

# Information for Patients and Contributors

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## 1. Introduction

This introductory page will help you understand the process of contributing, by summarizing what is needed, how to get it, and how to begin the upload process. If you would like to go straight to the contribution instructions, click [here](#).

## 2. Why we want your contributions.

As mentioned elsewhere on this site (see "[What this is all about](#)"), medical images can be invaluable in research - particularly in medical research, but also in other areas such as computer science, physics and digital photography. However, because medical images are almost always part of peoples' confidential medical records, it can be very difficult for scientists and engineers to obtain images to use in their research. We would therefore like to collect medical images from volunteers to create a library that can be used by researchers worldwide. To do this, we will accept contributions of images from members of the public, from which we will remove identifiable information (such as names and addresses), before re-distributing them.

## 3. What is needed.

To achieve the goals of the PCIR, we need to be able to provide to researchers:

- complete sets of images for a particular type of examination
- some information about the images, describing why they were taken and what they mean

We would therefore like you to contribute:

- your most recent complete set of images
- any previous or additional sets of images
- the reason the images were taken, and the names of any other medical conditions you have
- the radiologist's report(s) on the images (e.g., as a scanned paper document)
- if you have had a biopsy or surgery related to the reason the images were taken, the pathologist's report(s) on those

As an example of why we need this, suppose that you are healthy but have recently had a mammogram for screening. On its own, this set of images might be useful to an engineer to help develop software to measure breast density, or to detect abnormalities that might be visible to a radiologist, or to test digital image management software such as image compression tools.

However, the images would be more valuable if they were accompanied by those from your

previous years' examinations; that would allow researchers to do more, for example to develop and test tools that compare current and prior exams. If more than one type of test was performed, such as a breast MRI or ultrasound as well as the mammogram, then those images would also be helpful as they could be compared to one another.

Even more valuable would be information about the reason the examination was performed in the first place (often called the "indication" for the exam), as well as what was found in those images by your radiologist (the "report"). These are useful because they allow researchers to look for images that are particularly relevant to them. In the screening mammography example, it might be important to know whether the reason for the exam was for routine screening of a healthy person, or whether it was for screening someone in a high risk group (such as someone with a strong family history of breast cancer). It is also important to know if anything was found, how it compared to previous examinations, and what the radiologist's recommendation was. Ideally, all of this information will be present in the report.

Finally, most helpful of all, but possibly hardest to obtain, would be the results of tests on any tissue which might have been removed around the time the medical images were taken. These are important because they provide definitive evidence about what the medical images are showing. For example, if you needed to have a biopsy as a result of the screening mammogram, it would be most helpful to have a copy of the pathologist's report on that biopsy. In the unfortunate event that you needed surgery to remove a tumor, the pathologist's report on the surgical specimen is also helpful. These reports would allow researchers to compare the findings of images that were associated with a negative biopsy with those associated with a positive biopsy, or with some particular disease. It would also be helpful to know whether you were still healthy some time after the examination, perhaps at your next annual screening mammogram, and so we would encourage you to continue contributing every time you have a radiological examination.

You will find additional and more detailed information about what types of images are available in the FAQ section on [what we need](#).

#### **4. How to go about obtaining images.**

As far as the images are concerned, very likely you will find that your imaging center offers you a CD rather than a packet of film to take to your doctor. These CDs should be just fine for uploading; just make sure that your doctor gives it back to you, or makes a copy of it for you.

If you are not offered a CD by the imaging center, you could ask them to burn one for you before you leave; it is far easier for them to do it when the examination is available on the system. You may need to come back later for it or have it mailed to you, especially if they

want to include the report on the CD (which is a good thing).

If some time has passed since your examination, you can still call and ask for the images to be retrieved from their archive and put onto a CD for you. Larger facilities will store their images digitally for many years, especially if they have a system for managing their images called a "PACS" (Picture Archiving and Communications System). Not all facilities will do this, though, and some will archive their images on film rather than on computer, in which case they are not useful to us.

When you speak to your imaging center, be sure to ask about your old examinations as well as your most recent ones. Nowadays, many sites will retrieve your old exams from their digital archive when they look at your current exam, but they will not necessarily burn these old exams to your CD unless you specifically ask them to.

Hopefully there should be no fee charged by the imaging facility. They save a lot of money burning CDs rather than printing film, and are generally very happy to do this. If there is a fee it will be very small.

To summarize:

- you should be given a CD as a matter of routine after any imaging procedure
- if not, be sure and ask before you leave if they can burn one
- some sites may be able to retrieve your exams later, but not all will be able to
- do not forget to ask for your prior exams to be included on the CD as well

You will find additional and more detailed information in the FAQ section on [CDs](#).

## **5. How to go about obtaining radiology and pathology reports.**

As with images, it is usually just a question of asking. The question is, who to ask ?

In the case of the radiology report, you can ask your imaging center to mail or fax you a copy of the report when you go there to have the images taken; a paper copy is generally more readable than a faxed copy, but a fax is better than nothing at all.

Alternatively, you can just ask your own doctor for a copy - they will have their own copy because they ordered the test and need to know the result; their office staff can easily make an extra copy for you at your next visit. Indeed, they will probably have a complete collection of all your reports, so you can ask for those too.

Your own doctor is probably the best person to get hold of any pathology reports as well. Both your local doctor and your specialist certainly should have these and there is no reason they cannot make copies for you. But if necessary, you can also contact the pathology department directly, or the medical records department. Both will likely be able to help you,

but the medical records folks may charge a fee, and you should try to avoid this.

Most of these reports actually start out digitally, just like images. The problem is that it is not routine yet to exchange them electronically between doctors and facilities. Increasingly, imaging centers are adding them to the CD, which is helpful. But it would be unusual to be able to obtain the report in an electronic form separately from the CD. It would be even more unusual to find a doctor's office or facility that could give you the pathology report in an electronic form. It never hurts to ask, and if enough people asked maybe the service would be offered. One day you will be able to access all your medical records on the web (with the appropriate privacy and security measures of course), but that day is not here yet for most of us.

To summarize:

- you can get the imaging center to send you the radiology report, if it is not already on your CD
- your local doctor or specialist should have copies of all your reports
- you can get your pathology reports from pathology or medical records, but it may be harder or more expensive
- you can ask for electronic copies of your reports, but don't expect to receive them

Once you have your paper documents, you need to be able to upload them to the PCIR over the Internet. Once you have scanned them into digital files, the process is the same as uploading CDs. You will find additional and more detailed information on what is actually necessary to do the scanning in the FAQ section on [scanning paper documents](#). In short though, if you have a scanner attached to your computer and know how to use it, then great, otherwise there is always Kinko's and their ilk.

## 6. Privacy.

**Protecting your privacy is our highest priority.**

Accordingly, there is a large section of the FAQ devoted to answering questions about [privacy](#), what the risks and concerns are, and how we go about protecting your privacy.

Most importantly, if you have any concerns that are not satisfied, or are not happy in any way with the [agreement](#), **do not begin the contribution process**. Please feel free to use the email contact address on this [page](#).

## 7. No Feedback and No "Second Opinions".

Please be sure and understand that **you will not receive any feedback at all about the images that you submit.**

To protect your privacy, your contribution is anonymous. We do not ask who you are. We remove identification such as your name from the images. If anyone downloads images from the PCIR and interprets them, they will not be able to link the interpretation with the people who contributed the images. As well as protecting your privacy, this does also mean that the results of any such interpretation won't be of any use to you directly; there is no way for researchers to know whose images they are interpreting and communicate with you, or communicate with you via the PCIR.

We hope that you are willing to contribute anyway, in the interests of promoting science and assisting the common good. It is important, though, that you realise that The PCIR will not provide you with any sort of "second opinion" about your condition or treatment. See also the FAQ section on [benefits of contribution](#).

## **8. Start Contributing.**

Once you have gathered all the material you need, please proceed to the [Contribute Images](#) page to read the instructions for the uploading process.

Note that you do not have to contribute everything at once. You can upload the image CD now and various scanned paper documents later if you like.