



Your Rights

During Questionnaire Screenings

Questionnaires

A questionnaire is a form with questions that health care professionals sometimes use to ask you about your health. Sometimes they ask you questions out loud, and other times they ask you to write down your responses. You may be asked about:

- Feeling worried or sad
- Drug or alcohol use
- Hurtful or traumatic experiences
- Sexual activity



Questionnaires can help health care professionals identify possible concerns, figure out what other screenings you may need, and get you help.

Questionnaires should be done properly. This guide tells you about your rights.

You Can Always Say No

You **can refuse** any health screening questionnaire. Your health care cannot be denied because you chose not to complete a screening.

Before You Fill Out Any Questionnaire

You have the right to know:

- **Why** you need to complete it
- **Who** will see your answers
- **What happens** with your information

Communicate if:

- You have any questions about how your information will be used
- No one explains what the screening is for
- Someone says it is 'required'
- You did the same screening recently (in the past six months)

What You Can Do

If you are thinking...	You can communicate this...
I have taken this screening many times.	"I did this screening recently, so why do I need to do it again?"
I am already seeing a therapist/getting treatment/getting support.	"I decline the questionnaire because I am already receiving support for this from a [therapist/counselor/advocate]."
My doctor never looks at or talks about the results with me.	<p>Before a screening: "After I am done, can we talk about what the results mean and what support is available?"</p> <p>For a past screening: "I want to talk about my past screening results. What did they show and what was done because of them?"</p>
I am worried about being judged.	Remember: Health care professionals must keep your information private. Honest answers help them give you better care.
I am afraid I will get in trouble.	<p>Ask first: "Before I answer questions about [drugs/abuse], can you tell me what information you have to report and what stays private?"</p> <p>Know: Talking about drug use is usually private. Abuse situations might need to be reported, but health care professionals should tell you about this ahead of time.</p>
These questions are hard for me due to trauma.	<p>"Some of these questions are difficult for me. I would feel better if I could..."</p> <ul style="list-style-type: none"> • Have someone with me for support. • Do the questionnaire in private. • Take this home and finish it before my next visit. • Wait to do the questionnaire at my next visit."
I have decided I do not want to do this screening.	"I have decided not to complete this screening today."
I cannot complete this questionnaire.	"I need support to complete this. What accommodations are available?" Examples include larger print, more time, reading out loud, or electronic or paper copy.

When Health Information Stays Private or Not

Your health information is private.

This means no one can tell other people what you say or what is in your medical records unless it helps with your care, like referring you to a therapist. You must give permission before anyone shares your information.

Sometimes the law requires health care professionals to share information, like when someone might get seriously hurt. If someone needs to share your information, they should tell you why.

You have the right to know what might be reported before you answer questions.

What Information Should Be Kept Private

- Past or current drug use
- Mental health symptoms and history
- Most personal health information
- Sexual activity



What Information Might Be Reported

- **Immediate danger:** If your health care professional thinks you might hurt yourself or others, they may report it.
- **Intimate partner violence:** Depending on where you live, health care professionals may report intimate partner violence to the police, especially if there are serious injuries.
- **Child abuse:** If children are being hurt, it may be reported to the police or state child protection agency.



Important: Legal reporting requirements for health care professionals vary by state. Health care professionals should explain what they must report **BEFORE** asking sensitive questions. You can always ask what information must be reported.

When Your Rights Are Not Respected

- Document what happened (e.g., date, time, staff names, location).
- If you feel comfortable doing so, ask to speak with a supervisor or patient advocate during the visit, or contact patient relations at the health care facility after the visit.
- Know your resources: Find your state or territory's protection and advocacy agency by clicking on the following link and selecting your state or territory: www.ndrn.org/about/ndrn-member-agencies/
- If you feel that you have been discriminated against or treated unfairly due to your disability, you can file an Americans with Disabilities Act (ADA) complaint at www.ada.gov/file-a-complaint/

Summary of Your Rights

- ✓ You **can refuse** any screening questionnaire.
- ✓ You can **ask questions** before deciding to do the questionnaire.
- ✓ You can **request accommodations** for your disability
 - For example, alternative format, assistance completing the questionnaire, more time, a quiet room, bring someone with you, etc.
- ✓ You should **get explanations** about the purpose and results.
- ✓ You should **know what is private** and what might be reported.
- ✓ You can **stop a screening** at any time for any reason.

Remember

- **Your health care, your choice.** You decide what information to share.
- Past negative experiences are valid. It is okay to be cautious.
- Good health care professionals will respect your questions and work with you.
- You deserve care that considers your whole person, not just screening results.

Screening for All



**Making preventive health screenings
accessible for everyone.**

More resources available at
mcd.org/screening-for-all



Screening For All is an initiative funded by the Centers for Disease Control and Prevention (CDC)'s National Center on Birth Defects and Developmental Disabilities (NCBDDD) to address the significant barriers people with disabilities face in accessing preventive health screenings.

Developed by MCD Global Health, this project provides patients and health care practitioners with evidence-based tools and resources to make preventive health screenings accessible to all patients. Questions or comments can be sent to info@mcd.org.

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