



[www.transparencyls.com](http://www.transparencyls.com)

## HIPAA Privacy Policy

### 1. PURPOSE

*[Patients & Physicians might provide Transparency Life Sciences with confidential patient data. The TLS Protocol Builder and Patient Surveys are designed to ask non-confidential questions and therefore get in return non-confidential answers. Never-the-less, it is possible that you inadvertently will provide us with private healthcare data. In order to protect your healthcare information we follow common sense and when appropriate, strictly adhere to HIPAA guidelines in the event that any private patient data is supplied.]*

### 2. NOTICE FOR USE AND SHARING OF PROTECTED HEALTH INFORMATION

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW THIS NOTICE CAREFULLY. We at TRANSPARENCY LIFE SCIENCES pledge to have a relationship with you that are built on trust.

This trust includes our commitment to respect the privacy and confidentiality of your health information. This Notice is being given to you because federal law gives you the right to be told ahead of time about:

- How TRANSPARENCY will handle any medical information you

- might provide
- TRANSPARENCY's legal duties related to your medical information
  - Your rights with regard to your medical information.

### **3. SCOPE**

- a. This policy applies to all Transparency Life Science's employees, management, contractors, student interns, and volunteers.
- b. This policy describes the organization's objectives and policies regarding maintaining the privacy of patient information.

### **4. HOW WE MAY USE AND DISCLOSE (SHARE) YOUR PROTECTED HEALTH INFORMATION**

When you need health care, you give information about yourself and your health to doctors, nurses, and other health care workers and staff. This information, along with the record of the care you receive, is "protected health information" (PHI or "health information"). This information is kept in a paper form such as your medical record and in an electronic form on the computer.

As part of the TRANSPARENCY crowd-source process we collect user profile information and user survey responses that sometimes include specific health information. For example, in the user registration we ask if you have a specific interest in a therapeutic area. It can sometime be assumed that your interest stems directly from actually having a healthcare issue within the stated therapeutic area.

TRANSPARENCY uses and shares your health information primarily for medical research and training. For example, TRANSPARENCY may share your health information with outside health care providers for purposes such as improving treatment or research; in some cases, these providers have a specific relationship with TRANSPARENCY, such as contract research organizations (CRO)'s that might conduct a clinical study for TRANSPARENCY. In addition, other outside parties

who receive your information in order to perform services on TRANSPARENCY's behalf (business associates") must also take steps to keep your health information private.

This Notice will tell you how TRANSPARENCY uses and shares your health information for these and other purposes. It will also tell you when we need to get your specific permission to do so.

## **5. Health Care Operations**

Except where prohibited by Massachusetts state or federal laws (see section 4), TRANSPARENCY may legally use and share your health information for health care operations. We do not need to ask for your specific permission to do these things, as explained below:

TRANSPARENCY may use and share your health information for activities that are known as health care operations. These are activities that are needed to design and improve its website and carry out its mission. Some of the information is shared with outside parties who perform these health care operations or other services on behalf of TRANSPARENCY ("business associates"). These business associates must also take steps to keep your health information private.

Examples of activities that make up health care operations include:

- monitoring the quality of care and making improvements where needed
- making sure health care providers are qualified to do their jobs
- meeting standards set by regulating agencies; such as, Joint Commission of Accreditation of Hospitals
- storing your health information on computers
- managing and analyzing medical information

## **6. Uses and Disclosures (Sharing) of Your Health Information for Other Purposes**

TRANSPARENCY may legally use and/or share your health information with others in the following areas without your specific permission:

- For clinical research that is approved by a TRANSPARENCY Research Committee when written permission is not required by federal or state law. This also may include preparing for research or telling you about research studies in which you might be interested
- As required by state and federal laws and regulations
- For specialized government operations

## **7. Uses and Disclosures (Sharing) of Information that Require Your Written Permission (Authorization)**

Massachusetts state or federal laws require that we obtain your written permission before using or disclosing the information listed below:

- Sharing information about genetic testing (as defined by state law) or genetic test results
- Using and sharing health information for research, research preparation, or recruitment, when the appropriate

TRANSPARENCY Human Research Committee determines this is required under federal and state laws

## **8. YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION AND HOW TO EXERCISE THEM**

The Right to Ask for Limits on the Use and Sharing of Your Health Information.

- You have the right to ask for restrictions on the use and sharing of your health information for treatment, payment, or health care operations. You can also ask for restrictions on using this information to notify you about appointments, etc. TRANSPARENCY is not required to agree to your request. If we do, we must put the restriction in writing and abide by it except if you need to be treated in an emergency. You may not ask us to restrict uses and sharing of information that we are legally

required to make.

#### The Right to Look at and Get a Copy of Your Health Information.

- You have the right to look at and get a copy of your health information that TRANSPARENCY keeps of your healthcare information. You must ask for this in writing. We will respond within thirty (30) days from receipt of your request. If you ask for a copy of your records, you will be charged a fee.
- If your request is denied, we will explain the reasons in writing and tell you which rights you have, if any, to a review of the denial. We may offer to give you a summary or explanation of the information you requested as long as you agree in advance to this and to any fees that it might cost. If you ask for information that we do not have, but we know where it is, we must tell you where to direct your request.

#### The Right to Ask for a Paper Copy of this Notice.

- You may ask for a paper copy of this Notice from the contact listed below. You can ask for a paper copy even if you agreed to receive the Notice by email.

### **9. OUR DUTIES WITH RESPECT TO YOUR HEALTH INFORMATION**

TRANSPARENCY is required by law to keep your health information private. We are required to give people notice of our legal duties and privacy practices with respect to your health information.

TRANSPARENCY must abide by the terms of the Notice currently in effect. TRANSPARENCY reserves the right to change its privacy practices and the terms of this Notice at any time. TRANSPARENCY reserves the right to make the new Notice provisions effective for all protected health information that it maintains. If it does so, the updated Notice will be posted on the TRANSPARENCY web site and in all TRANSPARENCY registration areas for public viewing. You may request a copy of the current Notice at any time by calling any of the

people listed at the end of this notice, or you may view it on our web site at

## **10. HOW TO COMPLAIN IF YOU BELIEVE YOUR PRIVACY RIGHTS HAVE BEEN VIOLATED**

If you think that we may have violated your privacy rights or you disagree with any action we have taken with regard to your health information, we want you, your family, or your guardian to speak with us. If you present a complaint, your care will not be affected in any way. It is the goal of TRANSPARENCY LIFE SCIENCES to give you the best care while respecting your privacy. You may file a complaint by contacting a representative at any of the TRANSPARENCY sites that are listed at the bottom of this notice. You may also send a written complaint to the Secretary of the Department of Health and Human Services, 200 Independence Avenue, SW, Washington, DC 20201, or email to [HHS.Mail@hhs.gov](mailto:HHS.Mail@hhs.gov). We will take no retaliatory action against you if you file a complaint about our privacy practices.

## **11. PERSON TO CONTACT FOR INFORMATION OR WITH A COMPLAINT** If you have any questions about this Notice or any complaints, please contact a representative

at any of the TRANSPARENCY sites that are listed at the bottom of this notice.

## **12. EFFECTIVE DATE OF THIS NOTICE**

This Notice is effective as of December 1, 2011

Please Contact

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