UPL Guidance

Thought Starters
for Explaining Data

This document outlines some key challenges of explaining data (e.g., health statistics, research results, other numerical evidence) to patients, and provides thought starters to help address them. These thought starters are based on our learnings from building patient communications with patients and cross-disciplinary experts, across disease states.

Other available thought starter topics:

- Biological Processes
- Clinical Trials
- Health-related Finances
- Risks and Benefits

For more guidance on how to make your explanations more patient friendly, see the *UPL Rules* and the *UPL Style Guide*.

Resource contents:

☑ Guidance, standards, and best practices
○ Building blocks or assets
○ Assessment methods and tools

Applicable to:

○ All patient communications
☑ Specific topics

! **Ready But Limited:** This tool still has areas for improvement, and more resources will be added over time.

Why is it important for patients to understand data?

Understanding data related to their health and available treatments can help patients:

- Have meaningful conversations with their healthcare team
- Evaluate the risks and benefits of the treatment(s) they are considering
- Make informed decisions with their healthcare team

What are the key challenges for explaining data?

- Helping patients understand the significance and relevance of the data
- Explaining the logic and math behind the data
- Helping patients navigate and digest the data
- Striking the right balance between being concise and providing enough information
- Maintaining a fair balance of information (e.g., risks and benefits)

Thought starters for explaining data

There is no ‘one’ way to explain any given topic. Explanations are uniquely built for the specific audience — like patients from a particular disease state or demographic — and the objectives of the communication. These thought starters are meant to help you craft an explanation that works for your audience. The accompanying examples illustrate how these thought starters have been put into practice in existing UPL patient communications.

Build up patient knowledge incrementally.

Understanding data requires a certain level of foundational knowledge. Because patients come from all walks of life, with different backgrounds and experiences, allow them to learn what they need in order to make sense of the data, at their own pace. Anticipate the questions that patients might have and help them find answers in digestible chunks of information.

level 1
Starting the conversation about new treatment options

level 2
Understanding clinical trials: finding information about treatment benefits and risks

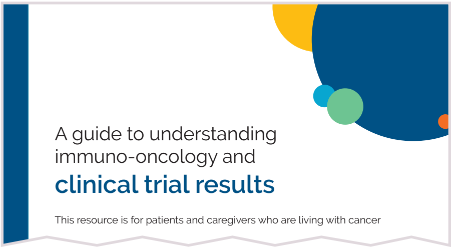
level 3
Taking a closer look at what clinical trials measure

level 4
Evaluating a treatment using clinical trial results

This example divides the content into four ‘levels.’ The content in each level incrementally builds the patient’s knowledge toward an understanding of the data.

When talking about clinical trial data, refer to ‘results’, not ‘endpoints’.

Patients found the word ‘endpoints’ off-putting, and preferred ‘results’ instead. The ‘end’ in ‘endpoints’ had a negative connotation for patients, evoking phrases such as ‘end of the line.’



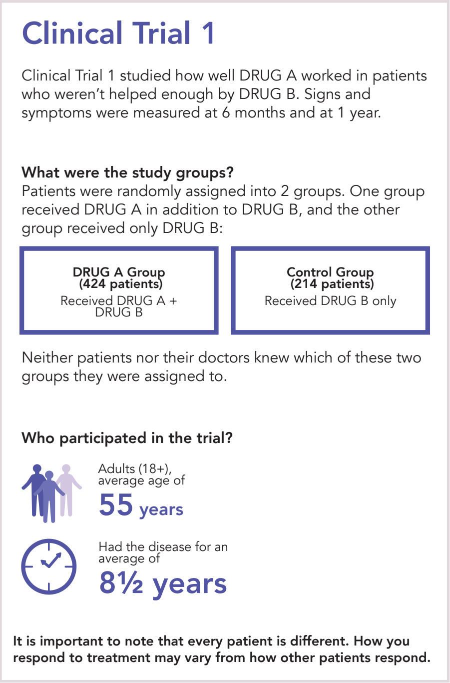
A guide to understanding immuno-oncology and **clinical trial results**

This resource is for patients and caregivers who are living with cancer

This example refers to clinical trial endpoints as clinical trial results.

Provide the necessary context for patients to interpret the data.

The meaning that can be drawn from presented data is heavily dependent on the context from which it was gathered. Including supplementary information such as definitions, where and how the data was collected, or how measurements are calculated can help patients make better sense of the data.



Clinical Trial 1

Clinical Trial 1 studied how well DRUG A worked in patients who weren’t helped enough by DRUG B. Signs and symptoms were measured at 6 months and at 1 year.

What were the study groups?
Patients were randomly assigned into 2 groups. One group received DRUG A in addition to DRUG B, and the other group received only DRUG B:

DRUG A Group (424 patients) Received DRUG A + DRUG B	**Control Group (214 patients)** Received DRUG B only

Neither patients nor their doctors knew which of these two groups they were assigned to.

Who participated in the trial?

Adults (18+), average age of
55 years

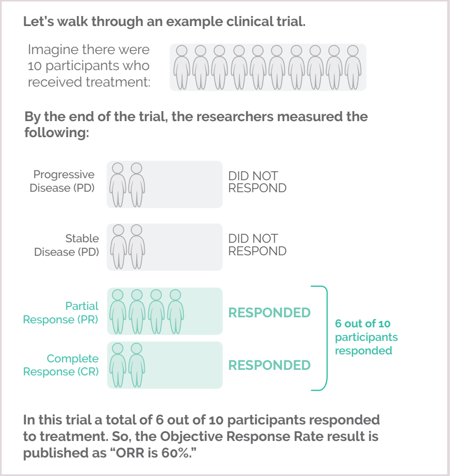
Had the disease for an average of
8½ years

It is important to note that every patient is different. How you respond to treatment may vary from how other patients respond.

The study design information helps patients understand the circumstances under which study data was collected, so they can evaluate the significance and relevance of the data.

Bring abstract concepts to life with simple examples.

Data can be difficult to grasp, partly because it requires an understanding of how it was collected, and partly because of the calculations. Using examples that are simplified versions of reality or calculations, walk patients through the thought process and help make sense of unfamiliar ideas.



Let's walk through an example clinical trial.

Imagine there were 10 participants who received treatment:

By the end of the trial, the researchers measured the following:

Progressive Disease (PD) — DID NOT RESPOND

Stable Disease (PD) — DID NOT RESPOND

Partial Response (PR) — **RESPONDED**

Complete Response (CR) — **RESPONDED**

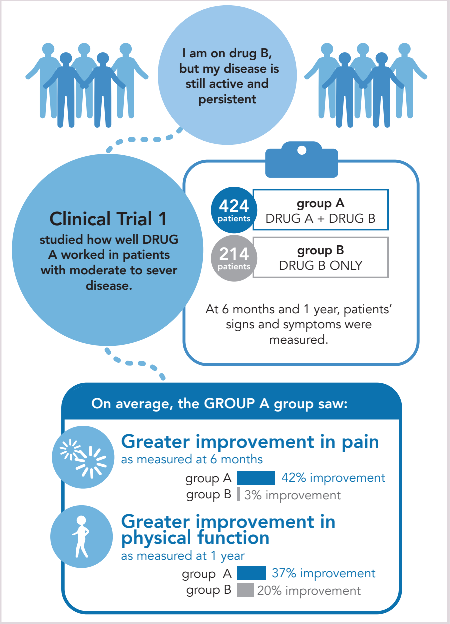
6 out of 10 participants responded

In this trial a total of 6 out of 10 participants responded to treatment. So, the Objective Response Rate result is published as "ORR is 60%."

By 'walking through' an example clinical trial, patients are able to see how the different clinical trial results are measured.

Help patients relate to the data.

A page full of numbers and data can be daunting and difficult to approach. Including details that patients can identify with (e.g., age, gender, a specific benefit or risk) can help patients find and engage with what is relevant to them.



I am on drug B, but my disease is still active and persistent

Clinical Trial 1

studied how well DRUG A worked in patients with moderate to sever disease.

424 patients — **group A** DRUG A + DRUG B

214 patients — **group B** DRUG B ONLY

At 6 months and 1 year, patients' signs and symptoms were measured.

On average, the GROUP A group saw:

Greater improvement in pain
as measured at 6 months
group A 42% improvement
group B 3% improvement

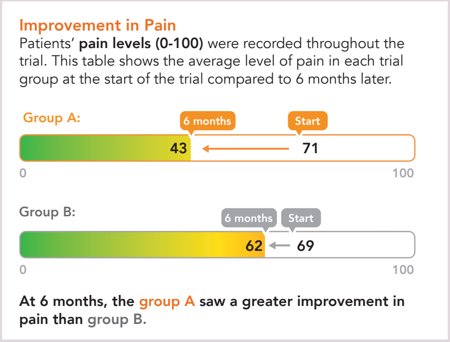
Greater improvement in physical function
as measured at 1 year
group A 37% improvement
group B 20% improvement

This example allows patients to focus on the data that is most relevant to them based on their treatment history.

A path guides patients from the background information to the clinical trial data, telling a visual story of where the data is coming from and why it is significant.

Make it easy for patients to interact with the data.

Data can be unappealing if it takes a lot of time and energy to read and understand. Showing data using clear and commonly seen methods can pull patients in and encourage them to compare and contrast the data. Summarizing key points that the data is illustrating also clarifies the message and can speed up comprehension.



Improvement in Pain

Patients' **pain levels (0-100)** were recorded throughout the trial. This table shows the average level of pain in each trial group at the start of the trial compared to 6 months later.

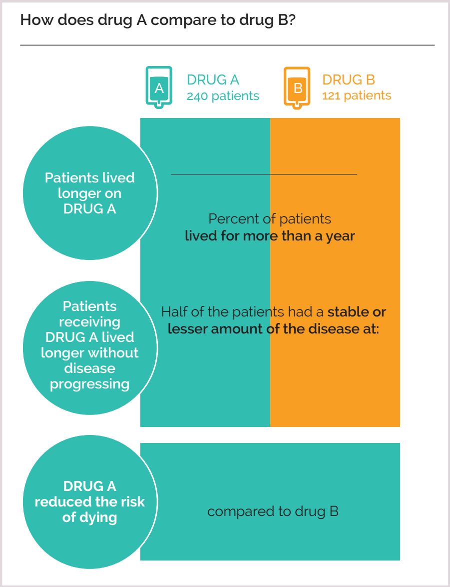
At 6 months, the group A saw a greater improvement in pain than group B.

The pain data in this example is formatted to look like the visual scale that doctors commonly use with patients to assess pain.

An explicit summary of the key point reinforces what the data is illustrating.

Be mindful of how the data flows and reads.

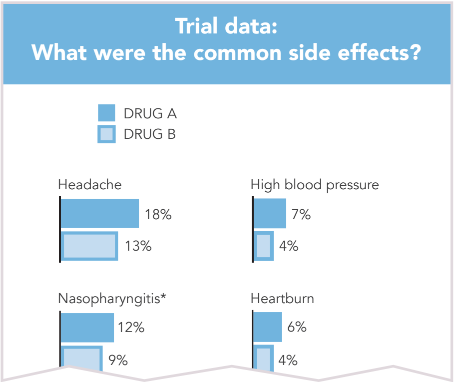
Data is numerical evidence, but it can make a weak argument when fragmented. Data should be presented in the context of a narrative or logical flow so that patients can follow the story it is telling. Visual cues like color coding or design elements can be used to reinforce the flow.



This example frames the data as answers to a simple question. The columns and colors bring coherence to the different elements, making the information easier to piece together and digest.

Balance the data.

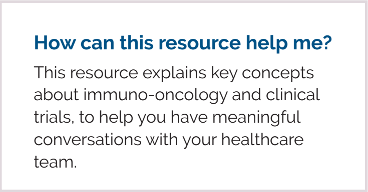
Patients value side effects data as much as, if not more than, efficacy data. This is because it allows patients to consider more than just the benefits. Data that presents more than one side of the story defers judgment to the patient and their healthcare team, and is often seen as more transparent, credible, and fair.



This example allows patients to compare the common side effects between treatments.

Enable and encourage further conversations with the patient's healthcare team.

Data is important to understand, but understanding is just the first step toward having a meaningful conversation about healthcare decisions. Whether the patient needs more help understanding the data, or is ready to talk about what the data means to them, they should be reminded to talk to their healthcare team.



How can this resource help me?

This resource explains key concepts about immuno-oncology and clinical trials, to help you have meaningful conversations with your healthcare team.

This example explicitly states its intention to help patients have meaningful conversation with their HCPs. It reinforces the message with comics showing example conversations.

Patient Experience

We are determined to ensure the voice of our patients is continuously present - to both inform and inspire - in ways that help teams across all business units achieve their goals, meet the needs of our customers, and provide a positive patient experience.

bridgeable

The UPL and its applications were created with the support of Bridgeable, a service design frm based in Toronto, Canada. Bridgeable has worked with BMS on all elements of the UPL, from overall strategy to creating and applying design capabilities and UPL tools, training BMS employees in UPL, and designing UPL.org. The team includes design strategists, interaction designers, and service designers, plus a team of biomedical communicators who specialize in visually communicating science and medicine.

NO-US-2400122