UPL GUIDANCE

UPL Best Practices

The Universal Patient Language® (UPL) has 9 foundational Best Practices that guide the way we communicate with patients and caregivers.

Each Best Practice includes detailed guidance that provides practical direction on how it can be applied to create more patient-friendly communications.

Resource contents:

- [x] Guidance, standards, and best practices
- [ ] Building blocks or assets
- [ ] Assessment methods and tools

Applicable to:

- [x] All patient communications
- [ ] Specific topics

Primed and polished: This tool has been validated extensively, and significant changes will be infrequent.

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A 2-page summary of the UPL Best Practices,
designed as a starting point or for quick reference

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About the UPL Best Practices

What are the UPL Best Practices?

The UPL Best Practices are a detailed set of guidance on how to create patient-friendly communications. This guidance is **based on what real patients and caregivers have told us** in conversations, workshops, and other engagements.

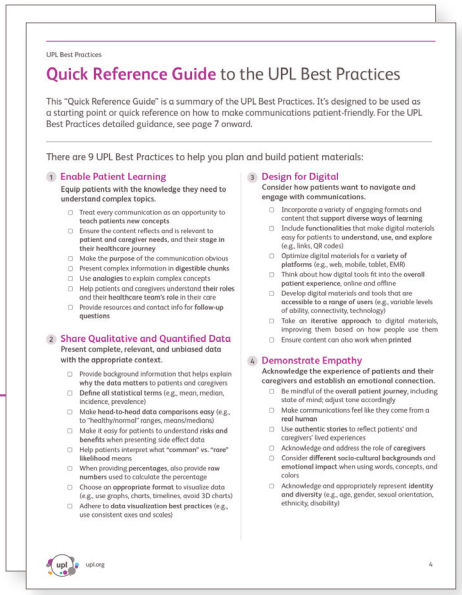
While every patient and caregiver population has unique needs and challenges, the UPL Best Practices offer guidance we've found to be true across a wide variety of contexts.

How should I use the UPL Best Practices?

You can use the UPL Best Practices in any of the following ways, depending on your **goals** and how much **time** you have:

Are you looking for a high-level summary?

Use the **Quick Reference Guide** to the UPL Best Practices (found on pages 4, 5, and 6)


UPL Best Practices

Quick Reference Guide to the UPL Best Practices

This "Quick Reference Guide" is a summary of the UPL Best Practices. It's designed to be used as a starting point or quick reference on how to make communications patient-friendly. For the UPL Best Practices detailed guidance, see page 7 onward.

There are 9 UPL Best Practices to help you plan and build patient materials:

1 Enable Patient Learning

Equip patients with the knowledge they need to understand complex topics.

- Treat every communication as an opportunity to **teach patients new concepts**
- Ensure the content reflects and is relevant to **patient and caregiver needs**, and their **stage in their healthcare journey**
- Make the **purpose** of the communication obvious
- Present complex information in **digestible chunks**
- Use **analogies** to explain complex concepts
- Help patients and caregivers understand **their roles** and their **healthcare team's** role in their care
- Provide resources and contact info for **follow-up questions**

2 Share Qualitative and Quantified Data

Present complete, relevant, and unbiased data with the appropriate context.

- Provide background information that helps explain **why the data matters** to patients and caregivers
- **Define all statistical terms** (e.g., mean, median, incidence, prevalence)
- Make **head-to-head data comparisons easy** (e.g., to "healthy/normal" ranges, means/medians)
- Make it easy for patients to understand **risks and benefits** when presenting side effect data
- Help patients interpret what **"common" vs. "rare" likelihood** means
- When providing **percentages**, also provide raw **numbers** used to calculate the percentage
- Choose an **appropriate format** to visualize data (e.g., use graphs, charts, timelines, avoid 3D charts)
- Adhere to **data visualization best practices** (e.g., use consistent axes and scales)

3 Design for Digital

Consider how patients want to navigate and engage with communications.

- Incorporate a variety of engaging formats and content that **support diverse ways of learning**
- Include **functionalities** that make digital materials easy for patients to **understand, use, and explore** (e.g., links, QR codes)
- Optimize digital materials for a **variety of platforms** (e.g., web, mobile, tablet, EMR)
- Think about how digital tools fit into the **overall patient experience**, online and offline
- Develop digital materials and tools that are **accessible to a range of users** (e.g., variable levels of ability, connectivity, technology)
- Take an **iterative approach** to digital materials, improving them based on how people use them
- Ensure content can also work when **printed**

4 Demonstrate Empathy

Acknowledge the experience of patients and their caregivers and establish an emotional connection.

- Be mindful of the **overall patient journey**, including state of mind; adjust tone accordingly
- Make communications feel like they come from a **real human**
- Use **authentic stories** to reflect patients' and caregivers' lived experiences
- Acknowledge and address the role of **caregivers**
- Consider **different socio-cultural backgrounds** and **emotional impact** when using words, concepts, and colors
- Acknowledge and appropriately represent **identity and diversity** (e.g., age, gender, sexual orientation, ethnicity, disability)

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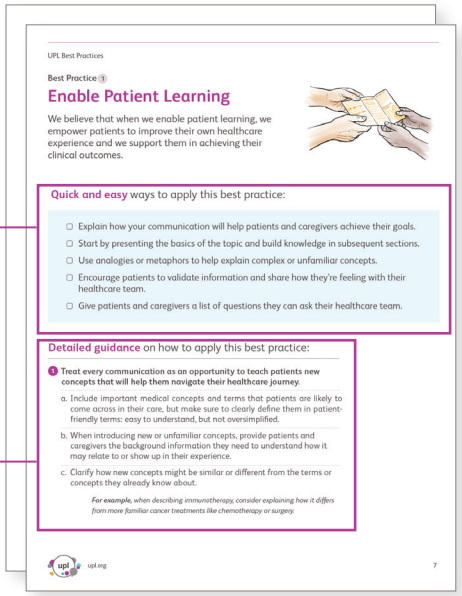
Are you short on time but still want to apply the UPL?

Use the **quick and easy ways to apply each Best Practice** (found in the blue box on the first page of each UPL Best Practice, starting on page 7).

Are you looking for a comprehensive understanding of how to apply the UPL?

Use the **detailed guidance** for each UPL Best Practice (starting on page 7).


UPL Best Practices

Best Practice 1

Enable Patient Learning

We believe that when we enable patient learning, we empower patients to improve their own healthcare experience and we support them in achieving their clinical outcomes.

Quick and easy ways to apply this best practice:

- Explain how your communication will help patients and caregivers achieve their goals.
- Start by presenting the basics of the topic and build knowledge in subsequent sections.
- Use analogies or metaphors to help explain complex or unfamiliar concepts.
- Encourage patients to validate information and share how they're feeling with their healthcare team.
- Give patients and caregivers a list of questions they can ask their healthcare team.

Detailed guidance on how to apply this best practice:

1 **Treat every communication as an opportunity to teach patients new concepts that will help them navigate their healthcare journey.**

a. Include important medical concepts and terms that patients are likely to come across in their care, but make sure to clearly define them in patient-friendly terms: easy to understand, but not oversimplified.

b. When introducing new or unfamiliar concepts, provide patients and caregivers the background information they need to understand how it may relate to or show up in their experience.

c. Clarify how new concepts might be similar or different from the terms or concepts they already know about.

For example, when describing immunotherapy, consider explaining how it differs from more familiar cancer treatments like chemotherapy or surgery.

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Quick Reference Guide to the UPL Best Practices

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There are 9 UPL Best Practices to help you plan and build patient materials:

1 Enable Patient Learning

Equip patients with the knowledge they need to understand complex topics.

- ▢ Treat every communication as an opportunity to **teach patients new concepts**
- ▢ Ensure the content reflects and is relevant to **patient and caregiver needs,** and their **stage in their healthcare journey**
- ▢ Make the **purpose** of the communication obvious
- ▢ Present complex information in **digestible chunks**
- ▢ Use **analogies** to explain complex concepts
- ▢ Help patients and caregivers understand **their roles** and their **healthcare team's role** in their care
- ▢ Provide resources and contact info for **follow-up questions**

2 Share Qualitative and Quantified Data

Present complete, relevant, and unbiased data with the appropriate context.

- ▢ Provide background information that helps explain **why the data matters** to patients and caregivers
- ▢ **Define all statistical terms** (e.g., mean, median, incidence, prevalence)
- ▢ Make **head-to-head data comparisons easy** (e.g., to "healthy/normal" ranges, means/medians)
- ▢ Make it easy for patients to understand **risks and benefits** when presenting side effect data
- ▢ Help patients interpret what **"common" vs. "rare" likelihood** means
- ▢ When providing **percentages**, also provide **raw numbers** used to calculate the percentage
- ▢ Choose an **appropriate format** to visualize data (e.g., use graphs, charts, timelines, avoid 3D charts)
- ▢ Adhere to **data visualization best practices** (e.g., use consistent axes and scales)

3 Design for Digital

Consider how patients want to navigate and engage with communications.

- ▢ Incorporate a variety of engaging formats and content that **support diverse ways of learning**
- ▢ Include **functionalities** that make digital materials easy for patients to **understand, use, and explore** (e.g., links, QR codes)
- ▢ Optimize digital materials for a **variety of platforms** (e.g., web, mobile, tablet, EMR)
- ▢ Think about how digital tools fit into the **overall patient experience**, online and offline
- ▢ Develop digital materials and tools that are **accessible to a range of users** (e.g., variable levels of ability, connectivity, technology)
- ▢ Take an **iterative approach** to digital materials, improving them based on how people use them
- ▢ Ensure content can also work when **printed**

4 Demonstrate Empathy

Acknowledge the experience of patients and their caregivers and establish an emotional connection.

- ▢ Be mindful of the **overall patient journey**, including state of mind; adjust tone accordingly
- ▢ Make communications feel like they come from a **real human**
- ▢ Use **authentic stories** to reflect patients' and caregivers' lived experiences
- ▢ Acknowledge and address the role of **caregivers**
- ▢ Consider **different socio-cultural backgrounds** and **emotional impact** when using words, concepts, and colors
- ▢ Acknowledge and appropriately represent **identity and diversity** (e.g., age, gender, sexual orientation, ethnicity, disability)

Quick Reference Guide *(continued)*

5 Use Plain Language

Explain complex topics in a straightforward and accurate way.

- ☐ Use an **approachable, conversational, down-to-earth tone**
- ☐ Address **patients in second person** ("you"), use **first person ("I") to reflect the patient voice**, refer to **organization in first person plural** ("we," "our")
- ☐ Use the **simplest words possible** to convey your message; few syllables per word, multiple short words in place of a single long word
- ☐ **Introduce acronyms properly** before using them
- ☐ Write **short sentences** with simple syntax
- ☐ Use technical and medical terms sparingly for **teaching purposes only**; define them in simple terms
- ☐ **Avoid colloquialisms** (e.g., "pushing liquids")

6 Communicate Visually

Visualize complex information to make it more digestible.

- ☐ Repeat important, complex concepts in **both words and pictures**
- ☐ Use **color** to connect words and visuals
- ☐ Use images when **explaining things that cannot be seen**, such as how things work in the body
- ☐ **Provide context about where something is happening in the body**, connecting to what patients can see and feel
- ☐ **Avoid a hyper-realistic visual style**
- ☐ Establish a **consistent visual language**, repeating shapes, elements, and colors
- ☐ Use **standard, recognizable shapes** whenever possible
- ☐ Use color with care to **accommodate color blindness** and to **support understanding**, limit to 5 colors
- ☐ Use **images of people** to communicate about patients' and caregivers' lived experiences

7 Format Materials for Understanding

Design layouts that are purposeful and easy to both read and navigate.

- ☐ **Maintain a coherent story** across each screen or page without repeating copy multiple times
- ☐ Use **hierarchy and emphasis** to focus the reader's attention and guide the sequence in which they read (e.g., use titles to categorize information, use size or color or bolding to emphasize, number sections for clarity)
- ☐ **Format text to optimize the intake of information;** avoid large blocks of text and use high contrast between text and its background
- ☐ Use **white space** generously and deliberately
- ☐ Design layouts to **support how patients will use the information** (e.g., checklists for actions, tabs to find appropriate section, etc.)
- ☐ **Use logos as sparingly as possible**, at a minimal size

8 Be Culturally Responsible

Create communications that are respectful, relevant, and meaningful across cultures.

- ☐ **Plan for cultural considerations from the start**
- ☐ **Involve patients, caregivers, or community members** throughout development whenever possible
- ☐ Go beyond translation by **adapting language, visuals, tone, and examples for understanding**
- ☐ **Recognize that language, dialect, and communication preferences** vary across communities
- ☐ **Reflect the intended audience** through authentic imagery and culturally appropriate design
- ☐ **Consider cultural beliefs,** trusted community members, and decision-making preferences
- ☐ **Collaborate with your intended audience** throughout development

Quick Reference Guide *(continued)*

9 Empower Caregivers

Recognize caregivers as a primary audience and support them throughout their journey.

- ☐ **Address caregivers directly**—not only as supporters of the patient
- ☐ **Be mindful that caregivers may identify by different terms,** such as care partners, carers, or loved ones, and reflect that language where appropriate.
- ☐ **Provide practical, actionable information** caregivers can use with confidence
- ☐ **Recognize that caregiver needs change** across different stages of the journey
- ☐ **Acknowledge the emotional, physical, and practical realities** of caregiving
- ☐ **Help caregivers understand** their role and what to expect
- ☐ **Connect caregivers with additional resources** and support when appropriate
- ☐ **Encourage shared understanding** between patients, caregivers, and healthcare teams

Best Practice 1

Enable Patient Learning

When we enable patient learning, we empower patients to improve their own healthcare experience and we support them in achieving their clinical outcomes.

Quick and easy ways to apply this best practice:

- ▢ Explain how your communication will help patients and caregivers achieve their goals.
- ▢ Start by presenting the basics of the topic and build knowledge in subsequent sections.
- ▢ Use analogies or metaphors to help explain complex or unfamiliar concepts.
- ▢ Encourage patients to validate information and share how they're feeling with their healthcare team.
- ▢ Give patients and caregivers a list of questions they can ask their healthcare team.

Detailed guidance on how to apply this best practice:

1. **Treat every communication as an opportunity to teach patients new concepts that will help them navigate their healthcare journey.**

   a. Include important medical concepts and terms that patients are likely to come across in their care, but make sure to clearly define them in patient-friendly terms: easy to understand, but not oversimplified.

   b. When introducing new or unfamiliar concepts, provide patients and caregivers the background information they need to understand how it may relate to or show up in their experience.

   c. Clarify how new concepts might be similar or different from the terms or concepts they already know about.

   For example, *when describing immunotherapy, consider explaining how it differs from more familiar cancer treatments like chemotherapy or surgery.*

2 Ensure the content reflects and is relevant to true patient and caregiver needs, goals, questions, and experiences.

a. Make sure the purpose of the communication is relevant, practical, and useful to patients and caregivers, addressing one or more of their specific goals or objectives. When possible, gain an understanding of their goals through direct research with them.

b. Provide clear, direct answers to patient and caregiver questions.

c. Make sure the content appropriately reflects the stage that the patient is at in their healthcare journey.

For example, *information on diagnosis will typically be less important to patients who have already been on a treatment for a while.*

3 Make the purpose of the communication immediately obvious so patients understand what information to look for and how to use it.

a. Clearly explain how your communication will help patients and caregivers achieve goals related to their healthcare journey or why the information might be important to them.

For example, *you might start your communication with a short explanation of which topics the material might help patients understand.*

This guide is a starting point to help you understand:	After reading this guide, we hope that you will feel more comfortable:
• **How immunotherapy works in your body**	• **Playing an active role in your treatment**
• **What your immunotherapy experience may be like**	• **Having open and honest conversations with your care team**
• **What help and support is available to you throughout your journey**	• **Explaining immunotherapy to your loved ones**

b. Be transparent about who sponsored or provided funds for the development of the patient communication.

For example, *"This patient guide was developed by the pharmaceutical company Bristol Myers Squibb."*

4 Present complex information in digestible chunks or sections to help patients build up their knowledge incrementally.

a. Start by introducing the basics of the topic. Build knowledge in subsequent sections, so that patients can choose their own pace and level of detail depending on where they are in their healthcare journey.

TIPS

- ***Recently diagnosed*** *patients and caregivers are often most interested in* ***identifying and connecting with others*** *in their community or in similar circumstances and* ***finding hope*** *in the available treatments.*
- *When patients and caregivers are learning about a* ***new treatment****, they often want to understand its potential effects on day-to-day lives, including* ***logistical responsibilities*** *(e.g., monitoring, required appointments) and* ***likely side effects*** *(including onset, resolution, risk, severity, and predictability).*

b. Provide patients with options to learn more complex information about a topic on their own, such as through links, sidebars, or pop-ups.

c. Ensure that the title or heading of each section directly addresses a patient need or question.

TIPS *Consider framing titles as questions patients might ask, such as **"What is happening inside my body if I have Rheumatoid Arthritis?"***

5 Consider using analogies or metaphors to help explain complex or unfamiliar concepts.

a. Use analogies or metaphors that patients and caregivers can easily understand and relate to.

***For example,** in an animation about a heart condition, we explained that in this disease, "muscles block the path out of the heart, like when construction on the road causes a traffic jam." Patients and caregivers validated that this analogy helped them better understand what was happening inside their heart.*

TIPS

- *Be selective about which concepts you explain using metaphors. Too many metaphors can be confusing for patients.*
- *Whenever possible, validate analogies and metaphors with patients and caregivers directly to ensure they are meaningful to the intended audience.*

6 Help patients and caregivers understand their respective roles and the role of their healthcare team in shaping care and making decisions.

a. Encourage patients to validate information with their healthcare team, and to turn to them as a key source of medical knowledge, interpretation, and advice.

b. Encourage patients to act as advocates for their health, acknowledging that they know their body best. This may include providing gentle guidance on how to prepare for appointments, and gently encouraging them to share how they/their bodies are feeling with their healthcare team.

***For example,** "Tell your healthcare provider about how you're feeling, so that they can help you if you start to feel worse, and can record when something is working. You know your body best."*

c. Remind patients and caregivers that questions are welcome and expected. Help them prepare for specific conversations by including a list of possible questions they can ask.

7 Provide patients with contact information and/or resources for follow-up questions and additional information.

a. When including multiple contacts, specify whom to contact and for what.

b. Use the terms "healthcare provider" or "healthcare team" (rather than "doctor"), unless you're confident about the exact role of the relevant member of their healthcare team (such as "your rheumatologist," "your mental health professional," or "your GP").

c. When presenting information that has been simplified or summarized from primary research or source data, provide links and/or references to source material to help build trust with patients and caregivers.

d. Direct patients and caregivers to helpful additional third-party resources, but take care to ensure they are trusted, reputable, and accessible to a patient audience.

WHY? *Patients may feel more comfortable with, have better access to, or receive support from members of their healthcare team other than their doctor. Patients may also have more than one type of doctor on their healthcare team.*

TIPS *Some examples of trusted, reputable sources for healthcare information include:*

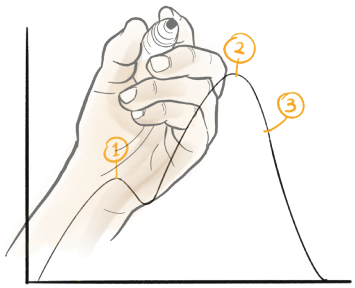
UpToDate *(http://www.uptodate.com/patient)*

NIH.gov *(for United States health information) or other websites sponsored by government agencies*

Best Practice 2

Share Qualitative and Quantified Data

When we appropriately share qualitative and quantified data, patients will be more informed and confident in engaging with their healthcare provider throughout their treatment journey.



Quick and easy ways to apply this best practice:

- ☐ Provide an explanation of why the data you're presenting might matter to patients.
- ☐ Present data in a way that makes it easy for patients to make head-to-head comparisons.
- ☐ When providing percentages, also provide the raw numbers that were used to calculate the percentage.
- ☐ When presenting side effect data, help patients understand what words like "common" and "uncommon" or "mild" and "severe" mean.

Detailed guidance on how to apply this best practice:

1 Provide background information that helps patients and caregivers understand why the data is relevant.

a. Explain why the data you're presenting might matter to patients and caregivers.

b. When using percentages, also provide the raw numbers that were used to calculate the percentage.

> ***For example,*** *"50% of patients (124 out of 248) experienced side effect X."*

c. Define statistical terms like mean, median, incidence, and prevalence in patient-friendly language.

d. Include relevant background information about the data, such as where and how the data was collected, or how measurements were calculated.

> ***For example,*** *"Clinical Trial 1 studied how well DRUG A worked in patients who weren't helped enough by DRUG B. Symptoms were measured at 6 months and 1 year."*

2 Present data in a way that helps patients and caregivers make meaningful head-to-head comparisons.

a. Consider comparing your data to other relevant healthcare data such as:

- "healthy" or "normal" ranges
- means, medians, or baselines
- similar data for other treatments

b. Use comparable data sets that contain similar information and were collected using similar methods.

c. When presenting data about the likelihood of an event or phenomenon, suggest whether it's "common" or "rare," and/or compare it to the likelihood of other familiar events.

> ***For example,*** *"The likelihood of experiencing heart-related side effects is not very common. About 1 in 250 people who take Medication X experience arrhythmias, which is similar to the likelihood of being born an identical twin."*

WHY? *Patients and caregivers often find it hard to interpret data in isolation. Comparisons can provide context that helps make the data more meaningful.*

3 When presenting data about treatments and their side effects, give patients background information that will help them better understand the risks and benefits of the treatment.

a. Quantify the benefits and risks of any treatment, using both traditional clinical trial results (or endpoints) and patient-reported outcomes.

b. When reporting side effects, define terms like "common," "uncommon," and "rare" and, when the data is available, report the percentage of patients who typically experience each side effect.

> ***For example,*** *you might use a table to clarify the likelihood of each side effect.*

	Symptom of CRS
Common *More than 20% (or more than 20 out of 100 people who experienced CRS) developed these symptoms*	Fever (98%)
	Low blood pressure (41%)
	Fast heartbeat (35%)
	Chills (31%)
Uncommon *Between 10–20% (or between 10 and 20 out of 100 people who experienced CRS) developed these symptoms*	Low blood oxygen (20%)
	Tiredness (12%)
	Headache (10%)
Rare *Less than 10% (or less than 10 out of 100 people who experienced CRS) developed these symptoms*	Buildup of yellowish pigment that is made during the normal breakdown of red blood cells (Hyperbilirubinemia) (<10%)
	Other rare symptoms

NOTE *Since there are no agreed-upon percentages associated with "common," "uncommon," and "rare," these may be different from communication to communication.*

c. Define subjective terms such as severe, moderate, and mild.

4 Appropriately format or visualize data to make it easier for patients to read and understand.

a. Carefully consider which format is most appropriate to present each type of data and communicate the intended message. This could include graphs, charts, a well-organized list, or numbers accompanied by descriptive icons.

b. Format or visualize similar types of data in the same way to make them easy to compare.

c. When presenting graphs, use axes that are proportional to the data and that have a consistent scale across graphs.

d. Avoid 3D charts. The perspective distorts how data is read.

e. Use timelines to visualize chronological data.

f. Highlight what's important using color, contrast, shapes, outlines, etc.

NOTE *For more guidance on visualizing data, see **the UPL Thought Starter for Explaining Data, UPL Thought Starter for Explaining Clinical Trials**, and/or the **UPL Style Guide** chapter on Data.*

WHY? *Inconsistent or non-proportional axes can distort the data and make it easy to misinterpret.*

NOTE *For more guidance on visually highlighting information, see Best Practice 7, **Format Materials for Understanding**, on pages 28 and 29.*

Best Practice 3

Design for Digital

When we design for digital, we learn more about patients and can create higher-value communications that better meet their evolving needs.

Quick and easy ways to apply this best practice:

- ☐ Break up online content into separate parts or pages that users can expand and collapse to focus on one layer of information at a time.
- ☐ Use direct links, QR codes, and "click-to-download" buttons to help users reach additional information or resources quickly and easily.
- ☐ For interactive patient tools, add functionality such as fillable fields, clickable radio buttons, and dropdown menus that patients can interact with.
- ☐ Ensure that all digital materials are still usable and readable when printed (using only black and white ink).

Detailed guidance on how to apply this best practice:

1. **When designing digital materials like websites, apps, or digital tools, think beyond text and images. Incorporate a variety of engaging multimedia formats and content that support diverse ways of learning.**

   a. Use interactivity, animation, video, and illustration to convey complex ideas, processes, and systems.

   b. Consider how and what kinds of digital tools might help support patients and caregivers in their healthcare journey and interactions with their healthcare providers.

   Some helpful examples might include:

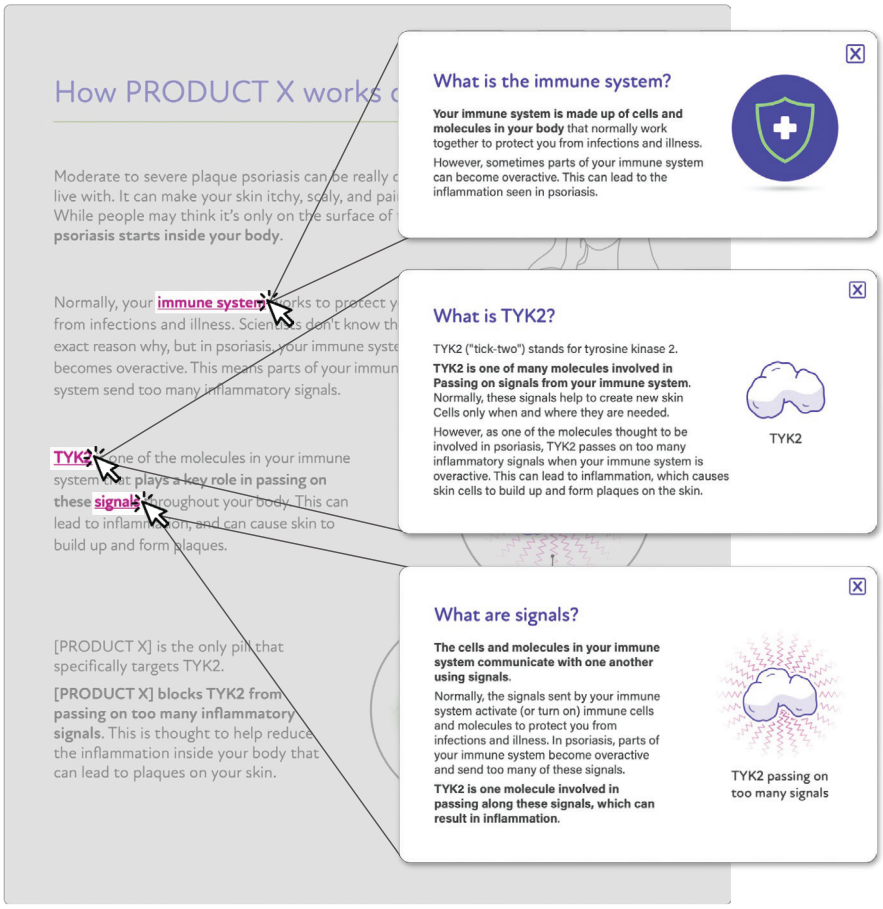
   - A digital or online journal to track symptoms
   - An online community to get peer support
   - A holistic "one-stop-shop" website for all information related to a disease (including treatment, finances, mental and social wellbeing and support, etc.)

- A fillable form about the patient's treatment preferences that can be integrated into their Electronic Medical Record (EMR)
- Digital educational materials designed to teach patients during telemedicine calls
- Location-specific (or "geo-targeted") information about the clinical trials available near the user's home
- Online "text-to-speech" tool that teaches patients and caregivers how to pronounce unfamiliar medical terms or treatment names

2 Include functionalities in digital materials that make them easy for patients and caregivers to understand, use, and explore.

a. Break up online content into separate parts or pages, and use dynamic, clickable widgets to allow users to selectively expand, collapse, and focus on one layer of information at a time.

For example, *clickable pop-ups can help patients access more detailed information.*



b. Use direct links, QR codes, and "click-to-download" buttons to help users reach the resources that are most important to them quickly and easily.

c. For tools that are designed for patients and caregivers to fill out or engage with, add interactive functionality such as fillable fields, clickable radio buttons, and dropdown menus.

3 When building digital tools like websites and apps, consider how they fit into the overall patient experience, both online and offline.

a. Think about how patients might use the digital materials you provide beyond the website or app. Design the content to support those scenarios and channels.

> ***For example,*** *since patients often share health information with friends and family, make online topics or pages easily shareable through email or social media.*

b. Remember that any given user may access digital tools or pages from a variety of platforms. Be sure to optimize digital materials for web, mobile, tablet, and any other platforms the materials may be accessed from (such as an Electronic Medical Record system).

4 Develop digital materials and tools that are accessible to a range of users, keeping in mind that they may have variable levels of ability, connectivity, and access to technology.

a. Be compliant with the latest Web Content Accessibility Guidelines (WCAG) from the Web Accessibility Initiative (WAI).

> ***For example,*** *since patients with multiple sclerosis can have poor eyesight, it's important to ensure materials for this audience can be read using a screen reader.*

b. Ensure that all content can work in both digital and print contexts—make print materials such as brochures available for download, and ensure that digital-only materials are still readable when printed.

c. Remember that not everyone has the same access to technology. Patients should still understand key messages if they are accessing from an older computer with reduced functionality or with a slow internet connection.

5 Take an iterative approach to building digital materials, testing and improving them after observing how people actually use them.

a. Consider planning, designing, and developing your digital material as a prototype or a "minimum viable product" and iterate based on user testing, real-world experience, and data.

b. Build in user analytics, A/B testing, and usability testing to understand what is most useful and engaging for patients.

TIPS *For more resources on this topic, refer to How People with Disabilities Use the Web:* ***http://www.w3.org/WAI/intro/people-use-web/***

TIPS *Test the readability of printed materials using black-and-white ink, as many users print without color by default.*

TIPS *Some ways to make content more accessible for older or slower technologies are:*

- *making content available for download or print so users can read it offline*
- *minimizing the file size of images and videos*
- *keeping the website or app interface simple*

Best Practice 4

Demonstrate Empathy

When we demonstrate empathy for patients and caregivers, we foster an emotional connection that makes our communications more meaningful and relevant.

Quick and easy ways to apply this best practice:

- ☐ Start the communication with an empathetic statement acknowledging any emotional, social, and physical challenges patients may have experienced.
- ☐ Be mindful of the emotional impact different colors can have—use cool and/or light colors to convey peace, tranquility, and softness; use warm and/or bold colors to convey energy, excitement, and activity.
- ☐ Acknowledge age, gender, sexual orientation, disability, and ethnic diversity in the representation of patients, caregivers, and healthcare providers.
- ☐ Explicitly acknowledge and address the role of caregivers.
- ☐ Reflect the lived experiences of patients and caregivers through authentic, character-based stories and anecdotes.

Detailed guidance on how to apply this best practice:

1 Be aware of the holistic patient journey for your target audience and be sensitive to that when developing communications.

a. Be mindful of words that may take on different meanings for patients at different points in their journey.

> ***For example,*** *saying that a treatment works by targeting a "protein" in the body can be confusing for newly diagnosed patients since they will often associate the word "protein" with their diet and nutrition. However, patients further along in their journey may have a better understanding of what a protein is and its role in their disease.*

b. Be mindful of the reader's state of mind and adjust your tone accordingly.
For instance, *are they recently diagnosed and potentially feeling overwhelmed? Are they hopeful about a potential new treatment? Are they on the path to recovery? Are they feeling concerned that their children will inherit their condition?*

c. Start the communication with an empathetic statement acknowledging any challenges patients may have experienced (emotional, mental, social, and physical).

   For example, *"One of the hardest things about this disease is that it may not be obvious to your friends and loved ones" can be validating for patients who want others to understand their condition.*

d. Keep in mind that patients and caregivers may be especially sensitive to phrases that might suggest the worsening of their condition or death.

   For example, *saying "Patients who took Medication X lived 10 months longer without cancer progressing." may make patients feel like the return of cancer is inevitable. Meanwhile, saying "When patients took Medication X, their cancer was stable for 10 months longer." is more neutral.*

2 Make sure communications seem to come from a real human being, rather than a team or company.

WHY? *Communications that lack the human element can come off as cold and disingenuous. Build in a more personal, human connection to build trust and empathy with the reader.*

3 Be mindful of the emotional impact different colors can have.

a. Cool colors like blue and green are often interpreted as tranquil, passive, and contemplative, while warm colors like red, orange, and yellow are often considered active, passionate, and engaging.

b. Use light and muted colors to convey calming, positive, soft messages.

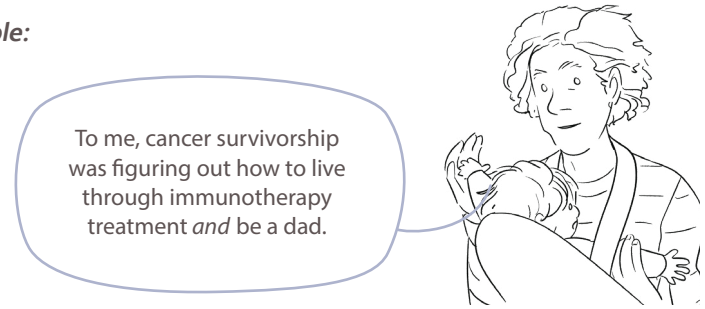
c. Use bold and bright colors to convey exciting, energetic, loud messages.

4 Reflect the lived experiences of patients and caregivers through authentic character-based stories and anecdotes.

a. Include images of patients speaking about their experiences and/or asking questions that they may have.

TIPS *For more guidance on visualizing people, see* ***Communicate Visually*** *rule 5 on page 24.*

For example:



b. Include real patient anecdotes where possible.

c. Include both the positive and negative sides to a story, including the physical, emotional, social, and mental health challenges associated with patient or caregiver experiences.

d. Acknowledge that every patient is unique and may have different challenges.

Best Practice 5

Use Plain Language

When we use plain language, patients feel less overwhelmed and less intimidated and are able to better understand our communications.

Quick and easy ways to apply this best practice:

- ☐ Use an approachable, conversational tone—refer to the patient as "you," your organization as "we," and use contractions.
- ☐ Use simpler words with fewer syllables, and multiple short words instead of longer, more complicated ones.
- ☐ Use multiple shorter sentences instead of one long sentence.
- ☐ Always include a simple, consistent explanation of any medical terms or acronyms—preferably in-context rather than only in a glossary.

Detailed guidance on how to apply this best practice:

1 Strive for an approachable, conversational, and down-to-earth tone.

a. Use first person plural ('we,' 'our') when referring to yourself or your organization.

b. Use second person ('you') when addressing patients directly.

c. Use first person singular ('I') when reflecting the patient voice.

d. Use contractions (such as "don't" instead of "do not") to help language sound less clinical and formal.

e. Beware of "marketing speak." Try to use words and phrases that patients and caregivers are likely to use and understand in their everyday lives.

> ***For example,*** *taglines like "pump up the immune system" or "kick cancer to the curb" may be catchy, but may not be helpful in helping patients better understand their condition or treatment.*

2 Use the simplest words possible to convey your message.

a. Use words with fewer syllables where possible, since these are generally easier for patients to understand.

b. Use multiple short words rather than a single long word to convey your message. Be especially careful using terms that are common in the healthcare industry but are rarely used by patients. If you need to use a term like this, be sure to define it in plain language.

> ***For example,*** *words like "pulmonary" can still be used, but also include its definition 'relating to the lungs.'*

c. Assess the reading level of any written content using established readability metrics such as the FORCAST, Fry, or New Dale-Chall readability formulas. Aim for a 5th to 6th grade reading level.

> TIP *Use readability indices with care. Leave out medical and technical terms from your submissions to get a more realistic index rating.*
>
> *For more information on Readability Indices, see the* ***UPL Style Guide*** *chapter on Writing (section on "Readability Indices")*

3 Avoid using acronyms without introducing them properly.

a. Only use an acronym if the patient is very likely to encounter it elsewhere in their healthcare journey or in interactions with their healthcare team.

b. If you decide to include an acronym, remember that patients do not read every page, or even every paragraph. Write out the full meaning of the acronym at least once every three paragraphs.

c. Write out the long form of any Greek letters or symbols when they are first introduced so that patients know how to pronounce them.

> ***For example,*** *β-thalassemia (beta-thalassemia)*

> NOTE *There are some acronyms that are so commonly used that they don't need to be spelled out. For example, AIDS does not need to be written out as Acquired Immune Deficiency Syndrome.*

4 Write short sentences with simple syntax.

a. Use multiple short sentences rather than one longer sentence, since shorter sentences are usually easy for patients to understand.

b. Use the active voice, rather than the passive voice. Passive voice makes sentences wordy and can cloud meaning.

> ***For example,*** *"Your social worker* ***will make*** *the phone call." (active) rather than "The phone call* ***will be made by*** *your social worker." (passive).*

c. Generally, limit sentences to two clauses.

> ***For example,*** *"When you take your medication, you should always drink plenty of water."*

> NOTE *Using multiple, shorter sentences can sometimes make the content longer. However, patients have told us that they're not as concerned about the length of content as long as it's easy to understand.*

d. Do not nest ideas or clauses within sentences.

For example,

DON'T *"When you take your medication, **which you should do in the morning**, always drink plenty of water."*

DO *"When you take your medication **in the morning**, always drink plenty of water." or "**You should take your medication in the morning.** Remember to drink plenty of water with your medication."*

5 Use technical and medical terms carefully and primarily for teaching purposes so that patients can better navigate their healthcare conversations.

a. Always include a simple, consistent explanation of any medical terms.

b. Define terms in-context rather than on a separate page or only in a glossary.

c. Avoid using medical colloquialisms that patients may attempt to interpret literally, such as "pushing liquids."

d. Strive to use the same terms consistently within the same communication and across communications about the same disease.

***For example,** in the same material:*

- Don't use the word "therapy" to describe both a medicine and psychotherapy.
- Pick one word to describe "immunotherapy" and "I-O therapy"—don't use both.

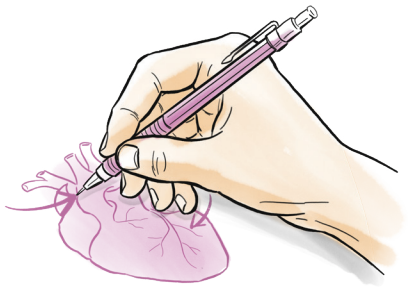
NOTE *Be sure to also define day-to-day terms that may have specific meanings in a medical context such as "**stage** of cancer" or "**alternative** treatments."*

TIPS *To ensure terms are defined accurately and consistently, it may be helpful to develop a list of terms and definitions that you and/or your team can refer back to whenever you use the term in a new communication or context.*

Best Practice 6

Communicate Visually

When we communicate visually, we gain an opportunity to reinforce and reiterate important information, so that patients are more likely to understand, remember, and take action.



Quick and easy ways to apply this best practice:

- ☐ Ensure that icons and images are accompanied by a label or words.
- ☐ When visualizing details inside a patient's body, provide context about where it is in their body so they can connect this information to what they can see and feel.
- ☐ Use a minimal number of saturated colors to highlight important details.
- ☐ In images of people, represent a diverse range of people with respect to race, ethnicity, gender, age, body type, sexual orientation, disability, and emotional states.

Detailed guidance on how to apply this best practice:

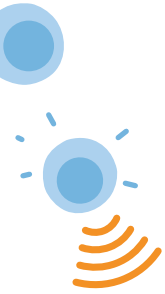
1 Repeat important, complex concepts in both words and pictures.

a. Ensure that icons are always accompanied by a label or words.

b. Use color to reinforce the connection between words and visuals.

For example, *in the excerpt below, color is used to connect specific medical terms with their accompanying images.*

> **T cells** are a type of white blood cell, and are part of your immune system.
>
> T cells are normally **activated** when they find a sign of a foreign invader. When this happens, they send **signals** to wake up other parts of your immune system to deal with the foreign invaders.

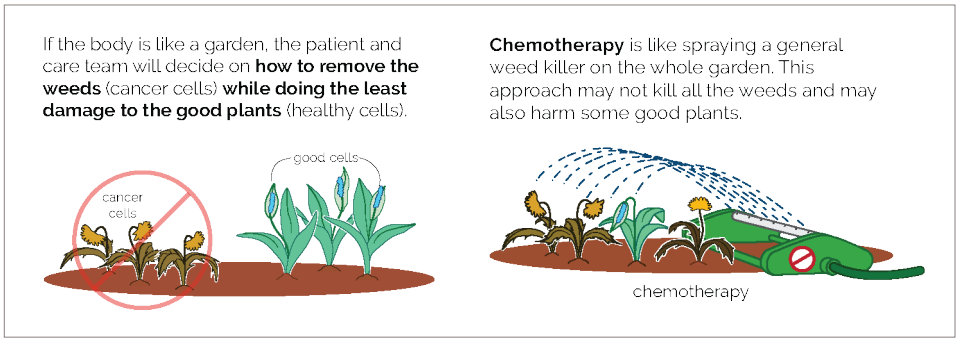


WHY? *While icons can help people navigate a communication, they are not effective for explaining complex ideas.*

2 Use illustrations when explaining details that cannot be seen, such as how things work in the body.

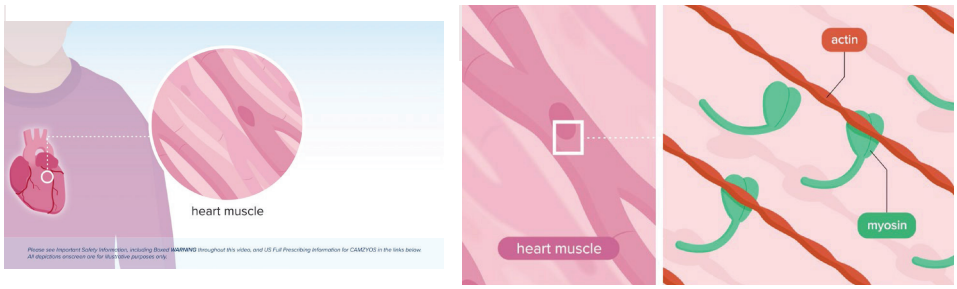
a. When possible, use visual metaphors or analogies to help patients connect new medical knowledge to existing knowledge outside of healthcare.

For example, *in the communication below, a garden analogy is used to explain how various cancer treatments differed from each other. Patients validated that this analogy would help them explain these concepts to family and friends.*



b. When visualizing details inside a patient's body, provide context about where it is in their body so they can connect this information to what they can see and feel.

For example, *you might start by visualizing a familiar organ (such as the heart) and where it exists in the body (the chest) before zooming in on the cellular or molecular processes that are happening inside.*



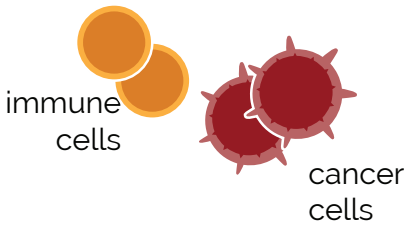
WHY? *Visual explanations are easier for most patients to understand.*

Refer to the ***UPL Thought Starter on Explaining Biological Processes*** *for more detailed guidance on this topic.*

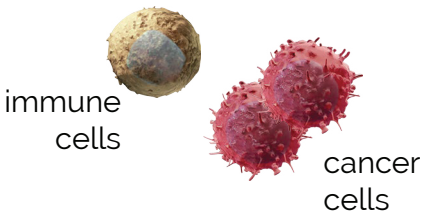
TIPS *To learn more about using metaphors, see* ***Enable Patient Learning*** *guidance 5a on page 9.*

c. Try to avoid a hyper-realistic visual style, which often distracts from the most important messages for patients.

DO *Use a simple visual style to help readers focus on processing the complex or medical information at hand.*



DON'T *Use a hyper-realistic style, as it can make a communication feel overwhelming and doesn't make the medical or scientific information any clearer for readers.*



d. In general, don't use images designed for healthcare providers in patient communications, since healthcare provider visuals are usually more difficult to understand.

e. Avoid using photographs to communicate complex scientific information or to show how processes work.

TIPS *On the contrary, it can sometimes be helpful to use images designed for patients to teach healthcare providers, as it can help them develop a shared language with patients.*

3 Establish, use, and repeat visual elements like color and shapes across materials and channels to establish a standard, familiar visual language.

a. Whenever possible, use standard, universally recognizable shapes and visual conventions to convey meaning.

For example:

red octagon = "stop!"

triangle with exclamation mark = "warning"

Wi-Fi symbol = "signal"

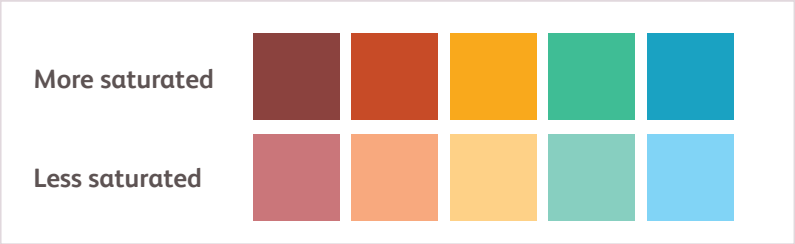
b. Consider including a legend explaining the meaning of icons or symbols that are repeated throughout the communication.

c. Use shapes to support the message you are trying to communicate. Typically, amorphous, soft, rounded shapes and lines are interpreted as "friendly" and "human," while acute angles and geometric shapes communicate "precision" and "order."

4 Use color with care to accommodate color blindness and ensure color is supporting understanding rather than detracting from it.

a. Use saturated colors to highlight and emphasize, but avoid combining multiple saturated colors.

WHY? *Combining saturated colors can visually interfere with one another.*



For example, *consider using a monochrome color palette with one or two complementary colors to accent and emphasize important visual elements.*

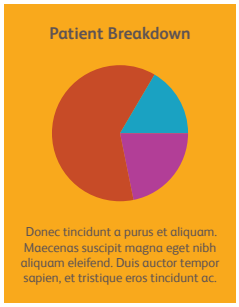
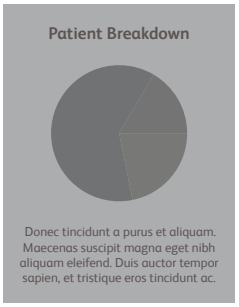
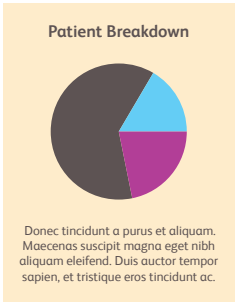
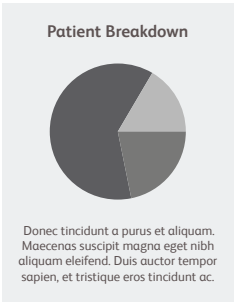
b. Use no more than 5 colors, if possible.

WHY? *Five is the number of colors that the eye can easily process in one glance.*

Reference: Lidwell, W., Holden, K., and Jill Butler. Universal Principles of Design. Rockport Publishers, 2011.

c. Make sure colors are not the only way you're conveying information. Consider using shape, texture, and lightness/darkness of colors.

For example, *when using multiple colors, use a combination of light and dark colors so that it's easy for patients to read even if they are colorblind or if they print the material using a black-and-white printer.*

	COLOR	BLACK-AND-WHITE
DON'T ✕ *Little contrast between the words and the background* ✕ *All three colors in the pie chart blend together when reproduced in black-and-white*		
DO ✓ *Dark text stands out on lighter background* ✓ *The three colors in the pie chart are easy to distinguish when reproduced in black-and-white*		

5 Include images of people to communicate about patients' and caregivers' lived experiences.

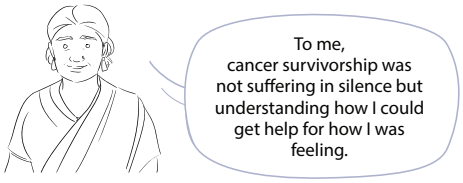
a. Where possible, use illustrations of people (rather than photos) to communicate patient stories and experiences.

b. If using illustrations is not possible or appropriate, use photos of people to create an emotional connection with patients. However, take care to follow rules c and d below when using photos, as patients may otherwise see them as prescriptive and/or inauthentic.

c. Strive for a range of facial expressions, as some patients may find it difficult to relate to overly positive expressions.

d. Use speech bubbles to normalize or suggest questions, experiences, or sentiments that patients might have.

For example:



e. Visually demonstrate that they are not alone by showing relationships between patients, caregivers, and healthcare providers.

For example:

Best Practice 7

Format Materials for Understanding

When we format for understanding, patients are more engaged while reading our communications, retain more of the information we provide, and derive greater value from our materials.

Quick and easy ways to apply this best practice:

- ☐ Establish a system of hierarchy for different levels of text information (i.e. titles, subtitles, and body text) and use this system consistently across the material.
- ☐ Avoid large blocks of text. Break them up with white space or graphic elements such as lines or boxes and use bullets for lists of related items.
- ☐ Use high-contrast text at the largest size possible (minimum 12 pt).
- ☐ Display information that is intended to guide patient actions as a checklist.

Detailed guidance on how to apply this best practice:

1 Maintain a coherent story across each page of a communication piece.

a. Do not repeat the same or similar copy multiple times within the same piece.

b. Integrate important information (such as reminders, calls-to-action, and important safety information) throughout the piece by incorporating those elements into the overall story you're telling.

c. Be careful when reusing content in a new context. Ensure that the story still flows and supports the overall purpose of your communication.

WHY? *When an image or phrase is repeated too often it begins to lose impact—the opposite effect to emphasis.*

2 Use hierarchy and emphasis to focus the viewer's attention on the page and guide the sequence in which they read it.

a. Establish a system of hierarchy for different levels of text information (e.g., titles, subtitles, and body text) and use this system consistently across the material to focus the reader's attention.

b. Be intentional about the order and placement of information on the page, keeping in mind that people tend to:
   - read from left to right and top to bottom
   - notice larger visual elements first (such as large images or titles)
   - be drawn to images of the human face

c. Use color or bolding to draw attention to critical information. Be selective in what you choose to emphasize to maximize the effect.

d. Number sections to make the intended reading order clear and make information easier to reference during discussions with members of their healthcare team.

TIPS *For more guidance on information hierarchy, see the **UPL Style Guide** chapter on Typography.*

3 Format text so that it's easy for patients to read and take in information.

a. Avoid large blocks of text. Break them up with white space or graphic elements such as lines or boxes. Use bullets for lists of related items.

b. Use white space (or "negative space") generously and deliberately to make text easier to read, scan, and focus on.

c. Use a grid to align text and graphic elements to minimize clutter.

d. Use high-contrast text at the largest size possible (minimum 12 pt) to accommodate readers with weaker eyesight.

TIPS **What is white space?** *White space or "negative space" is the space that is left empty around elements on a page like text, images, or other graphic elements.*

4 Design the layout of the document so that it supports how patients are likely to use the provided information.

a. Information that's provided for reference should include elements like tabs and/or a table of contents to help patients quickly navigate to the right section.

b. Display any information intended to guide patient actions as a checklist.

c. Provide space for taking notes directly into the contents of the document, rather than in a separate page or section.

d. If the document is intended to be printed, leave ample margin space for collating, hole punching, stapling, etc.

5 Use logos as sparingly as possible and keep them at a minimal size.

WHY? *Logos can be distracting and undermine trust with patients by making the communication seem focused on marketing rather than supporting patient learning.*

Best Practice 8

Be Culturally Responsible

When we communicate in culturally responsible ways, we help remove barriers to understanding, regardless of background, language, culture, or circumstance.

Quick and easy ways to apply this best practice:

- ☐ Plan for cultural adaptation from the start—not after content is complete.
- ☐ Go beyond translation by adapting language, visuals, and examples for understanding.
- ☐ Reflect the intended audience through authentic imagery and culturally appropriate design.
- ☐ Collaborate with patients, caregivers, or community members throughout development.
- ☐ Consider how cultural beliefs, trusted community members, and communication preferences may influence understanding.

Detailed guidance on how to apply this best practice:

1 Learn about the communities you want your communication to reach. Research cultural norms, values, and common languages.

a. Identify the audiences and communities the communication is intended to reach before creating the original version.

b. Plan for cultural adaptation from the start to reduce the need for significant revisions later. Before developing the original version, consider how the content may need to be translated or culturally adapted.

c. Invite members of the intended community into the development process early. Ask what they need, how they prefer to receive information, and what should be considered before the communication is created.

> ***For example,*** *a team developing a video may learn that some of its planned cultural choices did not resonate as intended. Co-creating with members of the intended community could help address those concerns.*

TIPS What Is Cultural Adaptation?
Cultural adaptation means adjusting health communications to better align with the cultural context of the intended audience. It goes beyond direct translation by considering how language, experiences, norms, values, beliefs, imagery, and design may affect how information is understood and received.

TIPS Refer to Our Culture-First Checklist
Use the checklist early in the development process to help consider cultural context from the start, rather than adapting communications later.

d. Choose words, examples, images, and references that are inclusive, relevant, and respectful of different cultures, languages, beliefs, and lived experiences so the content can be adapted without losing meaning or intent.

e. Inform writers, designers, and reviewers from the outset that the communication will be adapted so they can make decisions that support adaptation from the first draft.

2 Acknowledge the beliefs, concerns, and traditions of the community you're writing for.

a. Understand the beliefs, concerns, misconceptions, and experiences that may shape how the audience interprets health information and recommendations.

b. Frame health information in ways that connect to the audience's values, priorities, and lived experiences.

> ***For example,*** *in some communities, religious leaders, respected elders, or other trusted community members may influence how health information is understood and accepted. Communications can acknowledge these trusted influences when appropriate.*

c. Recognize who may be involved in healthcare decisions. Where appropriate, acknowledge the role of caregivers, family members, or trusted community members, while respecting the patient's autonomy and preferences.

> ***For example,*** *in some cultures, healthcare decisions are commonly made with input from family members rather than by the patient alone. Where appropriate, a treatment guide might include information for family members or caregivers—not just the patient—to support shared decision-making.*

Reflect cultural diversity and impact of family
Studies show that a value widely held in Spanish-speaking populations is prioritizing family over individual interest (familismo). Consider depicting family members as caregivers and as part of the care team.

Vaya acompañado
Ir acompañado de un familiar o amigo en las citas puede ayudarle a entender, recordar los detalles clave y sentirse apoyado.

This positions family members and friends as active participants in healthcare appointments, which directly reflects "familismo."

d. Consider cultural sensitivities that may affect how the audience receives the message and adapt the communication to reduce unnecessary barriers to understanding and engagement.

   ***For example**, in some cultures, discussing cancer, mental health, sexual health, end-of-life planning, infertility, or dementia may carry stigma.*

WHY? *People may view health and healthcare differently based on their culture, experiences, and community influences. Understanding these perspectives helps communicators identify potential barriers to understanding and engagement.*

e. Respect traditional, cultural, and spiritual health practices, and encourage people to discuss relevant practices with their care team.

   ***For example**, a communication about a new treatment can acknowledge that some patients also use traditional remedies. Encourage patients to tell their care team about everything they take so potential interactions can be discussed.*

f. Avoid generalizing cultural beliefs or experiences. Individuals within the same community may differ in their preferences, practices, and perspectives.

WHY? *People are more likely to engage with information when it feels relevant and respectful of what matters to them.*

3 Adapt communications so the audience understands the intended meaning, even after translation.

a. Choose visuals, photographs, illustrations, icons, symbols, and colors so they feel familiar, appropriate, and respectful to the intended audience. Be mindful that their meanings may vary across cultural groups.

   ***For example,** imagery that feels appropriate for one community may feel unfamiliar or uncomfortable for another. A resource may use different imagery for different communities while keeping the health information consistent.*

   ***In another example,** in some cultures, the color red may represent good luck and prosperity, while in others it may symbolize aggression, warning, or danger.*

b. Adapt examples and scenarios so they reflect the values, relationships, and lived experiences of the intended audience.

   ***For example,** materials for Chinese audiences may resonate more when they depict family involvement in healthcare decisions and caregiving rather than focusing only on the individual patient.*

c. Avoid references, analogies, idioms, expressions, or other language-specific elements that do not carry the same meaning in another language or culture.

   ***For example,** an expression such as "hit it out of the park" or a similar U.S.-specific cultural reference often needs to be replaced with a culturally meaningful equivalent rather than translated word for word.*

   ***In another example,** a literal translation of the English phrase "out of the woods" ("森から出た" - "came out of the forest") would be nonsensical in a medical context and would not convey the meaning of recovery or being past a critical stage of care. Japanese expressions for recovery are usually more direct and related to health status.*

WHY? *A direct translation can be linguistically accurate and still fail to communicate the intended meaning.*

4 Choose the language, dialect, and language conventions that best fit the audience.

a. Use the language, regional variation, and writing system that your audience uses every day.

> ***For example,*** *Spanish used by a Mexican community may differ in wording and meaning from Spanish used in Puerto Rico or Spain. Work with people from the intended community to choose language that sounds natural and communicates the intended meaning.*

b. Match the tone, level of formality, and names, titles, or ways of addressing people to what the audience considers respectful.

c. Adapt gendered language to reflect the linguistic and cultural expectations of the intended audience, including where gender-neutral language or masculine and feminine forms are preferred.

d. Where appropriate, consider bilingual communications to support conversations between patients, caregivers, and the care team.

TIPS **Language conventions**
The formatting and stylistic rules tied to a specific language or locale, separate from the language itself. This includes things like:

- *Date, time, and number formats*
- *Currency symbols and placement*
- *Units of measurement*
- *Capitalization and punctuation*
- *Sorting/alphabetization order*
- *Honorifics and name order*

TIPS *Since at least 50% of Spanish-speaking individuals in the U.S. consider themselves bilingual, consider creating dual language materials.*

English on the front | **Spanish on the back**

5 Design for the mechanics of other languages and writing systems.

a. Plan for differences in typography, reading direction, character height, and line spacing.

> ***For example,*** *Arabic is read from right to left, which may require redesigning page layouts, navigation, charts, and visual elements—not just translating the text. Chinese characters can also require adjustments to font size, spacing, and layout to maintain readability and visual balance.*

b. Leave room in layouts for text that expands or contracts after adaptation.

> ***For example,*** *English text is often longer after it is adapted into another language. A headline that fits neatly in English may become too long for the available space, causing text to wrap, overlap, or disrupt the layout.*

c. Localize units, dates, numbers, and currency to match what the audience uses.

d. Ensure visual elements remain clear and correctly aligned when text expands, contracts, or changes direction after adaptation.

WHY? *Layout issues can make a translated piece feel unfamiliar or difficult to navigate, which may affect trust and engagement from the reader.*

e. Consider how the intended audience prefers to receive health information, and how culture may influence communication preferences—not just language. Choose a format that reflects how they access and use information.

> ***For example,*** *a written resource may not be the best choice for a community that more commonly receives information verbally or through video, even when the written translation itself is accurate.*

6 Use the clearest equivalent for terms that may not translate word for word, and use it consistently.

a. When a direct equivalent word or phrase does not exist, describe the concept in clear, familiar language rather than relying on a literal translation.

> ***For example,*** *terms such as "caregiver" or "care team" may not have a direct equivalent—or may carry a different meaning—in another language. Instead of relying on a literal translation, use clear, familiar language that communicates the intended role, such as "the group of people involved in your care."*

The Spanish word for team, "equipo," alone usually refers to sports teams. Therefore, it's important to be specific when describing "equipo médico" or "equipo de atención médica" in the medical context. However, to simplify it further, "group" is more appropriate when referring to care teams, like "grupo de apoyo" or "grupo de profesionales."

Sea abierto y honesto
Informe a su médico o grupo médico sobre cualquier cambio que se produzca en su salud o en cómo se siente. Cuanto más sepan, mejor podrán ayudarle.

b. Once you choose an equivalent, use it consistently throughout the material.

7 Be mindful of how human diversity and identity are assigned and represented, both visually and through language.

a. Acknowledge and appropriately represent the diversity of patients, caregivers, and healthcare providers, including with respect to:

- race and ethnicity
- religion
- disability/level of ability
- age
- gender
- sexual orientation

NOTE *Be thoughtful when deciding on how to appropriately represent a given patient population. Over-representation of one group can lead to the exclusion of others while thoughtless representation can reinforce stigma.*

For instance, while lupus disproportionately affects women, it is still essential to include some representation of men so male patients don't feel excluded or unacknowledged.

b. Show enough detail to represent a diverse range of people with respect to race, ethnicity, gender, age, body type, sexual orientation, and disability.

For example:

c. Don't assume gender. Use medically focused language rather than gendered language.

For example,

DON'T *"Pregnancy testing is recommended for **females** of reproductive potential before starting treatment."*

DO *"**If you are able to become pregnant**, your healthcare team should do a pregnancy test before you start receiving treatment."*

d. If a particular demographic population is disproportionately affected by a specific disease or health experience, ensure that this group is adequately represented in the content.

***For example,** in a patient brochure about sickle cell anemia, some of the images should include patients who are African American, as African Americans are disproportionately affected by the condition.*

8 Ask and listen throughout the development process where possible.

a. Invite members of the intended audience to review the communication early and throughout development.

b. Include native speakers, those familiar with the culture, or community members who understand how the audience naturally communicates and experiences the topic.

c. Ask whether the language, visuals, examples, format, and explanations are understood and feel appropriate as intended.

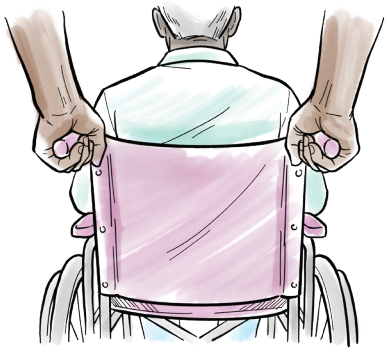
d. Make meaningful changes based on what you hear.

e. Seek a range of perspectives without expecting any one person or group to represent an entire community.

Best Practice 9

Empower Caregivers

When we empower caregivers, we help them better support the people in their care, navigate healthcare decisions with confidence, and look after their own wellbeing throughout the caregiving journey.



Quick and easy ways to apply this best practice:

- ☐ Address caregivers directly, not only as supporters of the patient.
- ☐ Provide practical information caregivers can use with confidence.
- ☐ Recognize that caregiver needs change throughout the journey.
- ☐ Acknowledge the emotional, physical, and practical realities of caregiving.
- ☐ Connect caregivers with additional support and resources when appropriate.

Detailed guidance on how to apply this best practice:

1 Speak to caregivers as a primary audience, not only as supporters of the patient.

a. When a communication is intended for caregivers, address them directly ("you") and write from their perspective rather than only embedding caregiver information within patient-facing content.

b. State clearly who the communication is for and what it will help caregivers understand or do.

> ***For example,*** *"This guide is for caregivers, or those who provide care for a patient. It will help you recognize symptoms, respond in the moment, prepare for conversations with the care team, and care for yourself."*

c. Use language that helps people recognize when the communication applies to them, even if they do not identify with the term "caregiver."

> ***For example,*** *instead of saying, "If you are a caregiver...," say, "If you help a family member or friend manage appointments, medications, or daily care..." so people can recognize that the information applies to them even if they do not identify as caregivers.*

WHY? *Caregivers are more likely to engage with information when they recognize it was designed for them.*

WHY? *People may provide significant care and support without describing themselves as caregivers. Using language that reflects what they do and how they are providing care helps them recognize that the information is intended for them.*

d. Recognize caregivers as individuals with their own questions, responsibilities, and information needs—not solely as an extension of the patient.

2 Acknowledge the caregiver's experience.

a. Recognize that caregiving can affect emotional, physical, social, practical, and financial wellbeing, as well as relationships and identities as people move into, through, or out of an active caregiving role.

For example, *a spouse or partner may need support transitioning from an intensive caregiving role back toward the relationship they had before treatment.*

b. Use language that reflects caregivers' lived experience without overstating or generalizing it.

c. Normalize uncertainty and questions throughout the caregiving experience.

For example, *"Many caregivers feel overwhelmed or uncertain at times. Questions are a normal part of caregiving."*

WHY? *Caregivers should feel supported rather than expected to have all the answers.*

d. Recognize that caregiving may begin gradually or suddenly, and that needs can change as the care journey evolves.

For example, *someone supporting a person with a progressive condition may take on caregiving responsibilities over time, while a stroke or other medical emergency can create those responsibilities immediately. Both experiences may lead to changing needs for information and support.*

e. Avoid implying that caregivers should manage everything on their own.

3 Equip caregivers to take practical action.

a. Provide specific, actionable guidance that helps caregivers know what to do, what to watch for, and when to seek additional support.

For example, *instead of "Watch for changes," say, "Call the healthcare team if your loved one develops a fever, has trouble breathing, or seems more confused than usual."*

WHY? *Practical guidance builds confidence and helps caregivers turn information into action.*

b. Explain what changes or symptoms may mean so caregivers understand why and when to take action.

c. Organize information into formats that are easy to find and use, such as checklists, an area to take notes, step-by-step guidance, summaries, or questions to ask.

> ***For example,*** *a simple "What to bring to the appointment" list—including when a symptom started, how often it occurs, what seems to trigger it, and what has already been tried—helps transform everyday observations into information the care team can use.*

d. Help caregivers prepare for care between healthcare visits, including tasks they may be expected to support at home. Provide clear guidance without assuming prior knowledge or expecting caregivers to act as healthcare professionals.

> ***For example,*** *if a caregiver needs to help with wound care, medication management, mobility, or other tasks at home, explain what they can safely do, what to watch for, and when to contact the care team.*

4 Empower caregivers as active participants in healthcare conversations and decisions.

WHY? *Caregivers are often significantly involved in a patient's healthcare journey.*

a. Frame the caregiver-patient relationship as a team effort.

> ***For example:***
>
> DON'T *"Your caregiver will do X."*
>
> DO *"You and your caregiver will do X together."*

WHY? *Relationships between patients and their caregivers are variable and unique. Some patients don't want to overburden their caregivers.*

b. Reinforce that caregivers' observations, lived experience, and questions contribute valuable information to the healthcare team.

c. Help caregivers actively participate in healthcare conversations by sharing observations and concerns, asking questions, seeking clarification, and confirming their understanding of treatment plans and next steps.

WHY? *Caregivers often notice changes that help inform care decisions.*

> ***For example,*** *prompt caregivers to share changes they have noticed and ask questions such as, "What does this mean for the treatment plan?" "What should I watch for at home?" or "What happens next?"*

d. Organize information in order of importance to help caregivers prioritize what they need to know and do.

Support is here for you, too
Resources for caregivers of people living with schizophrenia.

As a caregiver, you are there for your loved one as you both navigate their schizophrenia journey together. Over time, this responsibility can become overwhelming. It's important to know that no matter what you're facing or feeling, support is available for you.

You are not alone.
Being a caregiver can feel isolating, so it's important to connect with others who understand what you're going through. The National Alliance on Mental Illness (NAMI) has community and support groups specifically for caregivers. Find more information below.
NAMI support groups
nami.org/support-education/support-groups

Stay informed and empowered.
Understanding schizophrenia and the treatment options can help you feel more empowered to help. Clearly, hope, and empowerment. For insights into this condition, visit the Schizophrenia & Psychosis Action Alliance (SAPAA) caregiver resource page.
SAPAA
sanarbor.org/caregiver-resources

Navigate the system.
Caregivers often struggle to access important information because of common misunderstandings about HIPAA, the Health Insurance Portability and Accountability Act. The Caregiver Action Network provides information about privacy advocacy tools.
Caregiver Action Network
caregiveraction.org/managing-hipaa-schizophrenia

Your words matter.
Talk about schizophrenia with accuracy, clarity, and compassion. Using the right words can help people feel accepted, which can make it easier for you and your loved one to navigate the condition. Check out this guide from NAMI.
NAMI Division
nami.org/NAMIFirstMidAll-Media/PDFs/NAMI-Schizophrenia-Psychosis-Lexicon-Guide.pdf

Hold on to hope.
Many people with schizophrenia can experience symptom improvement. Know that this may be possible for the person you care for, too. Visit the Hope for Schizophrenia site to hear from others living with schizophrenia.
r/SWSZ
reddit.org/r/survivors

Get help in a crisis.
Whether you or the person you care for is facing a mental health crisis, there is 24/7 support available. **Call or text 988** or chat online for immediate support.
988 Lifeline
988lifeline.org

This is not a full list of local and national resources available. Bristol Myers Squibb does not endorse these organizations. The information links provided by Bristol Myers Squibb are meant for informational purposes only and are not meant to replace a physician's medical advice.
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It's not What's Wrong | It's Still Me

5 Connect caregivers with trusted information, resources, and support.

a. Provide trusted support organizations, educational resources, or community services when appropriate.

b. Make resources easy to locate and access by clearly explaining what they are, when they may be helpful, and how to connect with them through QR codes, accessible web addresses, or other appropriate formats.

c. Continue offering resources and opportunities for support beyond the initial diagnosis or transition into caregiving, and tailor them to the caregiver's situation, role, and stage of the journey whenever possible.

> ***For example,*** *when discussing a difficult stage in the caregiving journey, include information about caregiver support groups, services that provide temporary caregiving assistance, or other organizations that can offer support.*

WHY? *Caregivers often prioritize the needs of the person they are caring for over their own, leaving little time or energy to find support. Making trusted resources easy to find and access increases the likelihood they will use them.*

6 Reflect the full range of caregiving relationships.

a. Recognize that caregivers may be spouses, partners, parents, adult children, siblings, friends, neighbors, chosen family, faith-community members, young (or youth) caregivers, or distance caregivers.

b. Use caregiver terminology that reflects the audience and context. Terms may resonate differently across communities, cultures, and disease areas.

Ways to Refer to Caregivers

There's no single term that fits every audience or situation—use this table as a starting point to help you choose the language that best reflects your intended audience's relationships, preferences, and context.

Term	Description
Caregiver	*The most widely recognized term for someone who provides regular support to a person managing a health condition.*
Care Partner	*A collaborative alternative to "caregiver," framing the relationship as a team working alongside the patient rather than a one-way role.*
Carer	*The term commonly used outside the U.S., particularly in the UK, to mean the same thing as "caregiver."*
Care Team	*A broader term that groups caregivers, care partners, and healthcare providers together as the people supporting a patient's care.*
Direct Care Worker (home health aide, personal care aide, CNA)	*Paid professional staff who provide hands-on daily care, distinct from unpaid caregivers and care partners.*
Family/Relationship-Based Terms (spouse, partner, child, sibling, parent, friend)	*Names the specific relationship to the patient rather than the caregiving role itself.*
Loved One	*Refers to the person receiving care, often used alongside caregiver or care partner language.*
Support Person	*A flexible, informal term for anyone who provides support, without specifying a particular role or relationship.*

c. Avoid assuming every caregiver has the same role, responsibilities, decision-making authority, available support, or capacity to provide care.

> ***For example,*** *a spouse who helps make healthcare decisions may have a very different role from a friend who provides transportation or a family member who manages medications from a distance.*

d. Recognize that caregivers may also be caring for other people or managing responsibilities outside this particular care experience.

7 Encourage caregivers to care for themselves while respecting their circumstances.

a. Acknowledge that a caregiver's own health and wellbeing affect their ability to care for someone else.

b. Normalize taking breaks, accepting help, and using available support services.

c. Offer realistic, flexible suggestions rather than creating additional expectations or obligations.

> ***For example,*** *instead of "Make sure you take time for yourself every day," say, "When you're able to, even a few minutes to step outside, stretch, or connect with someone you trust can help you recharge."*

d. Adapt wellbeing guidance to the caregiver's circumstances, including their available time, support, health literacy, and access to care.

WHY? *Self-care guidance should reduce burden—not become another responsibility caregivers feel they are failing to meet.*

Universal Patient Language

At Bristol Myers Squibb (BMS), we believe language should never be a barrier to care. Universal Patient Language (UPL) transforms how BMS communicates with the world—turning complex content into understandable messages that improve access, trust, and outcomes.

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