MAKING CHOICES: Screening for Thyroid Disease

A decision aid for people exposed to I-131 from the Nevada atmospheric nuclear tests

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

Acknowledgment

This decision aid was developed using the decision support format of the Ottawa Health Decision Centre, at the University of Ottawa and Ottawa Health Research Institute, Ontario, Canada, ***www.ohri.ca.***

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This workbook is for you if:

- You lived in the United States between 1951 and 1963
- You are concerned that exposure to I-131 from the Nevada nuclear weapons tests may have affected your thyroid gland
- You want to consider options for thyroid screening

You will learn about:

- I-131 radioactive fallout and the risk of thyroid disease
- The pros and cons of thyroid screening
- How to decide if you should be screened

This workbook focuses on the pros and cons of thyroid cancer screening. It will help you make an informed decision about thyroid cancer screening. At the back of the booklet there is a worksheet to aid your decision-making.

We suggest you complete the worksheet and discuss it with a health care professional. Then you can make a final decision about thyroid cancer screening.

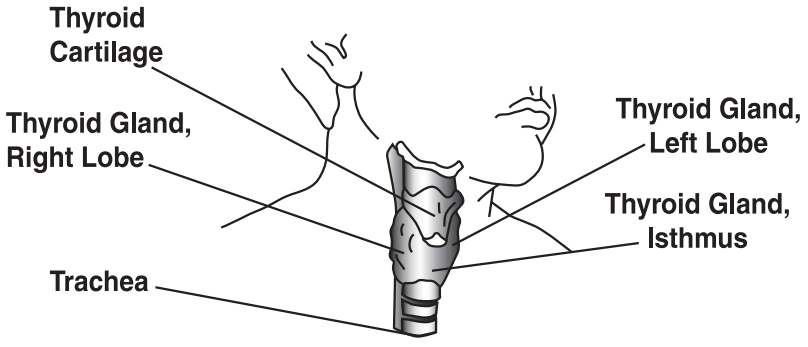
What is exposure to iodine-131?

Between 1951 and 1963, the United States conducted about one hundred aboveground nuclear weapons tests at the Nevada Test Site. These tests released radioactive materials, including iodine-131 (I-131), mainly during 1952, 1953, and 1957. I-131 released from the tests was carried by the wind and deposited on soil and vegetation throughout the United States. The areas most affected were downwind of the test site, to the north and east of Nevada. The areas least affected were on the West Coast of the United States. Because I-131 breaks down quickly, most exposure occurred within three months after each test.

The most common way people came in contact with I-131 was through contaminated milk. This was because the I-131 fell onto pasture grasses eaten by cows and goats, and was absorbed into their milk. The I-131 concentrated in the thyroid glands of people who drank milk. Children usually drink larger amounts of milk, so young children absorbed more I-131 than adults did. Children's thyroid glands are smaller as well, so the larger amount of I-131 was concentrated in less tissue. Children may have received 10 times the I-131 doses that adults did as a result of the Nevada tests. People, particularly children, who were exposed to I-131 from the tests, probably have an increased risk for thyroid disease.

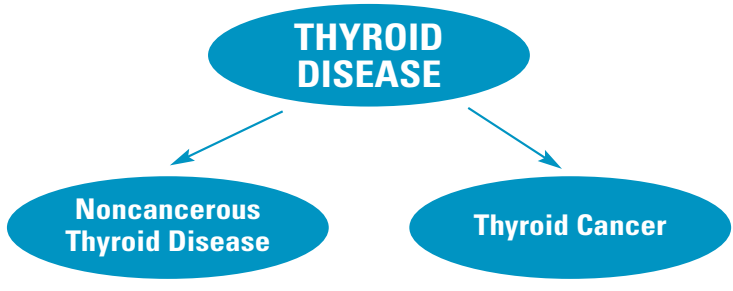
What is the thyroid gland?

The thyroid gland is located in the front of the neck, just above the top of the breastbone and overlying the windpipe. In most people it cannot be seen or felt. The gland normally takes up iodine from the food and the blood, and makes thyroid hormone. The thyroid controls many body processes, including heart rate, blood pressure, and body temperature, as well as childhood growth and development.



What is thyroid disease?

There are two main types of thyroid diseases: noncancerous thyroid disease and thyroid cancer.



Some thyroid diseases are caused by changes in the amount of thyroid hormones that enter the body from the thyroid gland. Doctors can screen for these with a simple blood test.

Noncancerous thyroid disease also includes lumps, or nodules, in the thyroid gland that are benign and not cancerous.

Thyroid cancer occurs when a lump, or nodule, in the thyroid gland is cancerous.

Check any symptoms of thyroid disease you think you have in the boxes below.

Symptoms of noncancerous thyroid disease:

Too little thyroid hormone	Too much thyroid hormone
☐ Depression or feeling blue	☐ Nervousness
☐ Trouble concentrating	☐ Anxiety
☐ Tiredness	☐ Tremor (shaking)
☐ Dry skin and hair	☐ Fast irregular pulse
☐ Weight gain	
☐ Feeling cold all the time	

Symptoms of thyroid cancer:

☐ A lump in the neck, sometimes growing noticeably

☐ Pain in the neck, sometimes going up to the ears

☐ Persistent hoarseness

These symptoms may not be the result of a thyroid condition. They are also associated with other medical conditions. If you checked any symptoms, **we suggest seeing a doctor**.

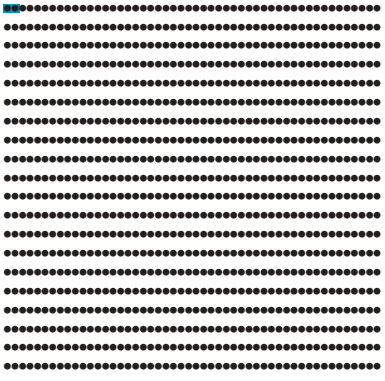
What is thyroid cancer?

Thyroid cancer is a slow-growing cancer that is highly treatable and usually curable. About 95 out of 100 people who are diagnosed with thyroid cancer survive the disease for at least five years.

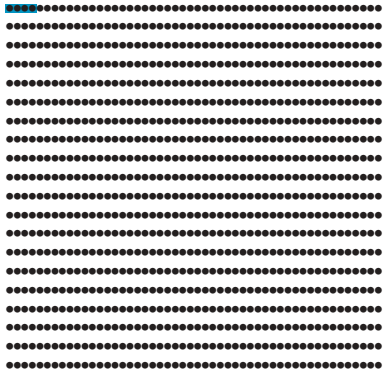
How common is thyroid cancer?

Thyroid cancer is not common and accounts for less than 2 percent of cancers diagnosed in the United States. In the United States, about 2 in every 1,000 men and about 4 in every 1,000 women who are currently cancer-free and aged 50 years will eventually develop thyroid cancer in their remaining lifetime. This is shown in the boxes below. Each box contains 1,000 circles. Each circle stands for a person. The blue circles show the number of 50-year-old men and women who will eventually develop thyroid cancer. The black circles show the number of men and women who will **not** develop thyroid cancer.

Men



Women



How common are other cancers?

Of 1,000 women who are currently cancer-free and aged 50 years, about 120 will eventually develop breast cancer in their remaining lifetime. Of 1,000 men who are currently cancer-free and aged 50 years, about 170 will eventually develop prostate cancer in their remaining lifetime.

About 203,500 women are diagnosed with breast cancer each year in the United States, while about 15,800 women are diagnosed with thyroid cancer. About 189,000 men are diagnosed with prostate cancer each year in the United States, while about 4,900 men are diagnosed with thyroid cancer.

Breast and prostate cancer are both much more common than thyroid cancer.

What was your I-131 dose from the Nevada tests?

The dose of I-131 people likely got from the Nevada tests depends on:

- How old they were at the time
- How much milk they drank at the time and whether that milk was processed
- Where they lived at the time

I-131 doses are measured in radiation absorbed doses (called rad). The National Cancer Institute estimates that the average dose to the adult population living in the United States at the time (between 1951 and 1963) was about 2 rad. Because children likely absorb more I-131, people younger than 15 at the time of testing

may have absorbed higher doses of radiation. Their thyroid glands were still developing during the testing period. And children were more likely to have consumed milk contaminated with I-131.

You can roughly estimate your I-131 dose using the following chart. Find the year in which you were born in the column on the left. Next, locate the column for the kind and amount of milk you drank during the nuclear tests (between 1951 and 1963). Then read your estimated dose in rad.

What is your estimated I-131 dose?

	Doses in rad by amount and type of milk				
	No milk	Processed milk		Farm cow	Farm goat
Year of birth	0 cups/day	1-3 cups/day	4+ cups/day	any amount	any amount
Before 1933	Less than 1	2	4	6	30
1933-1937	Less than 1	3	6	9	45
1938-1942	Less than 1	5	10	15	75
1943-1947	Less than 1	7	14	21	105
1948-1957	Less than 1	10	20	30	150
1958-1963	Less than 1	1	2	3	15
After 1963	Less than 1	Less than 1	Less than 1	Less than 1	Less than 1

Example: If you were born between 1948 and 1957, and drank 1-3 cups of milk a day of store-bought milk, your estimated dose of I-131 is about 10 rad.

Example: If you were born between 1958 and 1963, and drank 4 or more cups of milk a day of store-bought milk, your estimated dose of I-131 is about 2 rad.

Where did you live?

Depending on where you lived, your likely dose could be much higher or lower than the doses provided on the chart.

High-dose areas

Some counties in these states received higher doses: Montana, Idaho, Utah, Colorado, Wyoming, North Dakota, South Dakota, Nebraska, Kansas, Missouri, Nevada, and Arkansas.

If you lived in one of these states, your likely dose may be 2 to 3 times greater than the dose shown for you on the chart.

Low-dose areas

Some counties in these states received much lower doses: Oregon, California, Arizona, and New Mexico.

If you lived in one of these states, you may have received a dose 10 times smaller than that shown on the chart.

Dose calculator

If you want to calculate your exposure more accurately based on your county of residence, see the dose calculator on the NCI Web site (*www.cancer.gov*, search keyword: *I-131*).

How accurate are these doses?

Given the amount of time that has passed since the tests were conducted, scientists cannot be certain about how much exposure each person received. Because few data were collected at the time of the tests, scientists have used available information to make their best estimates. As a result of this uncertainty, these dose figures are very rough estimates. The uncertainty in the dose estimate may be up to 5 times lower or 5 times higher. For example,

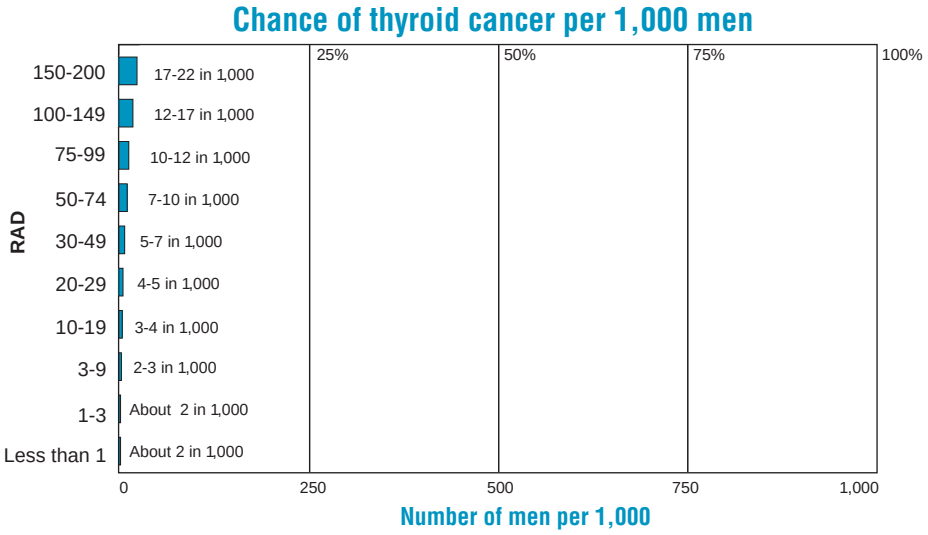
if you estimate your dose was 5 rad, your real dose was likely in the range of 1 to 25 rad.

What is your risk of thyroid cancer?

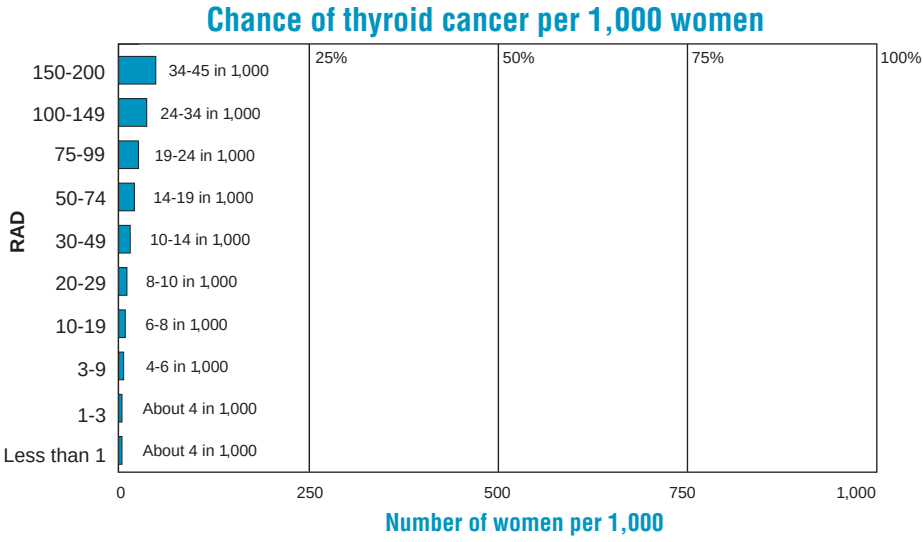
Now, you can use your dose estimate to roughly work out whether exposure to I-131 has affected your chance of developing thyroid cancer.

The figures that follow are for people who are 50 years old and cancer-free.

Look to find your dose in rad and read your chance in 1,000 of eventually developing thyroid cancer in your remaining lifetime.



Example: A 50-year-old cancer-free man who was exposed to about 10 rad has about 3 to 4 chances in 1,000 of eventually developing thyroid cancer. He has about 996 to 997 chances in 1,000 of not developing thyroid cancer.



Example: A 50-year-old cancer-free woman who was exposed to about 10 rad has about 6 to 8 chances in 1,000 of eventually developing thyroid cancer. She has about 992 to 994 chances in 1,000 of not developing thyroid cancer.

What is screening for thyroid disease?

Screening aims to detect thyroid disease early, before there are any symptoms.

- Many people think screening is always a good thing. But there are good reasons why you might choose not to be screened for thyroid disease. Screening tests are never 100 percent accurate. Some people who are screened for thyroid disease will get an abnormal screening result even though they do not have thyroid disease. Others may receive a normal screening result even though they have thyroid disease. These things happen with all screening tests.

- Whether you think it is worthwhile to get screened is your decision. There is no right or wrong choice. Some people will choose to be screened. And others will choose not to be screened.

- The worksheet that follows will focus on the pros and cons of thyroid cancer screening. Screening for noncancerous thyroid disease that increases or decreases the amount of thyroid hormones in the body involves a simple blood test. It is unlikely to cause you any harm, other than the inconvenience and cost of the blood test. About 14 in 1,000 women and about 9 in 1,000 men aged 60 years or older probably have undetected thyroid disease involving abnormal thyroid hormone levels. Through screening, these people may be identified and treated. Treatment is likely to be effective for those with clearly abnormal thyroid hormone levels. There is no good evidence on whether treatment is helpful in people with only mildly abnormal thyroid hormone levels.

What is involved in thyroid cancer screening?

Cancer screening is not just a matter of having a quick test. You need to consider what might happen after you get your screening test result.

Options for thyroid cancer screening

Doctors screen for thyroid cancer by feeling the gland, to check for a lump or nodule. If a doctor feels a nodule, it does not mean cancer is present. Most thyroid nodules are not cancer.

There are two methods of investigating a thyroid lump or nodule: 1) ultrasound, to locate and describe the lump, and 2) biopsy, to determine if the lump may be cancerous. Thyroid ultrasound creates pictures by bouncing sound waves off the gland. This

technique is painless and quick. But it cannot determine whether a lump is cancerous. The ultrasound device uses sound waves that people cannot hear. A computer uses the echoes to create a picture called a sonogram. From the picture, the doctor can see how many nodules are present, how big they are, and whether they are solid or filled with fluid.

If you choose to be screened by ultrasound, your doctor will arrange for you to have a scan at an x-ray practice or clinic. The scan is quick and painless. Thyroid nodules may be seen on the scan. If so, follow-up tests will generally be advised. These may be a repeat ultrasound scan in the future to see if the nodules have grown, fine needle aspiration, or surgery.

Confirmation of cancer requires biopsy, usually using a fine needle. Cells removed from a nodule during biopsy are directly examined in the laboratory.

What is fine needle aspiration?

A needle is put into the thyroid and cells are taken out. The cells are examined under a microscope. You may feel minor pain or get a bruise. A needle aspiration can usually tell whether there is cancer in the nodule. But in about 20 percent of cases the result is unhelpful, and people need to have another biopsy or surgery.

What are the pros of thyroid cancer screening?

#1 Reassurance for people who do NOT have cancer

Most people who are screened do not have cancer. These people benefit by being reassured that they do not have cancer.

#2 Early detection for people who DO have cancer

A few people will have cancer. These people will have their cancer found earlier than they would have otherwise, perhaps while it is very small. So, they may require less complicated treatment and have better chances of survival.

What are the cons of thyroid cancer screening?

#1 False alarms for people who do NOT have cancer

Some people will be falsely alarmed because a nodule is found. They may need to have repeat scans, fine needle aspiration, or surgery to see whether they have cancer. Ultimately, these people learn they do not have cancer. But they will have experienced stress and anxiety in the process of reaching a diagnosis, as well as inconvenience and possibly complications of unnecessary surgery.

#2 Uncertainty about the benefit of early treatment

Scientists know that most thyroid cancers can be cured. It is unclear if finding and treating those cancers early offers an added benefit. There are no reliable studies about the long-term benefit of thyroid cancer screening. No one knows for certain if thyroid cancers found early require less treatment than those found later.

#3 False reassurance for some people who DO have cancer

Screening does not find all the cancers. A few people will be falsely reassured. They do have cancer but their screening test is normal. So, they do not benefit from screening.

How many people have cancer correctly detected and how many people get false alarms?

The numbers of cancers detected and false alarms are different for screening by neck exam than for screening by ultrasound.

The charts that follow show the pros and cons of screening by neck exam and by ultrasound. The numbers on the charts are based on scientists' best guesses at how many people are affected. The exact numbers will vary for different places and people.

Screening 1,000 people by neck exam

PROS	CONS
920-960 people will be correctly assured they do not have cancer.	40-80 people will have false alarms and will be offered follow-up tests: • 40-80 people will be offered ultrasound scan • 20-40 people will be offered fine needle aspiration as well as ultrasound • 3-10 people will be offered surgery as well as ultrasound and fine needle aspiration
1-3 people will have cancer found early. They may need less complex treatment and may have better chances of cure.	The 1-3 people who will have cancer found early may not have better chances of cure. They might just know for a longer time that they have cancer.

Screening 1,000 people by ultrasound

PROS	CONS
800-850 people will be correctly assured they do not have cancer.	150-200 people will have false alarms and will be offered follow-up tests: • 70-120 people will be offered repeat ultrasounds and 70-80 people will be offered fine needle aspiration • 10-15 people will be offered both surgery and fine needle aspiration
4-6 people will have cancer found early. They may need less complex treatment and may have better chances of cure.	The 4-6 people who will have cancer found early may not have better chances of cure. They might just know for a longer time that they have cancer.

What is thyroid surgery?

Thyroid surgery may be needed to detect thyroid cancer that is not found by fine needle aspiration. Thyroid surgery is generally very successful. Most of the time only a part of the thyroid gland is removed. Nevertheless some people have adverse effects, which can include:

- Damage to the parathyroid gland (next to the thyroid gland). This causes temporary low blood calcium and muscle cramps in 10 to 15 out of every 1,000 people. A few people (about 7 out of 1,000) will need to take calcium supplements permanently.
- Needing to take thyroid pills. If the entire gland is removed, thyroid hormone replacement pills must be taken. If part of the gland is removed, between 1 and 10 people out of every 1,000 will need to take hormone replacement pills.
- Damage to the vocal cords and having a hoarse voice afterwards. Generally this is temporary, but in about 7 out of 1,000 people, the hoarseness is permanent.

- Getting an infection in the wound and needing antibiotics (about 3 out of 1,000 people).
- Bleeding during the operation and needing a blood transfusion (less than 1 out of 1,000 people).
- Dying from the anesthetic (less than 1 out of 1,000 people).

**These are average rates and will vary with different people, places, and surgeries.*

How can you decide whether to be screened for thyroid cancer?

Your options are:

1. Continue with your usual health care. If you develop a symptom (see page 4), see your doctor and have this symptom checked.
2. Ask your doctor to screen you by neck exam.
3. Ask your doctor to arrange an ultrasound.

Steps in making your decision. See the attached worksheet to work through these steps in your decision-making:

Step 1: What is your estimated dose of I-131 from the Nevada tests?

Step 2: What is your likely risk of developing thyroid cancer?

Step 3: How important is each of the pros and cons of thyroid cancer screening to you?

Step 4: Which of the two methods of screening is best for you?

Step 5: What questions do you have before deciding?

Step 6: Discuss your decision-making with your doctor.

WORKSHEET

Step 1: What is your estimated dose of I-131 from the Nevada tests?

To get your estimated dose of I-131 in rad, find the row on the left that includes your year of birth. Then find the column that best describes the kind and amount of milk you drank between 1951 and 1963.

What is your estimated I-131 dose?

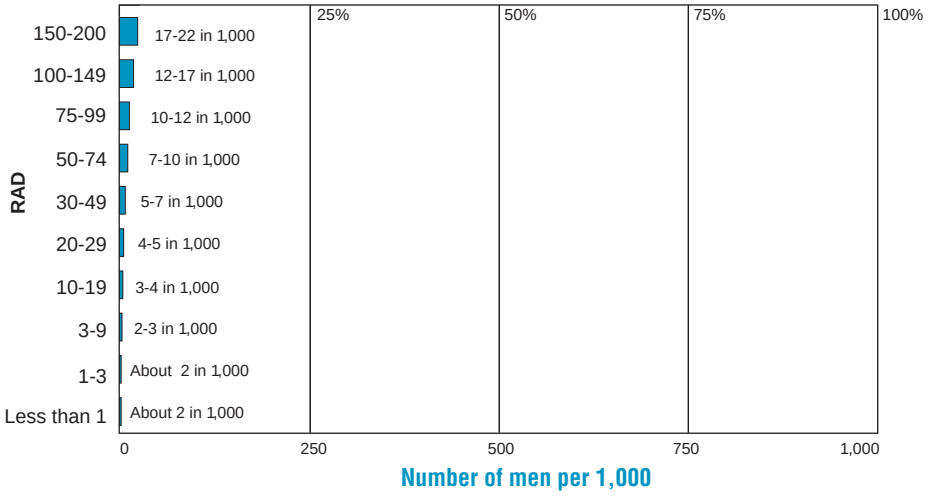
	Doses in rad by amount and type of milk				
	No milk	Processed milk		Farm cow	Farm goat
Year of birth	0 cups/day	1-3 cups/day	4+ cups/day	any amount	any amount
Before 1933	Less than 1	2	4	6	30
1933-1937	Less than 1	3	6	9	45
1938-1942	Less than 1	5	10	15	75
1943-1947	Less than 1	7	14	21	105
1948-1957	Less than 1	10	20	30	150
1958-1963	Less than 1	1	2	3	15
After 1963	Less than 1	Less than 1	Less than 1	Less than 1	Less than 1

Your estimated dose of I-131 in rad: _____

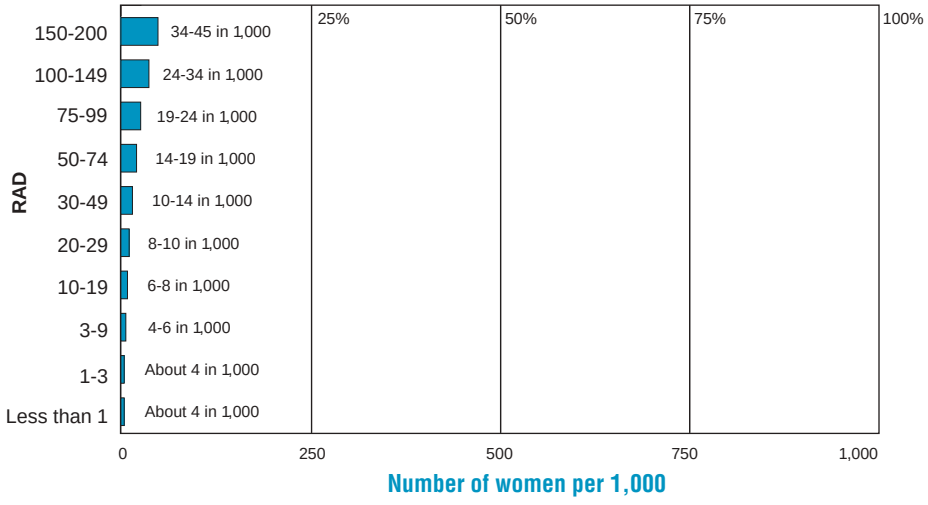
(For more precise estimates of dose, including effect of where you lived, see the individual dose calculator at *www.cancer.gov.)*

Circle the number that best shows your chance of eventually developing thyroid cancer. The first graphic is for men. The second is for women. Statistics are for people who are 50 years old and cancer-free.

Chance of thyroid cancer per 1,000 men



Chance of thyroid cancer per 1,000 women



Step 3: How important is each of the pros and cons of screening to you?

Pros

- 800 to 960 people out of 1,000 are correctly reassured that they don't have cancer
- 1 to 6 people out of 1,000 will have cancers found and treated early

Cons

- 40 to 200 people out of 1,000 will have false alarms causing anxiety, tests, and surgery when they don't have cancer
- Early detection may not increase the chance of cure

Your Priorities

Looking at the pros and cons given here, shade the diamonds below to show how important the following are to you (5 diamonds means very important; 0 diamonds means not important at all):

◇ ◇ ◇ ◇ ◇	Knowing whether or not you have cancer
◇ ◇ ◇ ◇ ◇	Avoiding anxiety caused either by false alarms or by knowledge that cancer is present; avoiding unneeded tests that may result from false alarms

If you shaded more diamonds in the first row, you are leaning toward being screened (continue to step 4). If you shaded more diamonds in the second row, you are leaning toward not being screened (go to step 5).

Ultrasound

- More cancers found and treated early (4-6 people out of 1,000)
- More false alarms (150-200 people out of 1,000)

Neck Examination

- Fewer cancers found and treated early (1-3 people out of 1,000)
- Fewer false alarms (40-80 people out of 1,000)

Your Priorities

Looking at the information about ultrasound and neck exam given here, shade the number of diamonds below to show how important the following are to you (5 diamonds means very important; 0 diamonds means not important at all):

◇ ◇ ◇ ◇ ◇	Early detection
◇ ◇ ◇ ◇ ◇	Avoiding false alarms

If you shaded more diamonds in the first row, you are leaning toward ultrasound. If you shaded more diamonds in the second row, you are leaning toward neck examination.

Step 5: What questions do you have before deciding?

Step 6: Discuss your decision-making with your doctor.

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