

Consent Form Review Sheet

Reading a clinical trial consent form at home

Before you start: This is a big document with a lot of medical language. You don't need to catch everything on your own as that's what your research team is for. This worksheet is here to help you slow down, mark what matters, and walk into your next visit with real questions instead of a blank stare. There are no bad questions here.

How to use this: As you read your consent form section by section, use the prompts below to know what to circle and what to write down. Bring this sheet with you to your next visit.

1. What is this study actually about?

Look for: the purpose of the study, what the researchers are trying to learn, and why they think this treatment or approach might help.

Circle: any words you don't recognize (drug names, medical terms, abbreviations).

Ask about: "Can you explain this in plain language?"

2. What will actually happen to me?

Look for: the schedule, i.e. how many visits, how often, how long each one takes, and whether anything (like a procedure or biopsy) is different from your regular care.

Circle: any visit, test, or procedure that sounds unfamiliar or that you're nervous about.

Ask about: "Walk me through a typical visit day, start to finish."

3. How long is this commitment?

Look for: the total length of the study, and what happens after it ends (does treatment continue, does monitoring continue, do you just stop?).

Circle: the total duration and any long-term follow-up requirements.

Ask about: "What does my life look like during this, and what happens the day the study ends?"

4. What are the risks and side effects?

Look for: the list of possible side effects, usually split into "common" and "serious/rare." Also look for what happens if something goes wrong.

Circle: any side effect that would seriously affect your daily life, work, or the people who depend on you.

Ask about: "What's the most likely side effect I'd actually notice? What do I do if it happens?"

5. Could this help me — and could it also not?

Look for: the honest language about benefit. Many studies will say there's no guarantee you'll personally benefit. That's normal and doesn't mean it's not worth doing.

Circle: any sentence about expected benefit vs. uncertain benefit.

Ask about: "Based on what's known so far, what's realistic for me to expect?"

6. Will this cost me anything?

Look for: what's covered (study drug, visits, tests) vs. what isn't. Look for mentions of travel reimbursement, parking, or compensation.

Circle: any dollar amounts, and anything that says "may not be covered by your insurance."

Ask about: "Will I be out of pocket for anything, and is there reimbursement for travel or time?"

7. Is this really my choice?

Look for: the section confirming participation is voluntary and that you can leave the study at any time, for any reason, without it affecting your regular medical care.

Circle: the sentence that says you can withdraw at any time.

Ask about: "If I want to stop halfway through, what happens to my regular care?"

8. What happens to my information?

Look for: who sees your health data, how it's protected, and whether it's shared with anyone outside the research team (sponsors, other researchers, databases).

Circle: anything about data sharing that makes you uneasy.

Ask about: "Who exactly will see my personal health information?"

9. Who do I call if something comes up?

Look for: contact names and numbers for the research team, and for questions about your rights as a participant (often a separate ethics board number).

Circle: the two phone numbers: one for medical concerns, one for participant rights.

Before your next visit, write down the following:

My biggest question is:

The part I want explained again in simpler terms is:

Something I circled that I want to talk through:

Remember: signing this form is not a final decision on your treatment, it's your permission to move forward with eyes open. You can take your time, talk to family, and ask as many questions as you need before you sign anything.