UPL Rules

The Universal Patient Language (UPL) has seven high-level foundational Principles that guide the way we communicate with patients. The UPL Rules provide detailed guidance about how each of the UPL Principles might be applied in practice to create more patient-friendly communications.

To assess how well the UPL Rules have been incorporated into a patient communication, see the *UPL Reflection Guide.*

Resource contents:

☑ Guidance, standards, and best practices

◯ Building blocks or assets

◯ Assessment methods and tools

Applicable to:

☑ All patient communications

◯ Specific topics

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

Table of Contents

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. **See each Principle for its associated rules.**

There are four principles that are most applicable when planning:

The remaining three principles are most applicable when building:

We would love to know how you have used the UPL Rules.

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!

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.

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

   a. Define or translate common medical terminology and jargon in patient-friendly terms — easy to understand, but not oversimplified.

   b. Provide the background that patients need to understand their overall medical situation.

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

   a. Make sure the purpose is something that is relevant to patients, addressing one or more of their specific goals or objectives.

   b. Be transparent about the vested interest in any patient communication.

3. **Provide patients with the information they need while respecting the role of their medical team as a key source for medical knowledge, interpretation, and advice.**

   a. Encourage patients to validate information with other sources, especially their doctor.

   b. Provide clear, direct answers to patient questions.

4. **Keep your content relevant to the patient journey.**

   a. Adults are primarily motivated to learn things that are relevant to them and their experience, so keep your communication focused on topics that are useful and practical for patients.

   b. Be explicit about how your communication will help patients achieve goals related to their healthcare journey.

   c. Use authentic and relatable patient stories to help patients understand important concepts. Include both the positive and negative sides to a story.

5. **Help patients understand and carry out their role in shaping their care and making treatment decisions.**

   a. Acknowledge that patients know their body the best, and that sharing how they/their bodies are feeling is crucial information that can affect their care.

      e.g., "Tell your doctor about how you're feeling, so that they can help you if you start to feel worse, and they can record when something is working. You know your body best."

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

6. **Use logos sparingly.**

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

   a. When including multiple contacts, delineate who(m) to contact for what.

   b. Include references and links to helpful resources from trusted, reputable sources third-parties sources.

      Why? Patients retain information longer when they are active recipients of that information.

      e.g., The physician-authored web resource, UpToDate, provides physicians with pseudo prescriptions for medical information. Using these, physicians can equip patients with key search terms or phrases and direct them to the UpToDate website to proceed with conducting research and asking questions at their own pace. **http://www.uptodate.com/patient**

8. **Present complex information in digestible chunks to help patients build up their knowledge incrementally.**

   a. Start by presenting the basics of the topic. Build the knowledge in subsequent sections, allowing patients to delve into the information at their own pace.

   b. Provide patients the opportunity to dive deeper into a specific topic by including "learn more" buttons or references.

Share Qualified, Quantified Data

We believe that when we appropriately share qualified, quantified data, patients will be more informed and confident in engaging with their healthcare provider throughout their treatment journey.

Your Treatment Journey
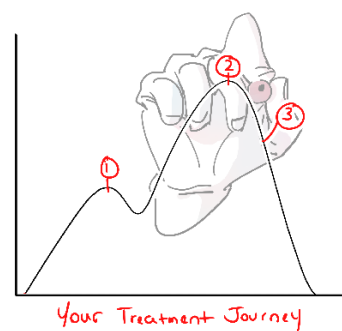
9. **Provide appropriate context and comparisons along with the data to make it meaningful and useful for patients.**

   a. Provide an explanation of why the data (and its visualization) might matter to patients.

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

   c. Provide "healthy" or "normal" ranges for numbers, for easy comparison.

   d. Compare actuals against means, medians, or baselines.

   e. When providing percentages, also provide the raw numbers that were used to calculate the percentage.

      e.g., 50% of patients (124/248) experienced side effect X.

   f. Present data in a way that makes it easy for patients to make head-to-head comparisons.

10. **If quantifiable data is available, it should always be made available to patients with appropriate context.**

    a. When presenting potential side effects, qualify how likely each is.

    b. Try to quantify the benefits and risks of any treatment, using both traditional clinical trial results (or endpoints) and patient-reported outcomes.

    c. Make the details of the data available in a format that is easy for patients to understand.

11. Represent numbers visually.

    a. Use graphs and charts to show data sets. Choose a representation that is appropriate for the data and message you are communicating.

    b. Avoid 3D charts. The perspective distorts how data is read. Things displayed in front are perceived as larger and more important than what is shown in the background.

    c. When displaying similar types of data, use a consistent visualization method to allow for easy comparison.

    For more guidance on visualizing data, see the *UPL Style Guide.*

12. Adhere closely to data visualization best practices and avoid common mistakes.

    a. Visualize data correctly: use full, proportional axes for data so that differences between values are presented consistently.

    b. Use consistent scales, especially when showing multiple graphs.

    c. Highlight what's important.

    d. Use comparable data sets.

    For more common visualization mistakes: **https://infoactive.co/data-design/ch18.html**

13. Define statistical terms like mean, median, incidence, and prevalence.

Design for Digital First

We believe that when we design for digital first, we learn more about patients, and are able to create higher-value communications that better meet their evolving needs.

14. **Think beyond still images and written text: incorporate video, sound, interactivity, location awareness, and other multimedia formats to support multiple learning modalities and engage patients whenever possible.**

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

        Here is an example we like from the world of astronomy: **http://bit.ly/1wV7hiF**

    b. Remember that not everyone will access digital content from the same platform. Patients should still understand key messages if they are accessing from a mobile device or a very old computer with reduced functionality.

15. **Incorporate functions that allow the user to consume, explore, and expand information at their own pace.**

    a. Use dynamic, clickable images and links to break complex information into discrete parts. This allows users to selectively expand and collapse layers and levels of information.

    b. Provide links to complete source data.

16. **Help users to sort and find information that is most relevant to them and their situation.**

    a. Build in functions that will allow users to save, forward, and share information.

    b. Create shareable content that will allow patients to participate in and re-appropriate information and stories if they choose to do so.

17. **Link to existing resources whenever possible, rather than re-creating new content, as this helps to build trust and reduces unnecessary duplication.**

18. **Don't just build a website. Think holistically about patient experiences online and offline.**

    a. Consider the context in which patients are likely to access the materials, and how patients might use the information beyond the website.

       e.g., A patient might share something from a website on Facebook or print it for use in a discussion with their healthcare team.

    b. Don't make assumptions about the way patients will reach a given webpage, or the order in which they will access content.

       e.g., Consider the various channels and touchpoints by which a patient could access a website: mobile or desktop, email link, web search, or social media. Prioritize a channel but not to the exclusion of others.

19. **Be compliant with web standards and web accessibility standards so that the resource will be available to users with a range of hardware, software, and disabilities.**

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

20. **Plan, design, and develop your communications as prototypes, to be iterated upon and improved after observing how people use them.**

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

    b. Start with 'minimum viable products' and iterate based on real-world experience.

21. **Continue to produce print materials but in a digital context.**

    a. In print materials, prominently direct patients to useful web resources whenever it's relevant to do so.

    b. Provide downloadable, printable versions of all printed communications on the web so that everyone can access them.

    c. Keep information and content consistent across all media.

    d. Designing for Digital First doesn't reduce the need for printed materials. Print is as important as ever, but digital can help overcome some of the limitations of print, e.g., expensive to produce and ship; slow to update.

Demonstrate Empathy for Patients and Caregivers

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

22. Repurpose with care.

a. Carefully consider how content should be adapted or changed for your current audience and/or communication objective.

Why? Carelessly repurposed content is not tailored to the audience or purpose of the communication — it comes across as thoughtless and disingenuous.

23. Remember that words, concepts, and colors can be interpreted differently depending on the socio-cultural background of patients.

a. Be mindful of inadvertently using words or phrases that might be off-putting or offensive to different cultural groups.

e.g., Avoid using sets of four when designing for those with Chinese or Japanese cultural backgrounds as this can be associated with death to them.

b. Patients from different cultural backgrounds may have different expectations around who is involved in medical decision-making. Be sensitive to the possibility of differences and don't make assumptions.

c. Be mindful of how a color's meaning may vary between different cultural groups.

e.g., In some Eastern cultures, red might represent good luck and prosperity, while in the West it can sometimes symbolize polarizing concepts of competition, vigor, and excitement, or aggression, warning, and danger.

24. 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.

e.g., A man undergoing treatment for prostate cancer may associate 'digital' with 'digital rectal exams' rather than an online resource.

b. Be mindful of the reader's state of mind and adjust your tone accordingly.

e.g., Are they recently diagnosed and potentially feeling overwhelmed? Are they hopeful about a potential new treatment? Are they on the path to recovery?

c. Consider including an empathic statement in the beginning of the communication acknowledging any challenges patients may have experienced (emotional, mental, or physical).

   e.g., "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.

25. **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.

26. **Be mindful of the emotional impact different colors can have.**

   a. As a general rule, cool colors such as blue and green are interpreted as tranquil, passive, and contemplative whereas warm shades such as red, orange, and yellow are considered to be active, passionate, and engaging.

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

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

27. **Use shapes appropriately to support the message you are trying to communicate.**

   e.g., Amorphous, soft, rounded shapes and lines are interpreted as "friendly" and "human."

   e.g., Acute angles and geometric shapes communicate "precision" and "order."

28. **Be mindful of how the human form, gender, ethnicity and race, and appearance are assigned and represented visually.**

   a. Acknowledge age, gender, and ethnic diversity in the representation of patients, caregivers, physicians, and other healthcare providers.

   b. Be sensitive to representations of the "average" family structure, body physique, patient profile, and other characterizations.

   c. Include identifiable details and characteristics when it is necessary to support the message. Abstract the human figure where gender and ethnicity are not meaningful or significant.

Use Plain Language

We believe that when we use plain language, patients feel less overwhelmed and less intimidated and are able to better understand our communications.
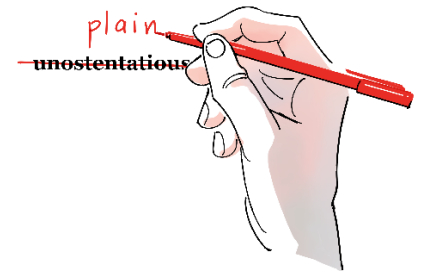
29. **Strive for an approachable, conversational, down-to-earth tone, rather than formal or clinical.**

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

   b. When addressing patients directly, use second person ('you').

   c. When emulating the patient voice, use first person singular ('I').

   d. Words and phrases shouldn't be slangy, but colloquialisms and contractions are allowed and even encouraged.

30. **Use the simplest words possible to convey your message.**

   a. In general, the fewer syllables in a word, the easier it will be for patients to understand.

   b. It will often be better to use multiple short words rather than a single long word to convey your message. But this is a matter of judgment — you wouldn't write 'a plant you can eat' just to avoid using the word 'vegetable.'

   c. Be especially watchful for terms that are very common within the healthcare industry, but rarely used by patients. If using a term throughout a communication, be sure to define it first.

   e.g., Words like 'pulmonary' can still be used, but also include its definition 'relating to the lungs.'

31. **Avoid using acronyms without introducing them properly.**

   a. You should only use an acronym if the patient is very likely to encounter it elsewhere.

   b. If you must use 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. There are some acronyms that are used so commonly that they do not need to be spelled out. e.g., AIDS does not need to be written out as Acquired Immune Deficiency Syndrome.

32. Write short sentences with simple syntax.

    a. It is better to have two short sentences than one longer sentence.

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

        e.g., "Your doctor will make the phone call" (active) rather than "The phone call will be made by your doctor" (passive).

    c. Generally, limit sentences to two clauses.

    d. Do not nest ideas or clauses within sentences.

33. Technical, medical terms should be used 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. Provide links or references to more detailed, complex explanations.

    c. Simple metaphors are a useful way of explaining medical terms, and are encouraged.

        e.g., "Tachycardia is like a lake with too many ripples."

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

    e. If a medical term is mainly used for communications between healthcare providers, avoid using it in patient communications.

    f. Respect the reader's intelligence — beware of condescension.

34. Avoid colloquialisms where the literal meaning could be confusing; e.g., "pushing liquids."

    Why? Those for whom English is a second language may not be familiar with the colloquialism and may try to understand it literally.

Communicate Visually

We believe that 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.
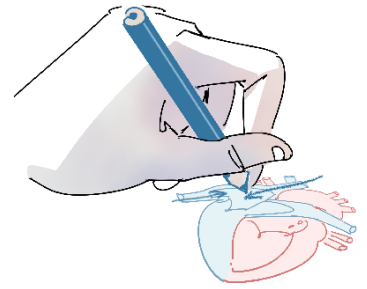
35. **Repeat important, complex concepts in both words and pictures.**

    a. A label or words should always accompany icons.

    > **Why?** Using icons alone is not sufficient; while icons can help people navigate a communication, they are not effective for explaining complex ideas.

    b. Photographs and decorative graphics can be used to create an emotional connection with patients, but they are often not effective when communicating complexity or serving a specific purpose such as helping the patient understand something, helping them organize their thinking, helping them interpret the text, or highlighting important information.

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

36. **Use images when explaining things that cannot be seen, such as how things work in the body.**

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

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

    > **Do** In this communication we used a garden analogy to explain how various cancer treatments differed from each other. From patient validation, we heard that it would help explain these concepts to family and friends.

If the body is like a garden, the patient and care team will decide on how to remove the weeds (cancer cells) while doing the least damage to the good plants (healthy cells).

good cells

cancer cells

Chemotherapy is like spraying a general weed killer on the whole garden. This approach may not kill all the weeds and may also harm some good plants.

chemotherapy

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

Do A simpler visual style can enhance the communication by providing visual aids that keep the focus on processing the complex scientific or medical information.
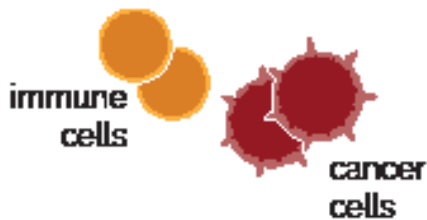
Don't A piece of communication can become overwhelming very quickly when complex scientific and medical information is accompanied by hyper-realistic visuals.
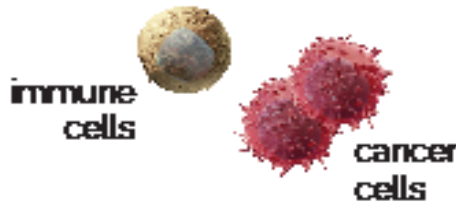
c. In general, do not re-use the same visuals from communications aimed at doctors, since they will usually be more difficult for patients to understand. (However, visuals from doctor communications will often be appropriate as a resource for patients who want to seek out more detailed, complex information.)

37. **Use a balance of consistent and novel visual elements to help the patient understand the visual communications.**

a. Repeat shapes, elements, and color throughout a communication and, where appropriate, across multiple communications and channels, to establish a standard and familiar visual language.

b. Use scale, line weights, and color (complementary, contrasting, and similar) to connect related elements, highlight important visual elements, or de-emphasize unimportant details.

There are many great examples of this rule in action here: Perception in Visualization **http://bit.ly/1KGd3xU**.

38. **Use standard, recognizable shapes whenever possible.**

a. Include visual conventions and internationally-recognized symbols to convey meaning.

e.g., 🛑 *red octagon = "stop"*

⚠️ *triangle with exclamation mark = "warning"*

39. **Use color with care to accommodate color-blindness, and to ensure color is supporting understanding rather than detracting from it.**

a. Limit the number of colors to five, if possible (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.

b. Do use color to highlight and emphasize.

e.g., Consider using a monochrome color palette with one or two complementary colors to accent and emphasize important visual elements.
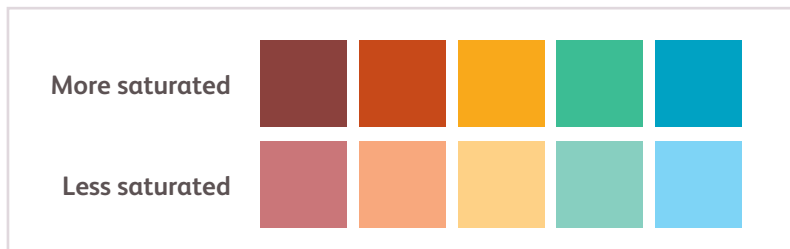
c. Exercise caution when combining saturated colors, as they can visually interfere with one another.

d. Make sure colors are not the only method for conveying important information. Vary the shapes, textures, and shades.

e.g., Road signage uses shape and color to convey meaning with redundancy to compensate for variations in eyesight, lighting, and incident of encounter (front and back): **http://bit.ly/1FQUiI4**

e. Be aware of emotional or cultural references, and use color appropriately (see Demonstrate Empathy rules).

Reference: Walker, Morton. The Power of Color. B. Jain Publishers, 1999.

Format Materials for Understanding

We believe that when we format for understanding, patients spend more time reading our communications, retain more of the information we provide, and derive greater value from our materials.

40. **Maintain a coherent story across each screen or page of a communication piece.**

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

   > **Why?** Too much repetition can relegate an image or phrase to a mere fixture — the opposite effect to emphasis.

   b. When including important information throughout a patient communication, (e.g., reminders, calls to action, important safety information) strive for integration with the overall story you are telling.

   c. Be careful when reusing content in a new context, and be sure to adapt it so that the story still flows and supports the overall purpose of your communication.

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

   Why?

   - Readers will usually begin reading a page in the top left corner, moving from left to right, from top to bottom.
   - Larger elements (visuals, headlines) will command more attention and be the first landing point for the viewer's eye.
   - People's attention will immediately be drawn to images representing the human face, so place human images adjacent to the most important element(s) on the page.

   a. Use titles to categorize information in a way that directly addresses patient needs.

   b. Use sub-headings and captions to support or elaborate on information conveyed through headlines.

   c. Use consistent formatting for each level of hierarchy (i.e., establish styles for treating each level consistently).

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

e. Consider numbering sections to make order for reading very clear.

42. **Format text to optimize the intake of information.**

a. Use a grid to align text and graphic elements, in order to minimize page clutter and distraction.

b. Use high contrast, large, and heavy type to accommodate readers with weaker eyesight.

c. 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.

43. **Group objects by applying the Gestalt Principles of visual perception.**

a. Proximity: Objects that are close together or connected are perceived as a group.

b. Closure: The eye will naturally fill in gaps in shapes to perceive a whole despite the missing information.

c. Continuation: Grouping and layout can be used to compel the eye to move through one object and continue to another.

d. Similarity: Objects that look similar are perceived as a group or pattern.

Find much more detail on Gestalt Principles here: **http://bit.ly/1hBygLn**

44. **Use white space generously and deliberately. White space refers to the following: space around graphics, margins, paddings, and gutters; line-spacing and letter-spacing within text; and space between columns.**

a. Use white space to create focus around important text or images and guide the reader around the page.

Why? A page full of text and images with limited white space is visually and cognitively overwhelming.

b. Provide ample white space around text to improve readability and scannability.

For more on white space, see this article: **http://bit.ly/1y80CYg**

45. **The layout of the document should support how patients would use the provided information.**

    a. Information that is provided for reference should include elements like tabs to help patients quickly navigate to the right section.

    b. Information that is intended to guide patient actions should be formatted like a checklist.

    c. Space for note-taking should be integrated with the content on which patients might like to take notes, rather than relegated to separate note pages or sections.

    d. If the document is intended for a binder, leave a margin big enough for hole punching along one edge (at least 1").

Patient Experience

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

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