



UNIVERSITY
OF WOLLONGONG
AUSTRALIA

University of Wollongong
Research Online

Faculty of Social Sciences - Papers

Faculty of Social Sciences

2002

Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results

Heather M. Davey
University of Sydney

Alexandra Barratt
University of Sydney

Elizabeth Davey
University of Sydney

Phyllis N. Butow
University of Sydney

Sally Redman
NHMRC National Breast Cancer Centre, sally.redman@saxinstitute.org.au

See next page for additional authors

Publication Details

Davey, H. M., Barratt, A. L., Davey, E., Butow, P. N., Redman, S., Houssami, N. & Salkeld, G. P. (2002). Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results. *Health Expectations*, 5 (4), 330-340.

Research Online is the open access institutional repository for the University of Wollongong. For further information contact the UOW Library: research-pubs@uow.edu.au

Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results

Abstract

Objective To determine women's preferences for and reported experience with medical test decision-making. **Design** Computer-assisted telephone survey. Setting and participants Six hundred and fifty-two women resident in households randomly selected from the New South Wales electronic white pages. **Main outcome measures** Reported and preferred test and treatment (for comparison) decision-making, satisfaction with and anxiety about information on false results and side-effects; and effect of anxiety on desire for such information. **Results** Overall most women preferred to share test (94.6%) and treatment (91.2%) decision-making equally with their doctor, or to take a more active role, with only 5.4-8.9% reporting they wanted the doctor to make these decisions on their behalf. This pattern was consistent across all age groups. In general, women reported experiencing a decision-making role that was consistent with their preference. Women who had a usual doctor were more likely to report experiencing an active role in decision-making. More women reported receiving as much information as they wanted about the benefits of tests and treatment than about the side-effects of tests and treatment. Most women wanted information about the possibility of false test results (91.5%) and test side-effects (95.6%), but many reported the doctor never provided this information (false results = 40.0% and side-effects = 31.3%). A substantial proportion said this information would make them anxious (false results = 56.6% and side-effects = 43.1%), but reported they wanted the information anyway (false results = 77.6% and side-effects = 88.1%). **Conclusions** Women prefer an active role in test and treatment decision-making. Many women reported receiving inadequate information. If so, this may jeopardize informed decision-making.

Keywords

tests:, women's, reported, preferred, decision-making, roles, preferences, information, benefits, side-effects, false, medical, results

Disciplines

Education | Social and Behavioral Sciences

Publication Details

Davey, H. M., Barratt, A. L., Davey, E., Butow, P. N., Redman, S., Houssami, N. & Salkeld, G. P. (2002). Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results. *Health Expectations*, 5 (4), 330-340.

Authors

Heather M. Davey, Alexandra Barratt, Elizabeth Davey, Phyllis N. Butow, Sally Redman, Nehmat Houssami, and Glenn P. Salkeld

Medical tests: women's reported and preferred decision-making roles and preferences for information on benefits, side-effects and false results

Heather M. Davey BPsych (Hons),* Alexandra L. Barratt MBBS, MPH, PhD, FAFPHM,† Elizabeth Davey MBBS, MPH,‡ Phyllis N. Butow BA(Hons) Dip Ed, M Clin Psych, MPH, PhD,§ Sally Redman BA(Hons), PhD,¶ Nehmat Houssami MBBS, MPH, MEd (Health), FASBP** and Glenn P. Salkeld BBus, GDipHEc, MPH, PhD††

*Research Assistant, Screening and Test Evaluation Program, School of Public Health, University of Sydney, Australia, †Senior Lecturer in Epidemiology, Screening and Test Evaluation Program, School of Public Health, University of Sydney, Australia, ‡PhD Student, Screening and Test Evaluation Program, School of Public Health, University of Sydney, Australia, §Director, Medical Psychology Unit, Department of Psychological Medicine, University of Sydney and Royal North Shore Hospital, Australia, ¶Chief Executive Officer, NHMRC National Breast Cancer Centre, Sydney, Australia, **Director, Sydney Square Breast Clinic, MBF, Sydney, Australia and ††Senior Lecturer in Health Economics, Screening and Test Evaluation Program, School of Public Health, University of Sydney, Sydney, Australia

Correspondence

Heather M Davey
Screening and Test Evaluation Program
School of Public Health
Room 319A
Edward Ford Building
University of Sydney
Sydney, NSW, 2006
Australia
E-mail: daveyh@health.usyd.edu.au

Accepted for publication

29 August 2002

Keywords: information preferences, shared decision-making, medical tests

Abstract

Objective To determine women's preferences for and reported experience with medical test decision-making.

Design Computer-assisted telephone survey.

Setting and participants Six hundred and fifty-two women resident in households randomly selected from the New South Wales electronic white pages.

Main outcome measures Reported and preferred test and treatment (for comparison) decision-making, satisfaction with and anxiety about information on false results and side-effects; and effect of anxiety on desire for such information.

Results Overall most women preferred to share test (94.6%) and treatment (91.2%) decision-making equally with their doctor, or to take a more active role, with only 5.4–8.9% reporting they wanted the doctor to make these decisions on their behalf. This pattern was consistent across all age groups. In general, women reported experiencing a decision-making role that was consistent with their preference. Women who had a usual doctor were more likely to report experiencing an active role in decision-making. More women reported receiving as much information as they wanted about the benefits of tests and treatment than about the side-effects of tests and treatment. Most women wanted information about the possibility of false test results (91.5%) and test side-effects (95.6%), but many reported the doctor never provided this information (false results = 40.0% and

side-effects = 31.3%). A substantial proportion said this information would make them anxious (false results = 56.6% and side-effects = 43.1%), but reported they wanted the information anyway (false results = 77.6% and side-effects = 88.1%).

Conclusions Women prefer an active role in test and treatment decision-making. Many women reported receiving inadequate information. If so, this may jeopardize informed decision-making.

Introduction

Decision-making shared by patients and doctors is advocated to involve patients in decisions about their care.¹⁻⁶ However, advocating such a role for patients ignores variation in patients' preferences for involvement in decision-making. While some patients want to make decisions themselves, others prefer to delegate decision-making to their doctor or share decision-making with their doctor. Previous studies have reported wide variation in preferences for involvement in decision-making about treatment.⁷⁻¹⁵ Many of the studies looking at treatment decision-making have been conducted with patients already in the health-care system⁷⁻¹⁵ who are more likely to select a passive decision-making role than healthy people.¹¹ The few studies that have used a community-based sample¹⁶ or included non-patient samples for comparison,^{11,14,15} have focused on decision-making preferences regarding treatment, to the exclusion of preferences for test decision-making. There are no data about preferences in relation to test decision-making and the extent to which these preferences would mirror results for treatment is unclear. Community sampling is necessary for eliciting information about test decision-making, as decisions about whether to undergo a screening and/or diagnostic test are usually the entry point to the health system made by people living in the community. The General Medical Council in the United Kingdom¹⁷ recently provided guidance to health care providers about information that should be given to people considering screening tests. To our knowledge, no similar guidance is available about information that should be given to people undergoing diagnostic tests.

It is currently unknown whether people want to participate in decisions about whether to undergo screening and diagnostic tests, whether they feel they are currently participating in these decisions, what information they are currently receiving and what information they would like to receive. Therefore, the aims of this study were to: (1) elicit women's preferences for test and treatment (for comparison) decision-making; (2) compare these to their reported experiences of medical test, breast test and treatment decision-making; and (3) assess women's preferences for information concerning false test results and test side-effects and their predicted anxiety about such information.

Methods

Participants

The sample consisted of women aged 30-69 years inclusive, who were resident in New South Wales (NSW) at the time the study was conducted, had access to a telephone listed in the electronic white pages and spoke English well enough to participate in a telephone interview. This age group is consistent with a previous survey on breast health¹⁸⁻²⁰ and includes both the age range with high rates of breast symptoms and breast tests²¹ and the age range targeted by the national mammographic screening programme.²² Although this programme is specifically aimed at women aged 50-69 years, it offers free mammograms to all women aged 40 years and over who have no symptoms of breast cancer. Therefore, the sample is likely to include many women who have had personal experience with breast tests.

Procedure

The Hunter Valley Research Foundation administered the survey using a Computer-Assisted Telephone Interviewing (CATI) system. Households randomly selected from the NSW electronic white pages were sent a letter introducing the study 1 week before the first telephone contact. Up to 10 attempts were made to contact the household. Once a household was contacted, the interviewer asked if a person fitting the eligibility criteria (an English-speaking woman aged 30–69 years inclusive) lived in the house. Where more than one person fitted the criteria, the number of people fitting the criteria was obtained and the CATI program selected one person at random (e.g. oldest, third oldest). Once a person was selected, no substitution was permitted. If she was unavailable, up to five further call attempts were made. The survey took approximately 20 min. Quotas were used to ensure at least 150 women were interviewed within each decade of age (30–39, 40–49, 50–59, 60–69) as responses from women from all age categories were of equal interest and we wanted good precision (95% confidence intervals of $\pm 8\%$) for estimates in the older age groups.

The Human Ethics Committee of The University of Sydney approved the study.

Survey development

The survey consisted of six sections designed to elicit information on women's sociodemographic details, preferences for test and treatment decision-making, reported test, breast test and treatment decision-making, and information needs related to medical tests. The majority of the survey consisted of questions developed by the researchers. Published questions were available for the sections on preferred decision-making role. Questions in this section of the survey were adapted from The Control Preferences Scale,²³ which uses five cards in a series of two-card comparisons to elicit information on respondents' desired role in decision-making. Initially developed using analysis of the way treatment decisions are made by patients, it has

been used to measure preferences in patient and non-patient populations.²³ A final draft of the survey was pilot tested to establish reliability and facilitate the revision of problematic questions. To establish test-retest reliability, 106 women completed the survey once and then again 1 week later. Questions and response options were presented in the same order for both administrations.

Reliability was assessed by the percentage of responses with exact agreement on both occasions and using κ (for categorical variables) and weighted κ (for ordinal variables) statistics. Comparison of answers given on both occasions showed agreement of 80% or higher for 44% of the questions, 60–79% for 41% of the questions and 50–59% for the remaining 15% of questions. Using Landis and Koch's classification,²⁴ 15% of questions had κ or weighted κ in the 'almost perfect' range (0.81–1.00), 18% of questions were in the 'substantial' range (0.61–0.80), 41% were in the 'moderate' range (0.41–0.60), 21% the 'fair' range (0.21–0.40) and 6% had κ below 0.20. A review of the questions showed that κ and weighted κ were high on questions that would be expected to stay the same, such as demographic items and items asking about previous tests (for example, *Have you ever had a mammogram?*, $\kappa = 0.981$). Reliability for these items was comparable with a previous Australian survey of women in the same age range.²⁰ Items with lower κ were judgment or preference questions (such as *were you given enough information about the potential benefits of the test?*), which previous research shows change over time.²⁵ Minor changes were made to the wording of some questions to facilitate respondent understanding. The survey was then pilot tested with a further sample of 30 women to assess the acceptability of the changes. The final version of the survey consisted of six sections. A copy of the survey is available on request.

Sociodemographic details

Information was obtained on participants' age, suburb or town of residence, postcode, country of birth, highest level of education completed and employment status.

Preferred test and treatment decision-making

This section was designed to elicit decision-making role preferences. Participants were asked to imagine a hypothetical situation in which they were considering whether or not to undergo a cholesterol test. To elicit a test decision-making preference from among the five options, each participant was taken through a series of questions comparing two options at a time, using the same approach as the card sort method developed by Degner and colleagues.²³ In summary, the options provided were: (a) she makes decisions alone; (b) she makes decisions after seriously considering the doctor's opinion; (c) she shares decision-making equally with the doctor; (d) the doctor makes decisions after seriously considering her opinion; and (e) the doctor makes decisions alone. The full wording of each option is available in the questionnaire. The same method was used to elicit the participant's preferred *treatment* decision-making role. Participants were asked to imagine they were making a decision such as whether to take the oral contraceptive pill or hormone replacement therapy.

Reported test and treatment decision-making

Participants were asked a series of questions about communication and decision-making with their current or last doctor. Questions elicited information on: whether women had a usual doctor and if so, what type of doctor this was; what role women played in making test decisions; and if they received enough information about test benefits and side-effects. In regards to reported test decision-making, participants were given two examples of a test (blood test for cholesterol and X-rays for suspected broken bones), asked to name a test they had undergone (screening or diagnostic) and to choose their decision-making role for that test from one of three options, which were: (a) she made the decision alone; (b) she shared decision-making equally with the doctor; and (c) the doctor made the decision alone. Analogous questions were used to elicit information on the participant's reported *treatment* decision-making role.

Reported decision-making role for breast tests

Participants were informed that tests for breast disease included mammography and breast biopsy. For mammograms, specific questions pertained to: whether women had ever had a mammogram; purpose of the mammogram (screening or diagnostic); time since last mammogram; information about potential benefits and side-effects; and decision-making involvement. For biopsy, questions elicited information on: whether women had ever undergone a breast biopsy; time since last biopsy; and information received about benefits and side-effects.

Information on test accuracy

Participants were informed that few tests are 100% accurate and that sometimes tests are normal in people who really have a disease and abnormal in healthy people. Participants were also informed that tests can have side-effects and were given the example of breast biopsy, which can have side effects of pain, bleeding and/or infection. This was followed by questions eliciting information on: (a) the perceived frequency of receiving information about false results and side-effects; (b) desire for this information; (c) perceived anxiety that this information might create; and (d) views on whether this anxiety would deter them from wanting the information.

Statistical analysis

Analyses were performed using SPSS v. 10.0 for Windows.²⁶ Significance testing was done using χ^2 tests for nominal variables and χ^2 tests for trend for ordinal variables, with *P* values of less than 0.05 considered statistically significant. All analyses were done separately for women who reported a usual doctor and those who did not. Results are reported for women with a usual doctor only, unless there was a significant difference between women with a usual doctor and women without one. In these instances, results for women without a usual doctor are reported separately in the text. Demographic characteristics were examined from the Australian Bureau of Statistics (ABS) census data²⁷ and data on age

breakdown, area of residence, education, occupation and country of birth (Australia vs. overseas) were tabulated according to ABS categories. As we deliberately over sampled older women, all results are presented as age-specific rates, or weighted for age where the weights were derived from the age distribution of NSW women in the census data.

Results

Characteristics of the sample population

Of the 743 eligible women contacted, 652 completed the survey, representing an unadjusted response rate of 87.8%. When adjusted for the estimated number of eligible women (based on census data) among the households that could not be contacted ($n = 228$) the response rate was 74.1%. Women aged 30–39 years were under-represented and those aged 60–69 years were over-represented compared to the population of women in NSW (see Table 1). There were no

significant differences between the age-adjusted survey population and the general population of women in NSW as derived from Australian Census data²⁷ for region, education, occupation and country of birth. Of the women surveyed, 91.1% reported having a usual doctor, 98.9% of these being a family doctor.

Preferred test and treatment decision-making

Table 2 shows women's decision-making preferences for tests and treatment. Most women preferred to share decision-making with their doctor. For tests and treatment, women younger than 60 ($\chi^2 = 18.009$, 1 df, $P < 0.001$; $\chi^2 = 9.984$, 1 df, $P = 0.002$, respectively), those with more education ($\chi^2 = 4.532$, 1 df, $P = 0.033$; $\chi^2 = 22.108$, 1 df, $P < 0.001$, respectively) and women who reported they currently share decision-making with their doctor ($\chi^2 = 29.003$, 8 df, $P < 0.001$; $\chi^2 = 64.861$, 8df, $P < 0.001$, respectively) preferred to make the decision themselves, either alone or after considering the

Characteristic	Study population (%)	Age-adjusted study population (%)	General population women aged 30–69 years* (%)
Age (years)			
30–39	23.5	–	33.0
40–49	27.6	–	29.8
50–59	25.6	–	20.6
60–69	23.3	–	16.6
Region			
Metropolitan	64.6	65.0	65.6
Rural	35.4	35.0	34.4
Education			
School only	62.0	59.9	58.5
Post-school	38.0	40.1	41.5
Occupation			
Full-time paid	29.0	31.2	28.6
Part-time paid	28.2	29.5	24.9
Unemployed	1.1	1.1	3.6
Student	1.1	1.2	2.1
Other†	40.5	37.1	40.9
Country of birth			
Australia	77.6	77.7	68.9
Other	23.4	22.3	31.1

Table 1 Comparison of demographic characteristics of the study population, age-adjusted study population and the general population of women aged 30–69 years in NSW

*According to Australian Bureau of Statistics census data.²⁷

†Includes home duties and retired.

Table 2 Preferred decision-making role for tests and treatment (by age)

	Age group (%)			
	30–39	40–49	50–59	60–69
Preferred <i>test</i> decision-making role				
	<i>n</i> = 204	<i>n</i> = 193	<i>n</i> = 147	<i>n</i> = 105
Woman decides	12.3	13.0	16.3	3.8
Woman decides after considering doctor's opinion	28.4	32.8	27.2	14.3
Decide together	52.0	55.4	50.3	63.8
Doctor decides after considering woman's opinion	5.0	4.7	3.4	6.7
Doctor decides	2.0	3.1	2.7	11.4
Preferred <i>treatment</i> decision-making role				
	<i>n</i> = 202	<i>n</i> = 194	<i>n</i> = 147	<i>n</i> = 104
Woman decides	4.5	5.7	9.5	3.8
Woman decides after considering doctor's opinion	37.1	36.8	30.6	23.1
Decide together	55.0	52.8	56.5	59.6
Doctor decides after considering woman's opinion	3.5	1.6	2.0	6.7
Doctor decides	0.0	3.1	1.4	6.7

Table 3 Reported decision-making role and information preferences for test and treatment among women with a regular doctor

	Test category (%)					
	Blood test, <i>n</i> = 383	X-ray, <i>n</i> = 83	Other imaging tests, <i>n</i> = 51	All tests (except pap smears), <i>n</i> = 517	Pap smear, <i>n</i> = 29	Treatment (%), <i>n</i> = 590
Reported decision-making role*						
Woman decided	11.5	10.8	7.7	11.0	48.3	5.4
Decided together	40.7	34.9	50.0	40.8	34.5	75.4
Doctor decided	47.8	54.2	42.3	48.2	17.2	19.1
Information on benefits*						
Wanted more	18.5	18.0	15.6	17.6	16.6	23.4
As much as wanted	79.4	80.7	82.4	79.8	66.7	73.5
More than wanted	2.1	1.2	2.0	2.6	16.7	3.0
Information on side-effects						
Wanted more	46.5	54.2	46.1	47.6	48.2	34.3
As much as wanted	52.7	45.8	51.9	51.4	51.7	63.3
More than wanted	0.8	–	1.9	1.0	51.7	1.8

*Significant difference between blood test, X-ray, scan and pap smear comparisons (*P* < 0.05).

doctor's opinion (active role). In addition, women who were in paid employment were more likely to prefer an active role in decisions about tests ($\chi^2 = 42.000$, 24 df, *P* = 0.013). Women residing in rural areas ($\chi^2 = 14.240$, 4 df, *P* = 0.007) were more likely to prefer an active treatment decision-making role. Country of birth was not significantly related to preferred test or treatment role.

Reported test and treatment decision-making experience

A total of 628 women were able to recall undergoing a test and to name or describe that test. Table 3 shows the reported test decision-making role by test category for those women who could recall a test and who had a usual doctor (*n* = 546). For comparison, women's

reported treatment decision-making role is also shown, although details of the specific treatment women had in mind when answering this question were not collected.

There was a significant difference in decision-making role ($\chi^2 = 38.678$, 6 df, $P < 0.001$) reported by women in the different test categories. However, the difference appears to relate to women who nominated pap smears. With the exception of these women, the pattern for reported decision-making role and information about benefits and side-effects is fairly consistent between tests, but differs from that for treatment. Reported decision-making role for tests was not associated with any of the demographic variables. Women with more education ($\chi^2 = 4.569$, 1 df, $P < 0.033$) and those born overseas reported wanting more information about test benefits ($\chi^2 = 10.674$, 3 df, $P = 0.014$). There was no relationship between satisfaction with information on benefits and age, region or occupation. People in 'other' occupations, including home duties and retired reported wanting less information about side-effects ($\chi^2 = 30.842$, 12 df, $P < 0.002$). None of the other demographic variables were associated with satisfaction with information about side-effects.

For treatment decisions, women with less education were more likely to report the doctor made the decision alone ($\chi^2 = 10.150$, 1 df, $P = 0.001$). Reported treatment decision-making role was not significantly related to age, region, occupation or country of birth.

Satisfaction with information about benefits and side-effects was not related to any of the demographic variables.

Women without a usual doctor

A total of 54 women reported not having a usual doctor. These women were more likely than those with a usual doctor to report the doctor made the test decision ($\chi^2 = 8.863$, 2 df, $P = 0.012$). For tests, 3.8% women said they made the decision alone, 67.3% the doctor made the decision and 28.8% shared decision-making with the doctor. There was no difference by age, region, education, occupation or country of

birth. For treatment decisions, information was collected separately for women without a usual doctor. These women were asked to think about their last doctor. A total of 36.2% women said they made the decision, 35.4% the doctor made the decision and 28.4% shared decision-making with the doctor. There was no association with any demographic variable.

Reported breast test decision-making experience

A total of 60.6% of women reported having ever undergone a mammogram. Significantly, more women with a usual doctor (62.4%) than without (42.1%) reported having had a mammogram ($\chi^2 = 8.930$, 1 df, $P = 0.003$). Women aged 50 years and over were more likely to have had a mammogram ($\chi^2 = 216.932$, 1 df, $P < 0.001$), but less likely to have had a diagnostic mammogram ($\chi^2 = 46.296$, 1 df, $P < 0.001$). Women who reported having had a diagnostic mammogram were asked to focus on that, all others to focus on their most recent screening mammogram. Women aged 50 years and older and those who had undergone diagnostic mammography were more likely to report the doctor made the decision ($\chi^2 = 5.279$, 1 df, $P = 0.022$, $\chi^2 = 85.786$, 2 df, $P < 0.001$, respectively). Overall, more women reported being satisfied with the information they received about benefits than the information they received about side-effects (Table 4). Reported decision-making role and satisfaction with benefits and side-effects was not related to any demographic variable.

Women without a usual doctor

Women aged 50 years and older ($\chi^2 = 17.451$, 1 df, $P < 0.001$) and those living in non-metropolitan areas were more likely to have had a mammogram ($\chi^2 = 6.814$, 1 df, $P = 0.009$). There was no difference by education, occupation or country of birth. Fewer women without a usual doctor were satisfied with the information they received. A total of 62.5% of women without a usual doctor were satisfied with the information they received on benefits, while 37.5% wanted more information. 54.2% wanted

Table 4 Reported decision-making role and information preferences for breast tests among women with a regular doctor

	Diagnostic mammogram (%), <i>n</i> = 177	Screening mammogram (%), <i>n</i> = 259
Timing of last mammogram		
< 2 years ago	27.0	80.3
2–5 years ago	40.0	16.5
6–10 years ago	17.1	2.7
> 10 years ago	15.9	0.5
Reported decision-making role*		
Woman decided	45.5	60.6
Decided together	49.4	25.7
Doctor decided	36.0	13.8
Information on benefits		
Wanted more	23.8	18.1
As much as wanted	73.8	79.2
More than wanted	2.3	2.7
Information on side-effects		
Wanted more	41.2	33.2
As much as wanted	57.6	65.9
More than wanted	1.2	0.9

*Significant difference between diagnostic and screening mammogram ($P < 0.001$).

more information about side-effects, 41.7% were satisfied with the information they received and 4.2% wanted less information.

Breast biopsy

A total of 11.5% of women reported having ever had a breast biopsy. More women aged 50 years or older reported having had a breast biopsy ($\chi^2 = 184.348$, 1 df, $P < 0.001$). There was no difference by region, education, occupation or country of birth. More women reported being satisfied with the information they received on benefits (67.2%) than on side-effects (42.5%). More information about benefits was wanted by 30.8% of women and 57.5% wanted more information about side-effects. There were no differences by any demographic variable.

Information on test accuracy

False results

Women most commonly reported their doctor never explained the possibility of a false test result (see Table 5). Although most women wanted information about false results the next

time they had a medical test, women less than 60, and students and women in paid work were more likely to want this information ($\chi^2 = 5.687$, 1 df, $P = 0.017$; $\chi^2 = 27.000$, 12 df, $P = 0.008$, respectively). Many women predicted the information would make them anxious but reported they wanted the information anyway. Women with less education ($\chi^2 = 15.533$, 1 df, $P < 0.001$) were more likely to predict information about false results would make them anxious.

Side-effects

One third of women said their doctor never explained a test may have side-effects (see Table 5). Women less than 50 ($\chi^2 = 10.851$, 1 df, $P = 0.001$) and women born in Australia ($\chi^2 = 14.796$, 3 df, $P = 0.002$) were more likely to report their doctor at least sometimes explained a test might have a side-effect. Almost all women wanted information about side-effects the next time they had a test, even though many reported it would make them anxious. Women aged 30–39 were more likely to want this information the next time they had a test ($\chi^2 = 6.733$, 1 df, $P = 0.009$). Women with less education

Table 5 Desire for and anxiety related to information about the possibility of a false test result and test side-effects

	False results (%)	Side-effects (%)
Possibility of this explained	<i>n</i> = 573	<i>n</i> = 549
Always	18.3	28.6
Often	13.1	14.6
Sometimes	28.8	25.5
Never	40.0	31.3
Want this information	<i>n</i> = 582	<i>n</i> = 591
Definitely yes	65.1	77.5
Probably yes	25.9	17.8
Probably no	5.5	2.4
Definitely no	3.4	2.4
Information cause anxiety	<i>n</i> = 580	<i>n</i> = 572
Definitely yes	16.4	10.1
Probably yes	30.2	33.0
Probably no	24.7	32.9
Definitely no	18.8	24.0
Want information despite anxiety*	<i>n</i> = 365	<i>n</i> = 280
Yes	77.6	88.1
No	16.2	9.6
Don't know	6.2	2.2

*Among those women who reported this information would definitely or probably make them anxious.

($\chi^2 = 9.493$, 1 df, $P = 0.002$) were more likely to predict this information would make them anxious.

Discussion

This survey is the first to interview a community sample about their preferences for involvement in test decisions and their information needs in relation to tests. The sample is representative of the general population of women aged 30–69 years in NSW as derived from Australian census data,²⁷ given that we deliberately over sampled older women, and achieved a high response rate. Thus, the results are likely to be applicable in other similar Western populations, although the transferability of the findings to other populations needs to be assessed.

The most striking finding of the study is that the majority of women reported they would prefer to participate equally in decision-making with their doctor for decisions about both tests and treatment or to take a more active role. This

finding was consistent across all age groups. Overall, only a small proportion of women (0.0–11.4%) reported they would want the doctor to make the decision on their behalf. The preference for shared decision-making is consistent with previous research on treatment preferences in community¹⁶ and non-patient samples.^{3,11,14,15} However, this is the first study to document similar preferences for shared decision-making in decisions about tests. Although preferences were very similar, women's reported experiences were strikingly different for tests and treatment. While the majority reported shared decision-making for treatment, overall the most common experience of test decision-making (excluding pap smears) was the doctor deciding alone. Thus, a discrepancy between preferences and reported experience is apparent in the arena of test decisions.

There were a number of differences in the demographic factors associated with the preferred decision-making role for tests and treatment. In particular, age was related to preferred test and treatment decisional role and receiving and wanting information about side-effects with younger women being more likely to want active involvement and more information. Education was also related to preferred test and treatment decisional role, satisfaction with information about test benefits, reported treatment decisional role, and predicted anxiety about information on false results and side-effects. The relationship between age and preferred treatment decision-making role is consistent with previous research, showing younger women are more likely to want an active role in decision-making.^{8,28–30} In addition, the relationship between education and preferred treatment decision-making role is also consistent with previous research showing people with more education prefer greater participation in decision-making.^{29,31} However, it is unclear to what extent these demographic relationships are practically important, as previous research has found that demographic factors account for not more than 15% of the variation in decision-making preference for treatment decisions.^{11,28} Therefore, it cannot be assumed that individuals who belong to demographic groupings generally

disinterested in active decision-making will themselves be so disinterested. Doctors may need to establish information and involvement preferences with each patient, perhaps at each consultation in order to clarify the patient's current preferences, as there is evidence that preferences may vary over time.²⁵

In this study, women with a usual doctor were significantly more likely to report an active role in test and treatment decision-making. This finding suggests that a pre-existing doctor-patient relationship may affect the extent to which a patient participates in decision-making. Further research is needed to determine if, and to what extent a pre-existing doctor-patient relationship influences the role a patient plays in making test and treatment decisions.

Women reported they want to be well-informed about the possibility of receiving a false test result, and about any adverse effects of tests. A large proportion of the women surveyed reported not being regularly informed that a test could have a false result or side-effects, and they reported being more satisfied with the information they received on the benefits of treatments and tests than the information on adverse effects. If women are not receiving balanced information about tests, it is questionable whether they are making an informed decision to undergo the test. It should be noted that this study relied on reported information: whether information is being provided but not 'heard' needs to be assessed.

In addition, many women recognized that being more informed about tests may provoke anxiety. These women nevertheless reported a strong desire for such information, even if they expect it will trigger anxiety. This finding supports guidelines released by The General Medical Council in the United Kingdom about the information that should be provided to people about the consequences of undergoing screening tests,¹⁷ including the probability of receiving a false report, and any adverse effects of the test or follow-up tests. Given that this study has included both screening and diagnostic tests, it seems reasonable that this recommendation should extend to people undergoing diagnostic tests.

The results also suggest that health-care providers, including family doctors, need to be aware that many women want information about test accuracy, that such information may cause anxiety, but that this anxiety does not prevent many women from wanting the information. Thus, health-care providers should not use concerns about anxiety to prevent them from offering women the chance to receive this information or providing it in cases where women want it. Combined with the findings on preferred decision-making role for tests, it appears that most women want information about test accuracy but also want input by the doctor into the decision about whether to undergo a test.

Before the findings of this study can be effectively incorporated into clinical practice and health-care professionals start providing this information, it would be pertinent to assess what type of information women want about test benefits, side-effects and the possibility of a false result; who they want to provide the information; when they want to receive it; how they want it presented; and what, if any, between-test differences exist. For example, do women want detailed statistical information about every possible side-effect; do they want to know the more common side effects or only the serious ones? Do they want this information in a booklet or from a doctor? These questions need to be answered as the provision of information about side-effects, benefits and false results is necessary if women are to be fully informed and able to participate in decisions about whether to undergo medical tests.

Acknowledgements

This research was supported by a grant from the National Health and Medical Research Council, Australia.

References

- 1 Bachmann MO. Ought patients to follow professional advice? *Health Expectations*, 2001; **4**: 141-143.
- 2 Coulter A. Paternalism or partnership? Patients have grown up – and there's no going back. *British Medical Journal*, 1999; **319**: 719-720.

- 3 Coulter A. Partnerships with patients: the pros and cons of shared clinical decision making. *Journal of Health Services Research and Policy*, 1997; **2**: 112–121.
- 4 Emmanuel EJ, Emmanuel LL. Four models of the physician-patient relationship. *Journal of the American Medical Association*, 1992; **267**: 2221–2226.
- 5 Entwistle V, Sheldon TA, Sowden A, Watt IS. Evidence-informed patient choice. Practical issues of involving patients in decisions about health care technologies. *International Journal of Technology Assessment in Health Care*, 1998; **14**: 212–225.
- 6 National Health and Medical Research Council. *General Guidelines for Medical Practitioners on Providing Information to Patients*. Canberra: Australian Government Printing Service, 1994.
- 7 Bilodeau BA, Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. *Oncology Nursing Forum*, 1996; **23**: 691–696.
- 8 Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Social Science and Medicine*, 1998; **27**: 1139–1145.
- 9 Davison BJ, Degner LF, Morgan TR. Information and decision making preferences of men with prostate cancer. *Oncology Nursing Forum*, 1995; **22**: 1401–1408.
- 10 Degner L, Kristjanson L, Bowman D *et al.* Information needs and decisional preferences in women with breast cancer. *Journal of the American Medical Association*, 1997; **277**: 1485–1492.
- 11 Degner L, Sloan J. Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiology*, 1992; **45**: 941–950.
- 12 Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Social Science and Medicine*, 1994; **39**: 279–289.
- 13 McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *British Medical Journal*, 2000; **321**: 867–871.
- 14 Rothenbacher D, Lutz MP, Porzolt F. Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *European Journal of Cancer*, 1997; **33**: 1184–1189.
- 15 Stiggelbout AM, Kiebert GM. A role for the sick: patient preferences regarding information and participation in clinical decision-making. *Canadian Medical Association Journal*, 1997; **157**: 383–389.
- 16 Vertinsky IB, Thompson WA, Uyeno D. Measuring consumer desire for participation in clinical decision making. *Health Services Research*, 1974; **9**: 121–134.
- 17 General Medical Council. *Seeking Patients' Consent: The Ethical Considerations*. London: General Medical Council, 1998.
- 18 Barratt A, Cockburn J, Furnival C, McBride A, Mallon L. Perceived sensitivity of mammographic screening: women's views on test accuracy and financial compensation for missed cancers. *Journal of Epidemiology and Community Health*, 1999; **53**: 716–720.
- 19 Barratt AL, Cockburn J, Redman S, Paul C, Perkins J. Mammographic screening: results from the 1996 National Breast Health Survey. *Medical Journal of Australia*, 1997; **167**: 521–524.
- 20 Barratt A, Cockburn J, Smith D, Redman S. Reliability and validity of women's recall of mammographic screening. *Australian & New Zealand Journal of Public Health*, 2000; **24**: 79–81.
- 21 Australian Institute of Health and Welfare (AIHW), Australasian Association of Cancer Registries and NHMRC National Breast Cancer Centre. *Breast Cancer in Australian Women 1982–1996*. Canberra: Australian Institute of Health and Welfare, 1999.
- 22 Australian Institute of Health and Welfare (AIHW). *BreastScreen Australia Achievement Report 1997 – 1998*. Canberra: Australian Institute of Health and Welfare, 2000.
- 23 Degner L, Sloan JA, Venkatesh, P. The control preferences scale. *Canadian Journal of Nursing Research*, 1997; **29**: 21–43.
- 24 Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics*, 1977; **33**: 159–174.
- 25 Butow PN, McLean M, Dunn SM, Tattersall MHN, Boyer M. The dynamics of change: cancer patients' preferences for information, involvement and support. *Annals of Oncology*, 1997; **8**: 857–863.
- 26 SPSS Inc. *SPSS version 10.0.5 for Windows*. Chicago, IL: SPSS Inc., 1999.
- 27 Australian Bureau of Statistics. Data provided on request.
- 28 Catalan J, Brener N, Andrews H *et al.* Whose health is it? Views about decision-making and information-seeking from people with HIV infection and their professional careers. *AIDS Care*, 1994; **6**: 349–356.
- 29 Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *Journal of the American Medical Association*, 1984; **252**: 2990–2994.
- 30 Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Annals of Internal Medicine*, 1980; **92**: 832–836.
- 31 Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine*, 1989; **4**: 23–30.