Purpose

- Emphasize the importance of information handling transparency

- Pool our collective experience and expertise in developing resources that are applicable to any organization involved in the electronic sharing of health information

- Improve, as an industry, in how we communicate with the public about what we do with their health information

Coauthored by:

Let's *TALK* Best Practices

Transparency

Accessibility

Language & Presentation

Keep it Real

Transparency

Commit to being transparent

- Conveying what we do in simple terms can be anything but simple.

- The important thing is to **try** and to commit to transparency.

Accessibility

Make your information handling best practices easy to find.

- Don't blend concepts of information handling practices into your general website privacy policy.
- The common usage of the term "Privacy Policy" in the context of websites is why we prefer "Information Handling Practices."

Ensure the information is practically accessible.

- Make publicly available without special effort.
- Post wherever their information will be impacted.
- Evaluate your demographics and consider different languages.
- Meet accessible web content standards.

Language & Presentation

Use as much plain language as possible.

- Spell out acronyms. Explain industry terminology and keep sentences short. Test for clarity.

Logically organize your information.

- Consider both the internal organization of the information within the documentation and the organization of the documentation itself.

- Don't cover too many business cases at once.

Remember your audience and the purpose of providing the information.

- Assume the person reading about your information handling practices is already concerned. No sales pitches and avoid jargon.
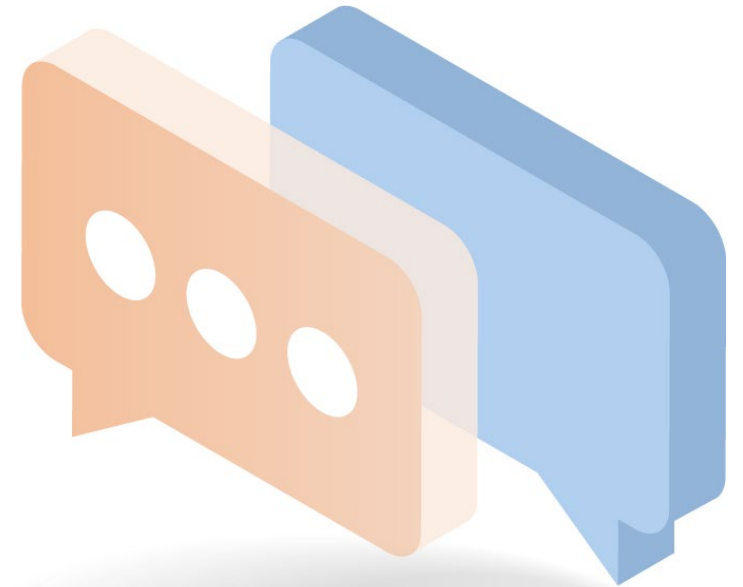
Keep it Real

Set realistic expectations.

- There is a substantial degree of misunderstanding about whether and how health information is regulated in the United States.

  - HIPAA

  - No HIE or HIN is exactly alike

- As EHI becomes increasingly available to individuals, it is crucial that they are provided the resources necessary to be informed about how and when their health information is *actually* private and protected.
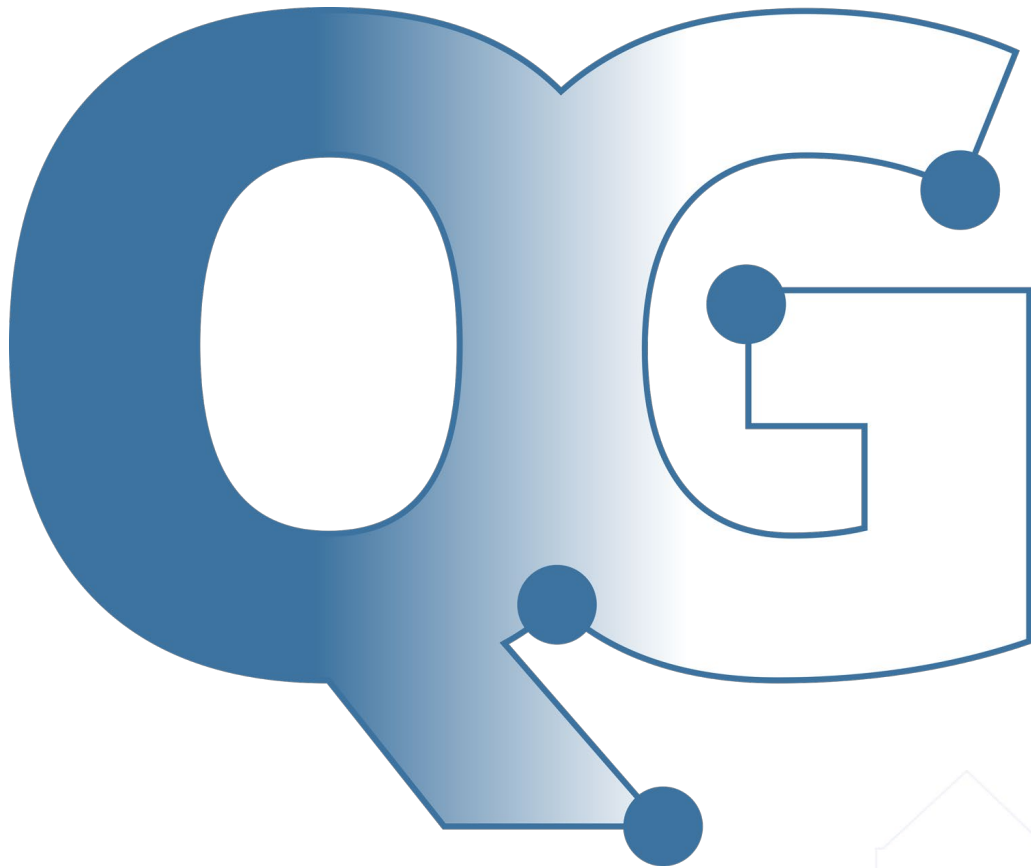
Sample
Questions and Guidance

More in the full Information Handling Transparency materials

What does your organization or product(s)/services(s) do?

What type(s) of information about me does your organization handle?

Who do you allow to access or request my health information?

For what reasons do you allow my health information to be accessed or requested?

Is ALL of my health information accessible for all of the reasons above? Are there any limitations?

Are users able to download, ingest, or otherwise keep a copy of my information? Once a user has a copy, what are _they_ allowed to do with my information?

Do you store information about me? If so, what do _you_ do with my information once you have it? Are you allowed to use it for other purposes?

Do you now, or will you ever, sell my information and/or use my information for marketing purposes? What about your users?

Can I get a list from you of everyone who has viewed, shared, or received my information through your organization or product/service?

Do I need to opt in or provide my consent in order for you to share some or all of my information?

Can I opt out of having some or all of my information shared through your organization or product/service?

Can *I* access or receive a copy of my information through your organization or product/service? What about the information of someone for whom I am a caregiver, such as a minor child?

Can I direct you to share my health information with a specific person or entity on my behalf?

How do you protect my information and keep it secure?

Is your organization regulated under HIPAA?

What happens if my information is inappropriately accessed, used, or disclosed? Will I be made aware? What will you do to make it right?

How do I contact someone in your organization if I have additional questions or concerns about how my information is handled?

Resources

Information Handling Best Practices

- U.S. Department of Justice, Civil Rights Division, Guidance on Web Accessibility and the ADA, available at https://www.ada.gov/resources/web-guidance/ (accessed July 24, 2023).
- World Wide Web Consortium (W3C), W3C Web Accessibility Initiative (WAI) homepage, available at https://www.w3.org/WAI/ (accessed July 24, 2023).
- U.S. Department of Health and Human Services, Example of a Policy and Procedure for Providing Meaningful Communication with Persons with Limited English Proficiency, available at https://www.hhs.gov/civil-rights/for-providers/clearance-medicare-providers/example-policy-procedure-persons-limited-english-proficiency/index.html (accessed July 24, 2023).
- Plain Language Action and Information Network (PLAIN) homepage, available at https://www.plainlanguage.gov/ (accessed July 24, 2023).
- Centers for Disease Control and Prevention (CDC), Plain Language Materials and Resources, available at https://www.cdc.gov/healthliteracy/developmaterials/plainlanguage.html (accessed July 24, 2023).

Information Handling Transparency Best Practices