Health-related patient-facing communications can be hard for patients to navigate. Complicated language, dense formatting, intimidating data, and unfriendly visuals can result in patients having difficulties locating and understanding the information they need.

The UPL Style Guide provides stylistic choices for wording, and for look and feel that can help communicate your content in a clear and consistent manner.
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We would love to know how you have used the UPL Style Guide.

Please email us at info@contactupl.org if you are interested in sharing your experience with us. We would love to know how it went!
The Universal Patient Language

The Universal Patient Language (UPL) is an evolving set of resources to help communicate to patients about complex topics. It was created in collaboration with patients, caregivers, advocates, healthcare providers, and visual communication experts.

The UPL has **seven foundational Principles** that guide the way we communicate with patients. Applying the UPL means creating patient communications that embody the principles of the UPL.

There are four principles that are most applicable when **planning**:

- We will **enable patient learning**.
- We will appropriately **share qualified, quantified data**.
- We will **design for digital first**.
- We will **demonstrate empathy for patients and caregivers**.

The remaining three principles are most applicable when **building**:

- We will **use plain language**.
- We will **communicate visually**.
- We will **format materials for understanding**.
The UPL Style Guide

The UPL Style Guide is a tool that will help you understand how patients want to consume complex health information, and how you can deliver on these needs in your patient communications.

Not just about looks
While most style guides focus on how things should look and feel, a significant portion of the UPL Style Guide is made up of recommendations for content creation. The recommendations are grounded in the actual needs of patients and accommodate for how they interact with information.

Plays nicely with others
The goal of the UPL Style Guide isn’t to replace or overwrite existing identities or branding. Instead, the UPL Style Guide supplements existing identities with elements and recommendations that resonate with patients.

We would love to know how you have used the UPL Style Guide!

Please email us at info@contactupl.org if you are interested in sharing your experience with us. We would love to know how it went!
Writing

Writing can be one of the clearest ways in which knowledge is shared, but the words and phrases need to be selected and constructed with care.

As healthcare and treatment information becomes more abundant and complex, patients experience an increasing need for communications that are tailored to their level of understanding.

The UPL writing style strives to communicate with patients as clearly and simply as possible, in a way that validates their experiences and inspires continued learning and education.
One of the principles of the UPL is ‘Use plain language.’

We use plain language so that patients with varying levels of scientific knowledge and literacy can understand our communications. This involves considerations such as writing at a 5th–6th grade literacy level and explaining scientific terms. This section serves as a guide to help you ensure your writing is understandable to patients.

**Use an active voice**
Write in first person plural (‘we, our’) or second person (‘you’). Use the active voice to ensure the meaning is communicated directly. Passive voice tends to make sentences wordy and can obscure meaning.

**EXAMPLE:**
✓ Ask your care team for a list of side effects so you can recognize and manage them as soon as they come up.

While maintaining a conversational tone, avoid colloquialisms or expressions where the literal meaning could be confusing.

**EXAMPLE:**
✓ Pushing liquids

**Use the simplest terms to convey your message**
Multiple short words are often clearer than a long, complex term, and similarly, multiple short sentences can be clearer than one long sentence. But this is a matter of judgment.

**EXAMPLE:**
✓ Vegetable makes more sense than
✓ A plant you can eat

Watch out for terms that are common within the healthcare industry, but are rarely used by patients.

**EXAMPLE:**
✓ Doctor or nurse are more commonly used by patients than
✓ HCP

**Acronyms**
Avoid using acronyms without introducing them properly. Patients are not likely to read every page, so write out the full meaning of the acronym at least once every three paragraphs. Some acronyms that are common outside of pharmaceutical communications, such as ‘AIDS,’ may not need to be written out.

**EXAMPLE:**
✓ Your doctor might do a test to count your red blood cells (RBCs).

Giving the full term before introducing the abbreviation clarifies what the acronym stands for.

Colloquialisms are highly dependent on cultural backgrounds and first languages — patients come from all walks of life and are very likely to misinterpret such sayings.
Technical and Medical Terms

Technical and medical terms should be included with the intention to teach patients terms that may help them navigate their healthcare journey more easily.

Medical terms such as ‘gastroenteritis’ will have to be used, even when writing in plain language. These terms should be accompanied by a simple explanation, and be consistent across communications that the same group of patients might see. More detailed, complex explanations should be provided in appendices, links, and references, whenever possible.

EXAMPLE:

This document has summarized the most important safety information for DRUG A. For more in-depth safety information, see the full Patient Information section of the Package Insert, or talk to your doctor.

Nesting

In general, limit sentences to two clauses and do not nest ideas within sentences. If a sentence is becoming nested, it is good practice to break it up into multiple sentences, as needed.

Many of your joints have a lining called the synovium. It is an important part of the capsules that support and protect your joints. The pain and swelling occurs because the synovium becomes swollen, or inflamed.

The pain and swelling occurs because the synovium, an important part of the capsules that support and protect your joints, becomes swollen, or inflamed.

The former is more descriptive and has a friendlier connotation.

All examples give the same information, but the latter are more difficult to understand due to nesting.
Writing in UPL goes beyond using plain language.

Patient communications should be conversational and human. They should be written for the patient, by a real person. Write to educate by being helpful and fostering learning, without coming across as condescending. When you anticipate what patients may be going through, what they may want to learn about, and what phrases they have been using with their physicians, you connect with readers and enable them to quickly see why the materials matter to them.

Here is a starting list of questions that can be used to evaluate, guide, and improve the writing and content:

- How well will patients be able to understand the ideas that are being discussed?
- If the topics are more complex (e.g., they require a certain level of health or numerical literacy), have you provided any tools for patients to build their knowledge?
- Have we separated more complex information into discrete sections to make it more digestible for the patient?
- How well have we answered the questions that patients might have?
- How have we motivated patients to continue reading through the materials?
- What are the patient’s goals for reading this material, and how are we helping them achieve these goals?
- How have we balanced OUR communication goals with the patient’s informational needs?
- Is there a clear story line or flow that guides patients through the material (e.g., the process of clinical trials)?
- Are any sentences more complicated or longer than they need to be?
- Have we used jargon? If so, have we explained the term to help build their vocabulary and knowledge base?
- How well will patients be able to understand the ideas that are being discussed?
- If the topics are more complex (e.g., they require a certain level of health or numerical literacy), have you provided any tools for patients to build their knowledge?
- Have we separated more complex information into discrete sections to make it more digestible for the patient?
- How well have we answered the questions that patients might have?
- How have we motivated patients to continue reading through the materials?

EXAMPLE: EXPLAINING CANCER IN THE BODY

Cancer is a complex topic that is usually explained with concepts from cell biology. The details would be distracting and even unnecessary for patients who only need a general understanding. Our approach instead uses an analogy that builds on something most people already understand — gardening:

Imagine your body is a garden, where the soil is your immune system. When you’re healthy, the soil is rich and well tended, and the garden is green. Normally, the soil is able to prevent weeds from growing out of control.
Readability Indices

Due to statistics on adult literacy, health and safety information should be written at a 5th–6th grade reading level. Readability indices can help determine the grade level of your writing based on the complexity of words and average sentence length in written content. See Table 1 on the following page (page 9) for commonly used readability indices.

*Indices are a way to estimate readability, but should be used with care. They are generally based on algorithms that analyze the quantifiable characteristics of text (e.g., syllables, sentence length), but are limited in their ability to evaluate the qualitative characteristics of the text and how the content might be understood by the reader.

**TIP:** To get a more realistic index reading, leave out medical and technical terms (e.g., Progression-Free Survival) from the text submission. Since we are always explaining these terms with plain language when they are first used in a document, we don’t need to measure their effect on readability.

---

**SAM — Suitability Assessment of Materials**

To assess the suitability of your materials, the SAM is a questionnaire for rating the readability and comprehensibility of health-related information.

For more information, visit: [http://aspiruslibrary.org/literacy/sam.pdf](http://aspiruslibrary.org/literacy/sam.pdf)
Table 1: Readability Indices

<table>
<thead>
<tr>
<th>Name</th>
<th>Application</th>
<th>Readability Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>FORCAST Readability Formula</td>
<td>Analyzes all words individually in all text (bullets, headings, lists, paragraphs). Particularly useful for questionnaires or forms.</td>
<td>1st grade through college</td>
</tr>
<tr>
<td>Fry Electronic Readability Formula</td>
<td>Analyzes running text and paragraphs of short and long documents. Before evaluating, the text must be cleaned of bullets, headings, and symbols. The Health Literacy Advisor (HLA) software does this cleaning automatically. Medical terms that are explained in plain language should not be included in this evaluation.</td>
<td>1st grade through college</td>
</tr>
<tr>
<td>New Dale-Chall Formula</td>
<td>Analyzes running text and paragraphs by scanning for words that are familiar to a 4th-grade reading level. Any words that are not included in this “familiar” list are considered difficult, and affect the evaluation of readability. Medical terms that are explained in plain language should not be included in this evaluation. Text must be given without formatting, so bullets, headings, and symbols must be cleaned from the text before evaluating. The Health Literacy Advisor (HLA) does this cleaning automatically.</td>
<td>5th grade to high school</td>
</tr>
</tbody>
</table>
Conversation

Conversations can be one of the most natural ways for people to share information, whether it be over the phone, online chat, or in person. In order to be effective, conversations need to be informative, truthful, relevant, and clear.

For patients, healthcare conversations can be difficult to navigate and remember. This is especially true when they are talking with individuals who may see things from a different perspective, or when the conversations contain an unending stream of new information or cover sensitive topics.

The UPL conversation style strives to create space for the patient’s voice and to deliver information in as useful and memorable a manner as possible.
Make it a two-way conversation
A conversation is much more engaging and memorable when more than one person is talking. Prompt the patient for input and help them relate information to their experience. Ask check-in questions to regain attention and encourage reflection. Give opportunities for patients to ask clarifying questions.

EXAMPLE:
✓ “You had mentioned you had an appointment next week — don’t forget to ask your doctor about ____.”

and

✓ “Is this something that you have discussed with your doctor?”

Relating the information back to something the patient has shared in conversation helps anchor the topic and makes it more relevant to the patient.

EXAMPLE:
✓ “Would you like me to repeat anything in that list?”

Use verbal patterns
It can be difficult to map out information in conversations without the help of visual aids or advanced formatting (e.g., bullet points, columns). Using words to preface each item in a list, or counting each item can help patients group and listen for important pieces of information.

EXAMPLE:
✓ “Remember to tell your doctor if you have the following: if you have x, if you have y, or if you have z.”

and

✓ “There are two ways you can get this information. One way is from our brochure, and the second is from our website.”

A preamble can help patients get a sense of what is coming and prepare them to listen for specific items.

EXAMPLE:
✓ “Would you like me to repeat anything in that list?”

Refer to other available resources
Remembering all the details from a conversation can be challenging. Whenever possible, provide visuals or additional documentation that patients can refer to before, during, and/or after the conversation. If not available, provide the patient an opportunity to take notes or record their thoughts.

EXAMPLE:
✓ “You can find more information on what we just talked about on www.info.com.”

and

✓ “Would you like to write down the website?”

When drafting any kinds of scripts, remember to read the conversation out loud, and preferably with another person. This will help you gauge the tone of voice and how it may come across to the patient.
Color

Color is a powerful tool for attracting attention and creating connections between important pieces of information — it can make or break a patient’s experience navigating health information.

Colors should be carefully selected and thoughtfully used, so that even those who may have color-perception deficiencies can benefit.

The UPL's color recommendations aim to improve the way patients navigate through complex documents and process information that is useful to them.
Color is not meant solely for decoration. In UPL, color is used meaningfully to facilitate navigation and improve readability, helping patients digest and comprehend complex documents. With that in mind:

- **Limit the number of colors on a page.** (Five is generally the maximum). Using too many colors can create unnecessary visual noise and confusion.
- **Use color to break information into digestible chunks.** Color can be used to focus attention on a group of information at a time, and connect relevant information.
- **Use color to emphasize key points.** Color can be used to highlight and draw attention to important words and ideas. For more on how color can be used with text, **SEE PAGE 19**.
- **Use fully-saturated colors sparingly.** Saturated colors in close proximity that share the same intensity can cause visual vibration, which can result in eye fatigue.
- **Avoid gradients.** Gradients should only be used to create depth. In most cases, depth negatively affects readability.
- **Consider the meaning of certain colors.** Be aware of the connotation certain colors may carry in relation to health. For example, red may be associated with ‘bad,’ ‘unhealthy,’ or ‘stop.’

![DO](image1.png)

- Design is limited to two colors. Each color is used to connect information that belongs together.
- Fully-saturated colors are used sparingly, so there are no visual conflicts.
- Limited use of light type on saturated background

![DON'T](image2.png)

- **X Too many colors on the page. Color has no meaning in this design.**
- **X All colors are fully saturated, creating unnecessary eye fatigue.**
- **X Large amount of white type on saturated color is difficult to read.**

While color can be helpful for most readers, do not rely on it as your only means of conveying information. Please **SEE PAGE 15** for more on accommodating for color vision deficiencies.
Accommodating for Color Vision Deficiencies

There are multiple types of color vision deficiencies. All of them impact the way that colors are perceived by affected individuals. To optimize materials for patients, inclusive of those with color vision needs, consider these guidelines:

- **Avoid combining colors of similar brightness (low contrast).** Please see the “don’t” example.
- **Maintain contrast between your type and the background.** Black on white provides maximum contrast, whereas lower contrast combinations, such as dark gray on light gray, can be difficult to read.
- **Verify that the content can still be navigated without color.** You can test this by printing your design in grayscale to see if there is still proper contrast between your colors. If words and objects appear to blend together, adjust your color values appropriately to maintain contrast.

For more on designing for color vision deficiencies, visit [http://webaim.org/articles/visual/colorblind](http://webaim.org/articles/visual/colorblind)
Typography
typography can greatly impact the readability of a body of text. Too small, and readers will need to squint. Too squiggly, and readers will take longer to decipher each glyph.

Readability becomes even more important when designing for patients, as their physical and emotional burdens can affect their ability to read and comprehend.

UPL typography strives to be easy-to-read and scannable, so that readers can focus their efforts on understanding what the words are trying to convey.
A typographical hierarchy prioritizes text so that readers can quickly and easily find what they are looking for. Establishing and following a clear, consistent hierarchy for text helps patients navigate the content for a more efficient reading experience.

**HEADLINES**
Headlines are the most salient text on the page, and should be approximately 150–200% the size of body type. This can vary depending on the size of the document you are designing. Avoid using all caps for headlines.

**SUBHEADLINES**
Subheadlines are meant for secondary sections within the content covered under a main headline. Subheadlines should stand out from body copy (approximately 100–150% the size of body type, bolded), but also be noticeably smaller than the headline size.

**BODY COPY**
The main content, usually prose, should be set at a size that can be read with ease. Small type can be very difficult to read for patients with vision problems, and can discourage thorough reading, or result in patients missing important information.

- For **print**, a 12 pt. type minimum is recommended for body text.
- For **digital**, a 16 pt. type minimum is recommended for body text (based on Google’s recommendations on legible font sizes).

In some circumstances, a 12 pt. minimum will not be possible for the body copy. A smaller size can be used in those situations, but a clear, obvious typographical hierarchy becomes even more critical.

**LABELS AND CAPTIONS**
When applying labels to diagrams, illustrations, or photos, a **9 pt.** type minimum in **bold** is recommended.

**SMALL TYPE OR FINE PRINT**
Type less than 12 pt. can be used, but only when necessary. Small type or fine print should be set at **no less than 8pt.**
About Clinical Trials

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Group A

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Group B

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HEADLINE
This headline is the most salient text on the page, following the guideline of headlines being roughly twice the size of body text.

BODY COPY
The main body of text is set in 12 pt., a comfortable size for most readers. The majority of type is set in black on a white background for easy reading.

SMALL TYPE
This type would not fit in the diagram at 12 pt., so it has been reduced to 9 pt.

SUBHEADLINES
Subheadlines are set smaller in size and bolded to provide separation from both the headline and body copy.

LABELS
Labels are bold and 9 pt.
Alignment

Left-aligned body copy and headings are recommended.

Setting long passages of text centered or right-aligned creates irregular spaces at the start of each line, making it difficult to track lines while reading.

Justified body text is not recommended. Justified word spacing is inconsistent, creating white space between words that is awkward and distracting.

Color

Body copy should be set in black. Color can be used to highlight important text, but should be used sparingly for maximum impact.

Long passages of text in white on a fully saturated color background can be difficult to read.

- Color can be used to attract the reader to important text within body copy. Remember to use it sparingly to maximize the impact.

Ideal Line Lengths

An ideal line length is anywhere between 45 and 75 characters.

Inappropriate line lengths can disrupt typical reading patterns and increase reading time.

- Since this page is set in three columns, the line lengths are closer to 45 characters.
Leading
Leading refers to the space between the lines of text. At most sizes, the ideal leading is 120% of the type size.

If leading is too tight, ascenders and descendents can clash, creating a difficult reading experience. If leading is too loose, the reader may find it challenging to move from one line to the next.

Tracking
Tracking refers to the space between the letters. Leave your tracking set to zero whenever possible, especially for body text.

If tracking is too tight, characters bump into each other and make each character difficult to discern. Too loose, and words blend into each other as the spaces between words become less distinct.

Old Style and Lining Figures
Some fonts include OpenType Old Style and Lining figure options for numbers.

Old Style figures are best used in a passage of text, as they are set with ascenders and descendents.

Lining figures all rest on the baseline and are uniformly the height of a capital letter, so they work best on their own. Lining figures set in a body of text stand out as if they were a word set in all caps.

Leading that is too loose or too tight makes it difficult for readers to read through paragraphs.

Improper tracking reduces the reader’s ability to parse individual words.

Old Style: 1234567890
✓ There are 8,491,079 people living in New York City.

Lining: 1234567890
✓ YEAR | AMOUNT
2014 | 67,235
2015 | 89,234

Old Style numerals fit well when used in a body of text. Lining numerals work when standing on their own.
Example of Type Guidelines

**DO**

- **ALIGNED LEFT**
  The left-aligned text has a straight line along the left edge, which gives the eye a consistent starting point.

- **IDEAL LINE LENGTHS**
  Proper line lengths allow the reader to move through paragraphs comfortably.

- **DEFAULT TRACKING**
  This type uses default tracking, keeping words intact and easy to parse.

- **IDEAL PARAGRAPH LEADING**
  The reader can clearly see which sentences belong together within a paragraph, and where paragraphs end.

- **OLD STYLE FIGURES IN TEXT**
  The numbers sit comfortably within paragraphs as old style figures.

---

**Getting to know your Healthcare Team**

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**Ipsum quo corepratem verepudam**

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**Getting to know your Healthcare Team**

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**Ipsum quo corepratem verepudam**

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Volojrum tly 68,345 gebissiny.

---

**DON’T**

- **IMPROPER TEXT ALIGNMENTS**
  The centered and justified alignments disrupt normal reading patterns.

- **TIGHTLY TRACKED TYPE**
  Type is tracked too tight, causing letters to run together. This makes it difficult for the reader to distinguish words.

- **IMPROPER LINE LEADING**
  Leading that is too loose or too tight creates an uncomfortable reading experience.

- **LINING FIGURES IN TEXT**
  The lining figures for numbers look too large compared to the surrounding text.
Considerations For Digital Typography

Digital typography requires special considerations because of its on-screen nature and interactive capabilities. For clearer digital typography that takes into account patients who may be older or have vision impairments, consider the following:

**Size**
To accommodate for vision impairments, follow Google’s text size recommendation 16 pt. minimum. When possible, consider including the functionality for readers to adjust the text size.

**Contrast**
As with print, maximize contrast between type and background. On screen, black text on white is significantly easier to read than white text on black. Avoid low contrast (e.g., using dark gray text on a light gray background).

**Hyperlinks**
Ensure hyperlinks are prominent and stand out as “clickable.” Styling hyperlinks consistently makes it easier for users to predict interactions and navigate the page. **Underline each link** and set it to a color different from the chosen palette so that it stands out from surrounding type. To keep links distinct from unclickable type, do not use underlines or the chosen link color for emphasis.

For more on designing for digital accessibility, visit [https://www.w3.org/WAI/intro/components.php](https://www.w3.org/WAI/intro/components.php)
Visual Elements

Visual elements, such as photos, illustrations, diagrams, and icons can be a helpful (and refreshing!) way to process information in a vast sea of words.

We do patients a disservice when we neglect to incorporate visuals. Important, complex ideas can easily be overlooked or misunderstood.

UPL visuals strive to reinforce and reiterate important concepts in an approachable and friendly way, so that patients are more likely to navigate, understand, remember, and use the information that is available to them.
Icons

Icons by definition distill the visual representation of something to its simplest form while still being recognizable. With their minimal level of detail, icons are not meant to be accurate or the ultimate representation of an idea. Their strength lies in attracting attention and generating curiosity without an overwhelming amount of detail.

Icons are used to:
• symbolize concepts or ideas
• mark sections for navigational purposes (e.g., visual bookmarks)
• call attention to important pieces of information (e.g., warnings)
• depict abstract ideas that are less familiar to the average patient (e.g., cells, cell signals)

Definitive features:
• low detail; basic, rounded shapes, few colors
• solid fills without outlines, or line drawings
• can be a white icon on a colored shape
• can exist as single elements

General guidelines for use:
• Always include a label or text with icons. Icons are simplistic and symbolic in nature, and can be interpreted differently depending on the context they are presented in.
• Assign one meaning to each icon. Using icons consistently builds a visual language that patients can use to navigate through materials. Assigning multiple meanings to a single icon, or vice versa, creates confusion.
• Use a consistent style of icons. While icons can be reversed, make sure that icons within a section have a cohesive look (e.g., all with backgrounds, or all without backgrounds).

[Images of icons with labels: Get urgent help, Talk to your doctor, Prescription medicine]

DO
✓ Low detail, rounded shapes
✓ Single element with minimal detail
✓ Draw attention to “urgent” icons by incorporating bright colors

DON’T
x Mix icon styles (e.g., some with backgrounds, others without)
Illustrations

Illustrations are more descriptive than icons, but less intricate than photos. The level of detail they provide is just enough to demonstrate empathy and facilitate learning, but not enough to be overwhelming.

Illustrations are used to:
• portray people (e.g., patient, caregiver, healthcare team)
• describe concrete, familiar objects (e.g., a part of the body or an everyday object)
• explain processes (e.g., how a drug works)

Definitive features:
• higher detail and more colors than icons
• generally line drawings, with optional solid fills
• may consist of multiple elements (e.g., an arrangement of icons and arrows)
• thicker line weights offer a friendlier visual appeal
Guidelines for portraying people:
• Show enough detail to convey personality and mood, but stay vague enough to leave age and racial/cultural backgrounds open to interpretation.
• Vary poses and clothing.
• Avoid reusing the same person in the same pose in the same piece of communication. However, consider showing the same person doing various things.
• Highlight the patient in a consistent manner.
• Strive for neutral expressions.

‘Different patient populations may have different preferences. Some patients will feel better looking at images with hopeful tones. Others may find a happy expression jarring and more challenging to relate to.'
Guidelines for describing concepts and processes, both concrete and abstract:

- Label relevant details, and highlight the important labels.
- When expanding details, use the same colors and composition in zoom-in frames so that comparisons are easy to make.
- Show the context in which an abstract or less-familiar process is happening, when possible (e.g., knee joint illustration should be shown near a knee).
- Differentiate concrete concepts from abstract ones via illustration style: Use line drawings to depict concrete, familiar objects (e.g., a hand opening a jar), and icons to depict the abstract (e.g., immune cells attacking cancer cells).

**DO**

- Correct scaling
- Consistent colors and composition in the macro illustration and zoom-in frame
- Relevant details labeled, with important labels bolded
- Contextualized zoom-in (zoomed in from the hand)
- Empathetic detail on the knuckles (pink for pain and inflammation)

- Simple illustrations for depicting cells
- Relevant details labeled
- Use of consistent and meaningful colors (red for cancer cell, green for healthy cell)
**Photography**

Seeing themselves in the content can be a powerful way for patients to connect with the material they are reading.

Photos often serve this purpose, but they can be overly prescriptive about specifics like age, sex, and gender. While this can build strong connections for some patients, it also has the potential to alienate others.  

For these reasons, the recommendation for UPL communications is to use illustrations whenever possible (See Page 25).
Structural Elements

Structural elements are simple graphics that don’t hold meaning on their own, but can add meaning by describing the flow or relationships between images or words. The proper use of structural elements can help patients understand how the information on a page fits together.

Structural elements are used to:
- describe information flow or relationships
- emphasize or call out information
- separate or group content

Structural elements include:
- Divider lines: used to differentiate sections within content
- Boxes and borders: used to highlight, differentiate, and section out information
- Leader lines: used to draw a connection between a specific part of an illustration and its label
- Arrows: used to show direction or information flow

An overview of your journey through a cancer clinical trial

Keep in mind that everyone’s journey through a clinical trial is unique. You can always choose to stop taking part in the trial at any time, and this will not affect your future medical care in any way.

Before you make the decision about participating

You’ll receive information about a specific clinical trial. The information will include an Informed Consent Form (ICF).

You’ll have time to read the ICF. You may want to take it home, take time to review the information, and talk to your family and friends as well as your doctor. You will have the chance to ask questions at any time.

You’ll make a decision about whether you want to take part in the clinical trial. You can take as long as you need to make this decision. If you decide to take part in the cancer clinical trial, then you will be asked to sign the ICF.

Make your decision

YES
You want to participate

NO
You don’t want to participate

(Continue reading on the next page to learn about what happens after you make your decision.)

WHAT RESEARCHERS DO IN CLINICAL TRIALS:
separate participants

GROUP 1

give treatment

standard treatment
take and record measurements

GROUP 2

give treatment

new treatment with or without standard treatment
take and record measurements

1 vs 2

compare the groups to evaluate the benefits and risks of new treatment

publish results

Arrows convey flow of information and describe relationships between words and images

✓ Colored boxes separate discrete steps of a process

✓ Divider lines differentiate the header from the content
Data

Data brings depth and credibility to medical information, but it is difficult to temper. Too much data can be overwhelming and immobilizing. Too little data can seem condescending or superficial.

The challenge with data is that it is often tailored to professionals such as healthcare providers, and not necessarily to patients. Patients are especially difficult to design for, as their average numeracy and experience with data are limited.

The UPL strives to make data approachable and intuitive, so that patients are able to use complete, relevant data to inform discussions with their doctor.
Data for Patients

When available and appropriate, data should be included to help patients understand the information involved in their healthcare journey, and to answer questions they may have about specific decisions they are considering.

Presenting data to patients requires a different approach than presenting data to professionals. Patients generally have:

• more varied educational backgrounds
• less familiarity with data, and therefore may be less inclined or able to decipher complex data representations
• significant emotional and physical burdens
• strong motivation to understand data but less ability to do so, sometimes resulting in frustration

Data for patients needs to be tailored to their needs and capabilities. Most importantly, it needs to be presented in a way that is intriguing but not overwhelming, and highlights its relevance, significance, and utility.

Common patient questions that may be answered with qualified, quantified data:

- How well does this treatment work?
- What does this mean for someone like me?
- Where did this information come from?
- What are the negatives and how likely are they?
- Is it worth it?
- What do the numbers on this page have to do with me?
General guidelines

- Select and focus on the data that is most relevant to patients and keep the message succinct, while providing adequate context.
- Present both the negatives and the positives, giving them equal prominence.

Data should be approachable, and easy to get into

- Visualize data whenever possible. Describing it in the copy buries the information and makes it difficult to grasp.
- Organize the information in a way that helps patients find data that is relevant to them (e.g., separate out special populations or different treatment histories).
- Show percentages along with normalized frequencies so that patients can see the weight of the information (e.g., 85% or 218 out of 256 people).
- Format equations clearly, separate from paragraph text. Do not write out the equation in the copy.

Data should be easy to navigate, and the message quick to grasp

- Use words (e.g., a narrative) or visuals (e.g., a dotted path) to guide patients through the data, and help them process the big picture that the data is supporting.
- Use an appropriate and clear method of visualization for the given data. See Page 33 for common visualizations and their applications.
- Use a minimal number of styles of visualization for data in a document, and use them consistently.

Data should be rich, helping patients gain a deeper knowledge

- Provide context and explanations that supplement the patient’s understanding of the data (what it means, where it comes from, etc.).
- If there are multiple levels to the data, build the patient’s knowledge incrementally. Provide patients the opportunity to dive deeper into the information at their own pace.
- Reuse icons for concepts that have already been introduced, allowing patients to see the relationship between the data and other parts of the communication.
- The quality of data presentation is a direct result of how color, typography, visual elements, and writing are used together.

For more specific guidance on how to share quantified and qualified data with patients, refer to the UPL Rules.
Common visual representations and their strengths and weaknesses

The method of data representation should be selected based on how patients would use it to answer their questions. A good test is to think of questions that a patient may have, and choose the graph or chart that answers those questions most clearly.

<table>
<thead>
<tr>
<th>Type of Graph</th>
<th>Variable</th>
<th>Level of detail</th>
<th>Used for</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bar graph</strong></td>
<td>Quantity</td>
<td>Precise numbers</td>
<td>Comparison</td>
<td>Use one variable per item. If you have multiple variables, split these up into multiple separate bar charts (shown on the same page, if desired)</td>
</tr>
<tr>
<td><strong>Line graph</strong></td>
<td>Trends over time, non-cyclical</td>
<td>Precise numbers</td>
<td>Comparison</td>
<td>Use for continuous data sets&lt;br&gt;As you add more categories to your graph (i.e. more lines), be mindful that you may need to reduce the number of periods of time shown in order to keep the graph clear for the patient audience</td>
</tr>
<tr>
<td><strong>Pictographs</strong></td>
<td>Quantity (frequency)</td>
<td>Gist (low numbers)</td>
<td>Frequency</td>
<td>Use only when this communicates more clearly than simply stating a number or frequency (e.g., percentages are more easily communicated numerically than with pictographs — you can simply state 1 in 5, or 20%)&lt;br&gt;<strong>ADDITIONAL INFORMATION:</strong>&lt;br&gt;Why use icon arrays: <a href="http://www.iconarray.com/why">http://www.iconarray.com/why</a>&lt;br&gt;Usefulness of a pictograph: <a href="http://onforb.es/1wb2LEQ">http://onforb.es/1wb2LEQ</a></td>
</tr>
<tr>
<td><strong>Pie chart</strong> or <strong>Donut chart</strong></td>
<td>Quantity</td>
<td>Gist</td>
<td>Proportion</td>
<td>Use only for data sets with 3 values or fewer&lt;br&gt;Don’t use in cases where labels are required for every slice (i.e., use for more stark comparisons.) Minimal differences are hard to discern in pie charts (e.g., a 6% slice looks too similar to a 7% slice)&lt;br&gt;<strong>ADDITIONAL INFORMATION:</strong>&lt;br&gt;Why we can’t use pie charts to compare data: <a href="http://bit.ly/14hIFZu">http://bit.ly/14hIFZu</a>&lt;br&gt;(Designing Data Visualizations: Representing Informational Relationships. By Noah Iliinsky, Julie Steele)</td>
</tr>
</tbody>
</table>

Further information on selecting the appropriate type of graph, and obstacles to avoid [https://infoactive.co/data-design/ch18.html](https://infoactive.co/data-design/ch18.html)
Example:

How do researchers figure out the change in the AMOUNT of cancer?

In clinical trials, researchers measure the change in the amount of cancer by looking at the difference between the baseline amount, taken at the first check-in, and the amount of cancer at a later check-in.

Visual narrative (dotted time line) that ties together the context of the data

Labels repeat the take-away information

Side by side layout allows an easy comparison of the data

GOOD

- Simple pictorial visualization of the data
- Visual narrative (dotted time line) that ties together the context of the data
- Labels repeat the take-away information
- Side by side layout allows an easy comparison of the data

GOOD

- Good visibility of side effects data
- Introduction explains significance of visualized data
- Legend explains how to read the graphs
Resources by Topic

**General Accessibility**

**UK Association for Accessible Formats:**
*Creating Clear Print and Large Print Documents*

This guide will be particularly useful for people aiming to create accessible printed materials, either for the general public (clear print) or specifically for people with low vision (large print).


**The Association of Registered Graphic Designers of Ontario:**
*AccessAbility Handbook*

The aim of this resource is not to tell professional designers what to do, but rather to remind everyone how to do better.


**Digital Accessibility**

**Usability.gov**

User experience focuses on having a deep understanding of users, what they need, what they value, their abilities, and also their limitations.

http://www.usability.gov/

**Web Accessibility Initiative**

This document shows how Web accessibility depends on several components working together and how improvements in specific components could substantially improve Web accessibility.

https://www.w3.org/WAI/intro/components.php

**Use of Color**

**Lighthouse International:**
*Effective Color Contrast*

It is important to appreciate that it is the contrast of colors one against another that makes them more or less discernible, rather than the individual colors themselves.

http://lis29-107.members.linode.com/accessibility/design/accessible-print-design/effective-color-contrast/

**WebAIM**

The key principle of web accessibility for users with color-blindness: perceivable: because they cannot perceive (see) the difference between certain color combinations.

http://webaim.org/articles/visual/colorblind

**Typography**

**Gov.UK: Office for Disability Issues**
*Accessible print publications*

Clear print standards help to maximize the legibility of print publications and should therefore be used for all printed materials. It can be particularly helpful for people who have visual impairments or dyslexia.

https://www.gov.uk/government/publications/inclusive-communication#accessible-print-publications

**Fontfeed:**
*Figuring Out Numerals*

Since the advent of OpenType and the implementation of Unicode, professional fonts now include up to six sets of numerals, and sometimes even more.

The UPL and its applications were created with the support of Bridgeable, a service design firm 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.

Acknowledgment

Our mission is to improve patient experiences by working with all parts of Bristol-Myers Squibb, using an approach that is holistic and rooted in collaboration.