

#### PATIENT & CAREGIVER EDUCATION

# Your Medical Information and the 21st Century Cures Act

This information answers frequently asked questions about different types of notes and test results you can see in MyMSK, our patient portal.

As a patient at Memorial Sloan Kettering (MSK), you can now view medical information that you have not been able to see in the past. You can also see the results of tests and medical scans sooner than you were able to in the past.

Patients have more digital access to their health information because of a law called the 21<sup>st</sup> Century Cures Act. MSK and other medical centers around the country must comply with this law by October 6, 2022.

Below, learn more about how you can see and understand the medical information in MyMSK.

## Frequently Asked Questions About Viewing Your Notes in MyMSK

The notes your healthcare provider writes after a visit may be available in MyMSK, our patient portal. They can include information about your exam, medications, test results, and the next steps in your care. Reading them can help you remember the details of your visit and feel more in control of your health. The notes from your visit are part of your medical record.

### When can I see my notes?

Beginning October 3, 2022, you will be able to see notes from visits with your healthcare provider in MyMSK as soon as they are available in our computer system. This can take up to a few weeks. Notes from some earlier visits are already available:

- Many outpatient visits that took place after August 24, 2021.
- Gynecology Surgery and Gynecologic Medical Oncology visits that took place after September 14, 2020.
- Survivorship Program visits that took place after December 1, 2019.

# How do I sign up for alerts about visit notes?

If you signed up to get email alerts about new lab results, you'll get one when a new visit note is in MyMSK. If you would like to get emails when you have visit notes and lab results, follow these steps:

- 1. Select the circle that has your initials in it on the top right of the MyMSK page.
- 2. Select Profile.
- 3. Select Settings.
- 4. Select Notifications.
- 5. Look for Account Activity. On the right, you'll see a + sign
- 6. Select +
- 7. Select Send Daily in the column next to "New lab results and visit notes available."

## Where can I find my notes?

You can read visit notes in MyMSK by following these steps:

- 1. On the blue banner at the top of the MyMSK page, select Medical Info.
- 2. Select Medical Documents.

3. You will see the notes listed as Visit Notes.

If you have trouble finding your notes, please call the MyMSK Help Desk toll free at 800-248-0593 or at 646-227-2593. They're available Monday through Friday between 9 a.m. and 5 p.m. (Eastern time).

### Who can see my notes?

You and anyone with access to your MyMSK account can see these notes. Family and friends who are an important part of your care can view your MyMSK account if you give them your permission. Remember, when you give someone this proxy access, they can see all of your medical records in MyMSK. This includes your visit notes, as well as records about your treatment, test results, and diagnostic information. They can see your billing information, but they can't see your consent, insurance, and registration forms.

You can view and update who has access to your account by following these steps:

- 1. Select the circle that has your initials in it on the top right of the MyMSK page.
- 2. Select Profile.
- 3. Select Account Access.

4. Follow the directions for viewing or changing account access.

### How can I share my notes?

You can share your notes and send them to anyone you want to see them. This includes your healthcare providers outside of MSK, your caregiver, and friends and family who support you in your care. Share your notes by downloading them to your computer, or through the MyMSK mobile app.

### When is it helpful to read my notes?

- After your visit, to make sure you understood what you and your healthcare provider discussed.
- Between appointments, so you can review your healthcare provider's instructions.
- Before your next visit, to help you remember what happened at the last visit. This also may help you think of new information to share with your healthcare provider, and new questions to ask.

## What if I don't understand my note?

You may not understand everything in your healthcare provider's note. The names of some visit notes may look a bit hard to read and understand because they're from

your electronic health record. Also, healthcare providers use medical words to explain your health to other members of your care team. It's common for patients not to know the meaning of some words. You can find definitions on websites such as the National Cancer Institute and WebMD. You can also use "Messages" in MyMSK to ask your healthcare provider about the note. Usually you will get their answer in 2 business days (Monday through Friday).

### What if I see a mistake in my note?

If you think your note is wrong or incomplete, contact the healthcare provider who wrote it by using "Messages" in MyMSK. Your care team will take a look and get back to you. Usually you'll get their answer in 2 business days (Monday through Friday). They may message you if they need more information from you, or more time to review the possible mistake. If there's an error throughout your medical record, you will need to fill out a form called a Patient Request for Amendment of Records. Your care team will tell you if you need to complete the form and will send it to you.

# The end of my note has "time spent" and "non face-to-face activities." What does that mean?

This is information MSK uses to describe your visit. "Time spent" means the time your healthcare provider spent on this visit. It can include time your provider spent reviewing records before the visit, documentation, and activities after the visit. It does not mean how long your visit lasted, or how long your provider spent with you during your visit. You also may see information about the "visit level." This describes how complex your visit was. You also may see other information, such as diagnosis codes, and whether this was a telemedicine visit.

### What if I want to see all my notes?

Seeing your visit notes in MyMSK is different from seeing all of your medical records. You can ask us for a copy of your medical records by following these steps:

- 1. On the blue banner at the top of the MyMSK page, select Medical Info.
- 2. On the bottom right of the page, select Ask for Your Medical Records.
- 3. Follow the instructions.

If you ask us for your medical records using this method, you will not see them here in MyMSK. If you have questions, please contact our Release of Information department by phone at 646-227-2089 or email HIMROI@mskcc.org.

## Frequently Asked Questions About Viewing Your Radiology Test Results in MyMSK

This information answers some common questions about viewing radiology test results. These test results are called a radiology report.

#### When can I see my radiology results?

Radiology results, also known as imaging results, (such as PET, MRI and CT scans) are available in MyMSK (our patient portal) as soon as they're in our computer system. This means you may see them before your healthcare provider reviews them or discusses them with you.

#### Where can I find my radiology results?

You can see the report about your results in MyMSK using the app or the web browser (desktop or mobile device):

• If you're using the MyMSK mobile app, select Medical Info. Then select Test Results.

• If you're using the web browser, select Medical Info on the blue banner at the top of the screen. Then select Test Results and Reports.

If you have trouble finding your test reports, please call the MyMSK Help Desk toll free at 800-248-0593 or at 646-227-2593. They are available Monday through Friday between 9 a.m. and 5 p.m. (Eastern time).

# How do I print or save my radiology report?

You can print or save your radiology results using MyMSK.

- If you're using a computer:
  - 1. Open MyMSK in your web browser.
  - 2. Click "Medical Info" on the blue banner.
  - 3. Click "Request Your Medical Records."
- If you're using the MyMSK app on a smartphone or tablet:
  - 1. Open the MyMSK app.
  - 2. Tap "Med Info" on the bottom of your screen.
  - 3. Tap "Export" in the top right corner of your screen. You can download your lab and test results, including your radiology reports.

If you do not have a MyMSK account, you can sign up at my.mskcc.org. You can get an enrollment ID by calling 646-227-2593 or your doctor's office.

If you choose not to sign up for MyMSK, you can get a copy of your radiology report by contacting our Release of Information department. You can email them at HIMROI@mskcc.org or call them at 646-227-2089.

# How do I send my radiology images to a healthcare provider outside MSK?

The healthcare provider can ask for the images by filling out our Radiology Image Request form. They can find it at www.msk.org/departments/radiology/radiology-image-request. This is called a Continuum of Care request. There is no charge.

You can also use MyMSK to ask us to send your radiology images to a healthcare provider outside MSK.

- If you're using a computer:
  - 1. Open MyMSK in your web browser.
  - 2. Click "Messages" on the blue banner.
  - 3. Click "Compose New Message."
  - 4. Click "Request a copy of your radiology exams."

- If you're using the MyMSK app on a smartphone or tablet:
  - 1. Open the MyMSK app.
  - 2. Tap the "Messages" icon at the bottom of your screen.
  - 3. Tap "New" at the top right of your screen.
  - 4. Tap "I want to send a message about another topic."
  - 5. Tap "Request a copy of your radiology exam."

If you choose not to sign up for MyMSK, you can ask us to send your radiology images to a healthcare provider outside MSK by filling out a Release of Information form. You can find it at www.msk.org/teaser/release-information-form.pdf. Print and sign the form, then fax it to the image library at 212-717-3020. You can also email the completed form to mskimagelibrary@mskcc.org

We will first try to send the images to the healthcare provider electronically. If that does not work, we will mail the CDs with the images. Let us know your email or phone number so we can update you on your request.

# How do I get a personal copy of my radiology images?

You can use MyMSK to ask for a personal copy of your radiology images. Follow the same steps as you would to ask us to send them to a healthcare provider outside MSK.

If you choose not to sign up for MyMSK, you can ask for a personal copy of your radiology images by filling out a Release of Information form. You can find it at <a href="https://www.msk.org/teaser/release-information-form.pdf">www.msk.org/teaser/release-information-form.pdf</a>. Print and sign the form, then fax it to 646-227-3545.

We can send your radiology images to you electronically or on a CD. There is a charge for personal CDs of radiology images. If you pick up the CDs from us, the charge is \$20 per CD. If we mail the CDs to you, the charge is \$28 per CD.

#### How are my scans read?

A radiologist is a doctor who specializes in medical imaging. Your radiologist will look at your scan images and write a report to your doctor. First, they may review your medical record. This lets them learn more about your health conditions and the treatments you had. If there are other scans in your MSK medical record, your

radiologist will compare them to look for changes. The report will have your radiologists findings (observations).

### What if I don't understand the report?

Radiologists use medical words to explain your health to other members of your care team. For most people, it's common not to know the meaning of some words. You can find definitions below and on websites such as www.radiologyinfo.org

Don't try to understand the results by yourself. Instead, talk with your doctor. They can help you understand the report, based on your medical history, physical examination, laboratory tests, and past radiology exams.

Here are some common terms used in radiology reports and what they mean.

General terms	
Artifact	Something that shows up in your scan that can make it harder for your radiologist to interpret the images. The artifact can be caused things such as metal in your body, or if you move during the scan.
Benign	Something that is not a cancer.
Indeterminate	This finding is seen in a few health

	conditions. We can't make a diagnosis just from the imaging study.
Infectious/inflammatory	Something in your scan that can be caused by an infection or inflammation (swelling). The swelling may be from a reaction to a drug, or an immune response.
Lesion	An area that looks unusual. A lesion can be benign (not cancer) or malignant (cancer).
Malignant	A cancer tumor that can spread to other parts of the body.
Mass	Abnormal tissue that can be benign (not cancer) or malignant (cancer).
Metastasis	A piece of tumor that has spread from the main tumor (also known as the primary tumor).
Nodule	A rounded or oval growth that can be benign (not cancer) or malignant (cancer).
Nonspecific	The finding is seen in many different conditions.
Physiologic	A normal situation for how your body works.
Reference range	Test results are often reported as numbers. To understand the numbers, we compare them to what's normal for

	most people. A "reference range" tells you what numbers are usually normal. Comparing your numbers to the reference range can show you and your doctor if there's a problem.
Tumor deposit, tumor implant	Words to describe a piece of tumor somewhere in the body.
Unremarkable	We found nothing abnormal or wrong to report about that part of your body.

Findings in body parts	
Atelectasis	A complete or partial collapse of some part of your lung. This often happens because your air sacs are deflated (have no air). At lectasis is very common. It can show up in the image if you did not take a complete breath. Sometimes it shows up because extra fluid is in the space around your lung. This is called a pleural effusion.
Blastic lesion, sclerotic lesion	Area where your bones grow faster.
Cyst in kidney or liver	A cyst is a pocket filled with fluid or other material. They are common, and usually not cancer. If a cyst concerns your radiologist, you may have more tests.
Diverticulum (or several diverticula, diverticulosis)	An outward bulging, most often found in the colon (large intestine). It is not cancer.

Fatty liver (also called hepatic steatosis)	This is a common finding that shows a higher amount of fat in the liver. It can be caused by liver disease or other conditions.
IPMN in pancreas	This is an abbreviation for Intraductal Papillary Mucinous Neoplasm. It is common and usually is not cancer. In a small number of cases, it can develop into cancer. Often, an IPMN needs follow-up imaging tests. The tests check if the lesion has grown or changed over time.
Lymph node sizes	The normal size of a lymph node depends on its location. Lymph nodes can get bigger for many reasons, such as an infection or tumor growth. Radiologists describe the sizes of enlarged (bigger) lymph nodes. Your doctor will interpret that information based on the disease you have.
Lytic lesion	An area within a bone of destroyed bone.
Opacity	A part of the lung that looks different than normal lung. It can be benign (not cancer) or malignant (cancer).
Stenosis, stricture	A narrowing of tubes, such as the ones that carry blood or are connected to the kidneys or intestines.

PET-CT	
Metabolic activity	The chemical changes that take place in
	cells and tumors.

Physiologic uptake (at PET-CT)	The normal use of sugar that all cells in the body need to survive.
SUV and liver reference values (at PET-CT)	During a PET scan, you're injected with radioactive material. Standardized Uptake Value (SUV) shows how much of that injected substance is found in an area of your body. Your PET scan report records this measurement.

CT	
Attenuation	This shows how much energy from X-rays
	is absorbed by a tissue or other substance
in your body. We sometimes use it to	
describe a narrowing of tubes, such as the	
	ones that carry blood.

MRI	
Hyperintense	Something that is brighter than another part of the image, such as muscle or liver.
Hypointense	Something that is darker than another part of the image, such as fat.
Signal	The brightness or darkness of each point in an image. Tissues and other substances give off different amounts of signal.

Ultrasound (Sonogram)		
Echogenic (also	A material or substance that is brighter	
called hyperechoic)	than the area around it on the ultrasound	

	image.
Hypoechoic	A material or substance that is darker than the area around it on the ultrasound image.

# The report mentions tiny lung nodules, or nodular thickening of adrenal gland. What does that mean?

Radiologists use words to describe what they see on the pictures of your insides. When an organ has something that usually is not there, we can describe it as a lesion, nodule, mass, lump, thickening, or nodularity (see list of definitions). These findings are not specific. Often, they do not mean there is cancer.

For example, a CT scan of a lung finds a tiny, benign (not cancer) nodule in about 2 out of every 3 people. It's often from scars from a past infection. We usually monitor these tiny or nonspecific lesions at follow-up exams. Benign lesions in general will not grow.

# What does "too small to characterize" mean?

Radiology equipment can show many tiny flaws inside your body. Just as no 2 people look the same from the outside, their insides also look different. Most of the time, tiny lesions are so small radiologists describe them

as "too small to characterize."

They usually do not mean there is a serious problem. Many are benign (not cancer) cysts, for example. We usually monitor them at follow-up exams. Benign lesions in general will not grow.

# The report mentions a possible tumor in a part of my body different from the one that was tested. Why?

An imaging scan can show an abnormality (something that isn't normal) in a different area than the one tested. You may not have any symptoms in this area. These "incidental" (additional) findings (observations) often are not serious.

Sometimes, they can mean there's a major problem. Finding the problem before it causes symptoms is very useful. That's why radiologists mention these results in their reports. They also can recommend what steps to take.

#### What is an anatomic variation?

Everyone's insides are not arranged the exact same way. Before birth, our bodies develop small differences. They're usually are normal and will not harm you.

# Why did my radiologist recommend another test?

Each kind of radiology scan gives certain information about the body. The information is different for each test, because each scan makes images of your body in different ways.

Another type of scan can give new, different information than a test you already had. Also, your radiologist can see something on one kind of scan, but not on another. Your doctor will decide the next steps in your treatment.

# Why did the radiologist recommend close-interval follow-up imaging in my report?

Many scans show results that are not important to your health. We learn if it's important by repeating a test. We often will ask you to get another scan either weeks or months later.

The second scan can tell us if the lesion grew or changed. A lesion that does not grow or change is less of a concern than one that does. It may not need testing, such as a biopsy (taking tissue samples from the lesion).

# How is a PET-CT scan different from a CT scan?

A CT scan uses x-rays to make a detailed view of the inside of your body. The

A PET-CT scan is an imaging procedure that uses radiation from an injected medicine. We use a PET-CT scan to find or check the growth of cancer tumors. We also use it to check the health of your tissues and organs.

The CT part of a PET-CT scan mostly helps your radiologist read the PET scan. CT scans use a very low dose of X-rays to take pictures. These CT pictures are not as clear as the ones from a regular CT scan. Your doctor may order a different kind of CT scan to get more information.

# Should I be worried about radiation exposure from my CT or PET-CT scan?

A scan uses a very small amount of radiation to let your radiologist see the inside of your body. The dose of radiation is at the lowest level possible to make the images your radiologist needs. Your doctor ordered the scan because its benefits are greater than the very small risk caused by the radiation. Visit

www.radiologyinfo.org/patient-safety to learn more about radiation doses.

# My report's impression section does not mention everything that's in the findings section. Why?

Radiology scans, such as CTs and MRIs, show thousands of details inside the body. Radiologists are doctors trained to recognize signs of disease or good health in different kinds of scans.

In the Findings section, they write their observations (findings) about items that may interest the doctor who ordered the test. In the Impression section, they give a summary of their findings. They choose the ones that are most important to your doctors so they can make decisions about your treatment.

# On follow-up scans, a different radiologist often re-measures the size of a lesion. Why do they get different measurements of the same lesion?

Measurements in radiology are not perfect. A lesion often has an uneven shape, fuzzy borders, or a different position. We expect to see slight differences in measurements. They usually are not big enough to need changes in your treatment plan.

# Why do my radiology reports from MSK look different from my reports from my other healthcare providers?

Reports from MSK look different from other radiology providers' reports, which have many paragraphs. At MSK, we use a special format called standardized reporting. Each of the more than 300 different types of imaging studies performed at MSK has its own format. It shows the results that are most important to your care plan. Our reports are easier to read and understand, and are more consistent.

# What do the numbers at the end of my report mean?

Every MSK radiology report has numbers printed at the bottom, called a standardized certainty lexicon. Our radiologists estimate the probability (chance) that you have a diagnosis. The numbers tell you whether it's likely a lesion could be a health problem. We don't do these estimates for breast scans.

Consistent with	Greater than 90%
Suspicious for/Probable/Probably	About 75%
Possible/Possibly	About 50%
Less likely	About 25%

Unlikely	Less than 10%
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If you have any questions about your radiology test results, please contact your MSK healthcare provider.

## Frequently Asked Questions About Viewing Your Genetic Test Results in MyMSK

This information will help you learn more about your genetic test results. It is not a cancer management plan. Talk with your healthcare provider before making any decisions about cancer screening or surgeries. They will help you make a cancer management plan based on your personal and family history of cancer and your genetic test results.

#### When can I see my results?

Your genetic test results will be available in MyMSK as soon as they're in our computer system. This means you may see your results before your healthcare provider has seen them or discussed them with you. Your healthcare provider will be in touch with you after reviewing your test results.

## Where can I find my results?

You can see your genetic test results in MyMSK using the app or the web browser (desktop or mobile device):

- If you're using the MyMSK mobile app, select Medical Info. Then select Test Results.
- If you're using your web browser, select Medical Info on the blue banner at the top of the screen. Then select Test Results and Reports.

If you have trouble finding your test results, call the MyMSK Help Desk toll free at 800-248-0593 or at 646-227-2593. They are available Monday through Friday between 9 a.m. and 5 p.m. (Eastern time).

### What does a positive test result mean?

A positive test result means that a change in a gene (known as a mutation) was found. That mutation may help explain why a person was diagnosed with cancer. It may also explain why certain types of cancer exist in a family.

A mutation may also mean that there is an increased risk of developing certain types of cancer. The risks for cancer and the specific type of cancer may be different for different mutations. For some mutations, the risks of specific cancers may be high. For other mutations, the risks may be lower.

A person with a mutation may be offered special or more frequent cancer screening exams to try to find any cancers as early as possible. The exact exams will depend on the gene that is mutated. For some mutations, there are no clear guidelines about the best screening exams to use, or how often to have them.

A person with a mutation may also be offered certain types of surgeries. These surgeries may help reduce their risk of developing cancer. Your healthcare provider will discuss your cancer management recommendations with you.

If a person has a mutation, family members may also carry this same mutation. If they do, they may also have an increased risk for the types of cancer linked to that mutation.

An MSK genetic counselor can help identify who in the family is at risk of having the mutation, who should be tested, and when is the right time (age) for them to get tested.

#### What does a negative test result mean?

A negative test result means that no mutation was found. This can happen for several reasons. For example:

- Your personal or family history of cancer could have happened by chance. Some types of cancer may occur in several people in a family without being caused by a genetic mutation.
- There may be a genetic mutation in other members of your family, but you did not inherit it.
- You could have a mutation in the gene(s) that was tested, but the mutation cannot be found by the current testing method. No one form of genetic testing can find all mutations in a gene.
- You may have a mutation in a different gene. For example, you could carry either a mutation in a gene that has not yet been discovered or a very rare genetic mutation.

# What does a variant of uncertain significance mean?

A variant of uncertain significance is a change in a gene that is not yet fully understood. We do not yet know if the change has any impact on your risk of developing cancer. Your healthcare provider will make cancer screening recommendations for you based on your family history. Future research may make it clearer whether or not a variant of uncertain significance leads to increased risks of cancer.

### Who should I contact if I have questions?

If you have questions, call the MSK healthcare provider who ordered your genetic test.

## Frequently Asked Questions About Viewing Your Lab Test Results in MyMSK

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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