to strategies to improve screening rates.

## Résumé

**Objectifs :** Examiner les connaissances des femmes de la région de St. John's à Terre-Neuve-et-Labrador au sujet du dépistage sérique maternel (DSM) et leur utilisation de cet outil.

**Méthode :** Nous avons sondé 300 femmes qui avaient récemment accouché. La question de savoir si la patiente avait entendu parler du DSM (avant la tenue de l'étude) et celle de savoir si elle s'était soumise à un DSM au cours de sa grossesse constituaient nos principaux critères d'évaluation.

**Key Words:** Maternal serum screening, prenatal care, women

Competing Interests: None declared.

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**Résultats :** Chez les 200 répondantes (taux de réponse : 66,7 %), 139 (69,5 %) avaient entendu parler du DSM et 53 (26,5 %) s'étaient soumise à un DSM (38,1 % de celles qui en avaient entendu parler). Les femmes de plus de 35 ans (59,0 %) avaient entendu parler du DSM dans une plus grande proportion que les jeunes femmes (31,5 %) ( $P = 0,001$ ). Parmi celles qui avaient entendu parler du DSM, les femmes qui s'étaient soumise à un DSM (96,2 %) ont, dans une plus grande proportion que les femmes ne s'y étant pas soumise (72,1 %), discuté de ce test avec leur médecin ( $P < 0,001$ ); 54,9 % des femmes ayant discuté du DSM avec leur médecin ont décidé de ne pas s'y soumettre. La plupart des discussions à l'égard du DSM (82,6 %) ont duré 10 minutes ou moins; la durée de discussion n'était pas associée à l'utilisation du DSM.

**Conclusion :** Près des deux tiers des femmes sondées avaient entendu parler du DSM; approximativement le quart d'entre elles s'y sont soumise. Ces résultats confirment que la plupart des médecins offrent le DSM à leurs patientes et laissent entendre que les préférences des patientes font en sorte que le DSM n'est que faiblement utilisé dans cette province.

La compréhension des raisons pour lesquelles les femmes ne se soumettent pas au DSM pourrait mener à l'élaboration de stratégies visant à améliorer les taux de dépistage.

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## INTRODUCTION

Maternal serum screening is a prenatal screening test completed in the second trimester that determines a woman's risk of carrying a fetus with Down syndrome, Trisomy 18, or an open neural tube defect, regardless of her age or medical history. Thus, invasive diagnostic tests (such as amniocentesis) can be offered more selectively to those screening positive, and detection rates can be increased substantially.<sup>1</sup> The Canadian Task Force on the Periodic Health Examination<sup>2</sup> and the Society of Obstetricians and Gynecologists of Canada<sup>3</sup> suggest that there is fair evidence to offer MSS to all pregnant women.

At the beginning of 2002, the Provincial Medical Genetics Program of Newfoundland and Labrador introduced the

Maternal Serum Screening Program. MSS is of particular interest to the people of Newfoundland and Labrador; before the program's introduction, the province had the highest incidence of neural tube defects in Canada (4 per 1000 births).<sup>4</sup>

The proportion of family physicians in Newfoundland and Labrador offering MSS to all pregnant women increased from 29% in 2000<sup>5</sup> to 54.2% in 2003,<sup>6</sup> but it remains below the rates in other Canadian provinces such as Ontario (87%) and Manitoba (73.7%).<sup>7,8</sup> In Manitoba and Ontario (but not Newfoundland and Labrador), MSS use is higher in urban than in rural areas.<sup>5,7,8</sup> The findings of two studies<sup>5,8</sup> indicate that a substantial proportion of physicians offer MSS only to women in "high-risk groups" such as those women over 35 years of age or women with a family history of Down syndrome or neural tube defects. This is a cause of concern, as MSS is intended to be a population-based screening program and the test offered to all women.<sup>9</sup> The fact that this isn't happening suggests that family physicians need more information.

Provincial testing laboratories monitor the number of MSS tests performed each year but gather limited patient and physician data. As a result, studies that assess factors related to MSS use have largely relied on physician self-reported data and focused on physician MSS practice. However, there is a substantial discrepancy between the physician-generated estimate of MSS use and the statistics produced by MSS testing laboratories.<sup>6</sup> Using a survey of women who have recently given birth, this study examines the characteristics of women from the St. John's region who (1) have heard and not heard of MSS and (2) have and do not have MSS. This study will validate previous evaluations of MSS uptake by comparing findings with physician reported data from the same area and time. It will also determine whether MSS rates in the province are low because physicians do not offering it or because women refuse it.

## **METHODS**

The Human Investigation Committee at the Faculty of Medicine, Memorial University of Newfoundland, approved this study (reference #03.62).

The survey was conducted between October 8 and November 27, 2003, at the Women's Health Centre of the Health Care Corporation of St. John's in St. John's, Newfoundland and Labrador, which is the designated birthing facility for

the St. John's region and the referral centre for the province as a whole. In 2000, 45.9% of all live births in the province occurred at this facility.<sup>10</sup> The St. John's region includes St. John's (the provincial capital) and its surrounding communities.

Medical service aides distributed self-administered written surveys and return envelopes to 300 women who had given birth to a singleton within the preceding 48 hours. The aides identified potential participants, delivered the surveys in the morning, and returned to collect them later that day.

The cover page of the survey outlined the study purpose and issues of consent. Women who completed and returned the survey were assumed to have consented to participation. The cover sheet advised women who chose not to participate in the study to return their uncompleted survey in the envelope, so hospital staff could not identify non-participants. To protect anonymity, the survey did not ask questions that could be used to identify individuals, and women were advised not to write their name or any other identifying information on the survey.

The survey gathered information on age and community of residence, and asked women whether they had heard of MSS prior to the study, whether they had seen their physicians (family physician or obstetrician) between 15 and 20 weeks of pregnancy, whether they had discussed MSS with their physicians and, if so, for how long, and whether they had MSS, ultrasound examination, or amniocentesis testing. We pre-tested the survey on family members, medical students, graduate students, professors, genetic counsellors, and physicians.

The survey data were entered and analyzed using SPSS software (SPSS Version 11.5 Chicago, IL). After using frequencies to describe the age, community size, and awareness of MSS, we used chi-square tests to examine the differences between women who had and women who had not heard of MSS. Among the women who had heard of MSS, we used chi-square tests to identify differences between women who did and did not have MSS testing.

## **RESULTS**

Of the 300 surveys handed out, 200 were completed for a total response rate of 66.7%. The age range of women in our study sample was representative of the age range of all women who gave birth in the St. John's region during the year.<sup>10</sup> Data were not available to determine the representativeness of our sample on the basis of other characteristics (such as size of home community).

Less than a quarter (22.5%) of the women in the sample were under 25 years old, 27.5% were 26 to 30 years old, 34.5% were 30 to 34 years old, and 15.5% were over 35

## **ABBREVIATIONS**

CME	continuing medical education
MSS	maternal serum screening

**Table 1. Characteristics of women who had and had not heard of MSS**

Characteristic	Had Not Heard of MSS n (%)	Heard of MSS n (%)	<i>P</i>
Age (years)			0.001
< 25	23 (37.7)	22 (15.8)	
26–30	20 (32.8)	35 (25.2)	
31–35	13 (21.3)	56 (40.3)	
> 35	5 (8.2)	26 (18.7)	
Community of residence			0.97
Urban (≥ 20 000 population)	33 (55.0)	75 (55.1)	
Semi-urban (10 000–19 999 population)	5 (8.3)	10 (7.4)	
Rural (≤ 9999 population)	22 (36.7)	51 (37.5)	
Saw physician at 15–20 weeks			0.002
No/can't remember	8 (13.1)	3 (2.2)	
Yes	53 (86.9)	136 (97.8)	
Discussed MSS with physician			0
No/can't remember	60 (100)	26 (18.7)	
Yes	0 (0)	113 (81.3)	
Had ultrasound			
No	1 (1.6)	2 (1.4)	
Yes	60 (98.4)	137 (98.6)	
Had amniocentesis			0.914
No	59 (96.7)	128 (92.1)	
Yes	2 (3.3)	11 (7.9)	
			0.221

years old. More than half (55.1%) lived in an urban community (greater than 20 000 population), 7.7% lived in a semi-urban community (10 000–19 999 population), and 37.2% lived in a rural community (< 10 000 population). Almost all (94.5%) had seen a physician between 15 and 20 weeks of pregnancy, the time when MSS should be ordered. More than half (58.8%) of the women recalled discussing MSS with their physicians, and 139 (69.5%) of the women had heard of MSS (from any source) prior to the survey. Fifty-nine (26.5%) of the women had MSS, almost all (98.5%) had ultrasound examination, and few (6.5%) had amniocentesis testing during their pregnancy.

A larger proportion of women over 30 had heard of MSS than of those under 30 (Table 1). There was no urban-rural difference in whether women had heard of MSS. A larger proportion of women who had heard of MSS (97.8%) than those who had not (86.9%) had seen their doctors between 15 and 20 weeks of pregnancy. As expected, all who had discussed MSS with their physicians had heard of the test; over half of these discussions (57.1%) lasted five minutes or less, 25.5% lasted 6 to 10 minutes, 12.2% lasted 11 to 20 minutes, and 5.1% lasted more than 20 minutes. There was no

association between awareness of MSS and having amniocentesis testing or ultrasound examination.

Of those who had heard of MSS, 53 (38.1%) had MSS. There were no statistically significant differences between those who had and those who did not have MSS in terms of their age, community size, whether they saw a physician at 15 to 20 weeks, the length of time they discussed MSS with their physicians, and whether they had an ultrasound or amniocentesis (Table 2). However, a larger proportion of those who had MSS (96.2%) than of those who did not (72.1%) discussed MSS with their physicians. Nonetheless, 54.9% (62 of 113) of the women who discussed MSS with their physicians decided not to have MSS.

## DISCUSSION

Two years after the introduction of an MSS program in Newfoundland and Labrador, almost two thirds of women surveyed said they were aware of MSS, slightly lower than estimated by physician report. A 2003 survey found that 60.1% of family physicians and 87.0% of obstetricians in Newfoundland and Labrador offered MSS to all their patients.<sup>6</sup> Roughly one-quarter of women surveyed had

**Table 2. Characteristics of women who heard of MSS and had and did not have MSS**

Characteristic	Did Not Have MSS n (%)	Had MSS n (%)	P
Age			0.407
< 25 years	16 (18.6)	6 (11.3)	
26–30 years	23 (26.7)	12 (22.6)	
31–35 years	34 (39.5)	22 (41.5)	
> 35 years	13 (15.1)	13 (24.5)	
Community of residence			0.21
Urban ( $\geq$ 20 000 population)	45 (53.6)	30 (57.7)	
Semi-urban (10 000–19 999 population)	4 (4.8)	6 (11.5)	
Rural ( $\leq$ 9999 population)	35 (41.7)	16 (30.8)	
Saw physician at 15–20 weeks			0.169
No/can't remember	3 (3.5)	0 (0)	
Yes	83 (96.5)	53 (100)	
Discussed MSS with physician			0
No/can't remember	24 (27.9)	2 (3.8)	
Yes	62 (72.1)	51 (96.2)	
Length of MSS discussion*			0.331
$\leq$ 5 minutes	31 (59.6)	25 (54.3)	
6–10 minutes	15 (28.8)	10 (21.7)	
11–20 minutes	5 (9.6)	7 (15.2)	
> 20 minutes	1 (1.9)	4 (8.7)	
Had ultrasound			0.728
No	1 (1.2)	1 (1.9)	
Yes	85 (98.8)	52 (98.1)	
Had amniocentesis			0.07
No	82 (95.3)	46 (86.8)	
Yes	4 (4.7)	7 (13.2)	

\*Of those who had discussed MSS with a physician

MSS, similar to the 22% rate reported by the provincial laboratory.<sup>6</sup> These findings support rates of MSS reported by physicians in previous studies. The findings also suggest that the low use of MSS in the province largely stems from patient-related factors (such as knowledge of the test, individual preferences) rather than a lack of awareness or physicians not offering the test.

Age is associated with women's awareness of MSS (although among those who were aware of MSS, age was not correlated with having MSS). These findings confirm previous physician studies<sup>6</sup> and echo the findings of an Ontario patient survey.<sup>11</sup> Goel et al. found that women over 35 tend to be better informed about birth defects and prenatal tests. We found that MSS awareness and use were not related to the size of the woman's community of residence, which is in keeping with the findings of recent physician

surveys in the province, but which is not the case in other parts of Canada.<sup>5,6</sup> This difference might be explained by the CME programs in Newfoundland and Labrador: because much of the province's population is rural, programs have targeted rural physicians. Our study findings suggest that CME that was part of the launch of the MSS program in Newfoundland and Labrador was equally effective in reaching urban and rural practice communities.

Discussing MSS with a physician was related to both a woman's awareness of MSS and her decision to have the test. More than half the women who discussed MSS (62/113, 54.9%) with their doctors opted not to have the test, and more than half the discussions lasted less than five minutes. This highlights the need for a better understanding of what women learn about MSS, whether they feel they are sufficiently informed about the test, and what influences

their decisions to have or not to have MSS. A qualitative study of Ontario mothers found that women have identified three global areas (personal values, social support, and quality of health information) that influence the decision to have MSS.<sup>12</sup> However, we were unable to find Canadian studies that described women's reasons for choosing to have or not have MSS. A Dutch study,<sup>13</sup> found reasons women most commonly gave for not having MSS or nuchal translucency screening were that the tests were uncertain and unreliable, the women were not at high risk, and the women would not abort the fetus. The most commonly given reasons for having the tests were that the women wanted to know about the health of their child, the tests did not involve risk, and the women were at increased risk of having a child with Down syndrome.

MSS was not associated with either having amniocentesis (although this should be interpreted carefully given the small numbers) or ultrasound. Future studies should assess whether amniocentesis is preceded and/or indicated by MSS to determine whether amniocentesis is being offered more selectively following the introduction of MSS. Future studies should also assess why women accept routine ultrasound examination as part of their prenatal care but have yet to accept MSS.

### Strengths and Limitations

The study surveyed patients from one region (albeit the most populous) in the province. Although only two thirds of all distributed surveys were returned, the response rate is reasonable given the dependence on hospital staff to administer the survey and the limited opportunity for reminders and follow-up of non-respondents. It also produced a representative sample (based on age of respondents) and an overall MSS uptake rate that was in line with values reported by the provincial MSS laboratory. The study also demonstrates the feasibility of the survey approach for future, province-wide studies.

### CONCLUSION

Almost two thirds of women surveyed were aware of MSS, and roughly one quarter had MSS. These findings confirm

previous physician surveys that found that most physicians offer MSS to their patients and suggest that the low use of MSS in the province largely stem from patient-related factors. Understanding what women learn about MSS and why they chose to have or not to have MSS may lead to strategies to improve screening rates.

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