Building a Language

The core of the UPL Version 1.0 was built in just three short weeks in July and August 2014. By September, we were validating the UPL with a broad cross-section of stakeholders, while simultaneously applying it to create new patient communications. Over the course of building the UPL, it evolved from an ambiguous idea into a robust capability that could support the development of new patient communications. Through systems thinking, co-creation, and iterative prototyping, three key components of the UPL emerged: Principles, Tools, and Stewardship. Through numerous rounds of validation and feedback, we refined our UPL prototype to get to the very first "release" of UPL.

The comprehensiveness, maturity, and broad applicability of this first version are the direct result of the co-creation and validation sessions — and the immense energy, insight, and enthusiasm contributed by the participants.

Process Overview

The process of building the UPL was iterative, and based on systems thinking, co-creation, and prototyping. Perhaps most importantly, we integrated the building of the UPL itself and used it to build patient communications.

Systems Thinking

In building the UPL, we didn't focus on one particular disease, or a specific kind of patient communication. Throughout the whole process, we considered the patient experience holistically, and looked beyond typical communications in the pharmaceutical industry.

Co-creation

We invited external collaborators and internal Bristol Myers Squibb stakeholders to two different co-creation sessions. The first session focused on activities to define the initial architecture of the UPL, while the second session emphasized building out the UPL in more detail.

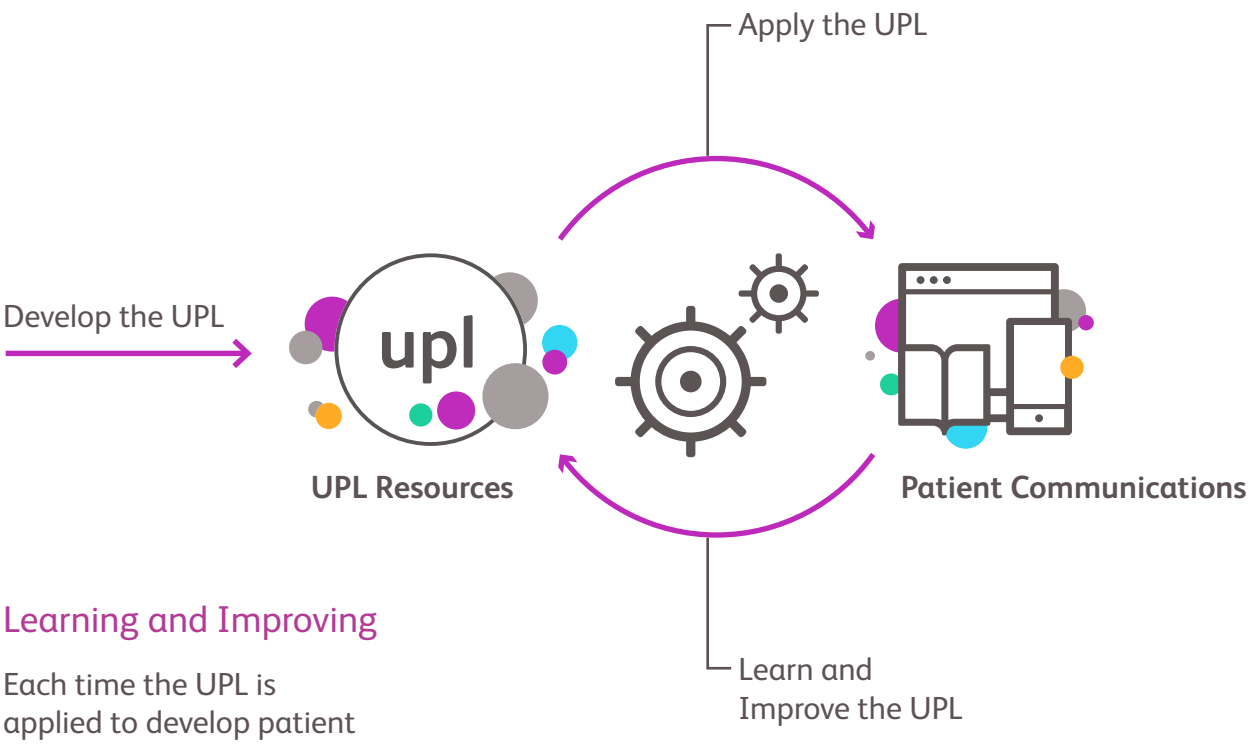
Prototyping

We iterated prototypes of the UPL by sorting and synthesizing the co-creation session outputs. The main components of the UPL began to emerge: Principles, Tools, and Stewardship. Validation sessions with Bristol Myers Squibb stakeholders, patient advocacy groups, and our external collaborators were also a key part of the prototyping process.

The Universal Patient Language

While the UPL was still evolving, we started to use it to build patient communications. Applying the UPL to concrete communications was integral to making it a concrete, practical resource.

Whenever we use the UPL at Bristol Myers Squibb, we follow a similar process. We think broadly about the whole healthcare system, and where and how the communication might be used. We conduct co-creation sessions to understand the needs of patients and other stakeholders. After co-creation, we iterate the resulting communication prototypes, and then further validate and refine them with patients. What we learn from building these patient communications gets fed back into the UPL itself. This additional layer of prototyping and iteration is invaluable, because it helps keep the UPL grounded in real needs — the needs of patients, and of anyone who might use the UPL on an ongoing basis.



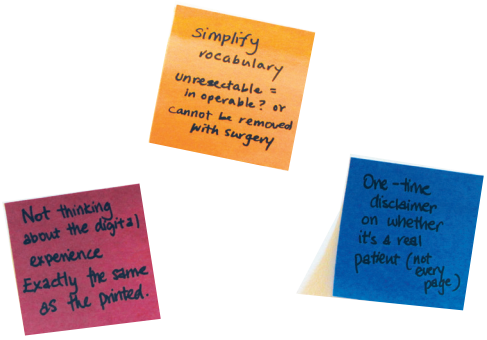
Learning and Improving

Each time the UPL is applied to develop patient communications, the insights and outcomes are fed back into improving the UPL.

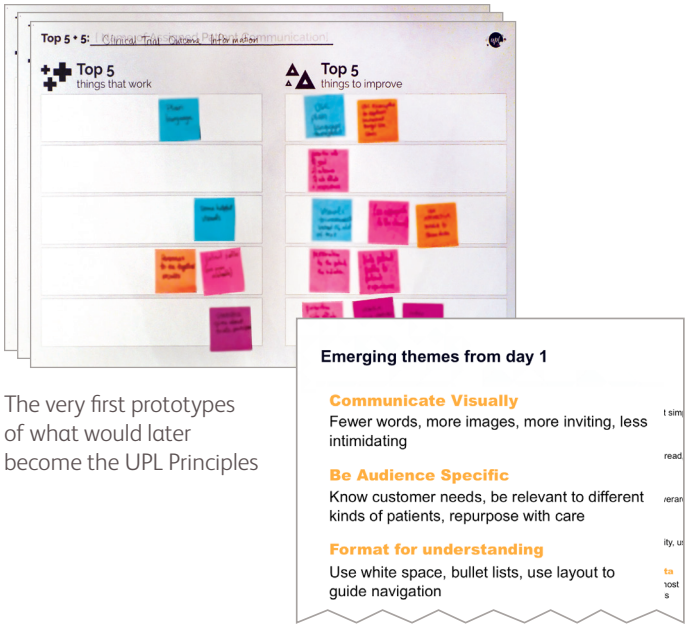
Co-Creation Session 1: **UPL Definition**

Our first co-creation session brought together expert collaborators and Bristol Myers Squibb stakeholders for the very first time. It was an action-packed session — twenty-five participants collaborating for eight hours over two days.

We started from the current state of patient communications produced by BMS. In small breakout groups, we asked teams to dissect different kinds of communications from every angle. What is working well? What can be improved? In all, we looked at dozens of different patient communications pieces, spanning disease state information, clinical trials outcomes, important safety information, promotional marketing, and clinical trial recruitment. After an hour and countless post-it notes, we started to prioritize our top five "things that work" and "things to improve." This was the very first prototype of what would later become the UPL Principles.



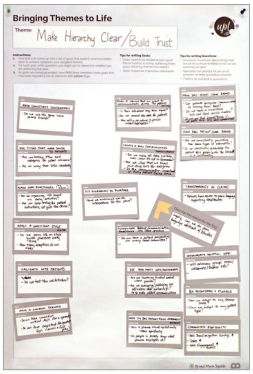
Our first refinement of that prototype would happen almost immediately. We synthesized the top-five lists from each group, to create a list of ten common themes from all teams. Some of these themes, like "Use plain language," still appear in the UPL Principles, many iterations later. Others, like "Make hierarchy clear," have shifted and evolved as we have tested and validated them.

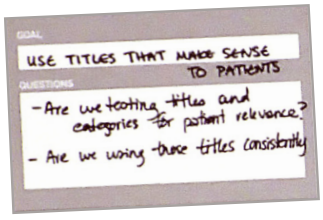


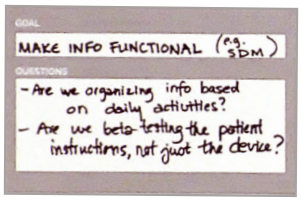
The very first prototypes of what would later become the UPL Principles

Examples of patient communications at BMS

On the second day, each team was assigned two themes to 'bring to life.' The starting point for the themes was very high-level: just a dozen words or so, capturing the key ideas from day one. Through the second day, we worked out the details. We alternated between defining broader goals we might accomplish with each theme, and prototyping communications that demonstrated the themes.







We left the session with piles of templates, sticky notes, and sketches. The first pieces of our UPL prototype were complete, and the next step was to iterate it.

Defining broader goals we might accomplish with each theme (left), and prototyping communications that demonstrate the themes (above)

Prototype Iteration: **UPL Architecture**

After the co-creation session, we went back to all of the prototypes we created during the workshop, and started to dig into the details. We sorted, synthesized, and simplified, so that the rich details contained in all those sticky notes and sketches could come together into a comprehensive form.

One piece of our prototype was obvious — the themes we had defined during the session. They would be refined over the weeks ahead, but clearly these foundational Principles would be a critical component of the UPL. But other key ideas also emerged from the session output. The Principles were important, but they weren't especially concrete. It was easy to agree with them, but unclear how to put them into action.

The UPL would need another dimension — something more detailed and more tangible, which people could use to help them design better patient communications that really embodied the Principles. Equally, our co-creation session made it clear that we would have to support the UPL with systems and processes to grow and sustain the resource.

Thus, the architecture of the UPL began to take shape. Our UPL would have three main components: Principles to guide communications, Tools to make the Principles actionable, and Stewardship to help the UPL grow and thrive.

Principles

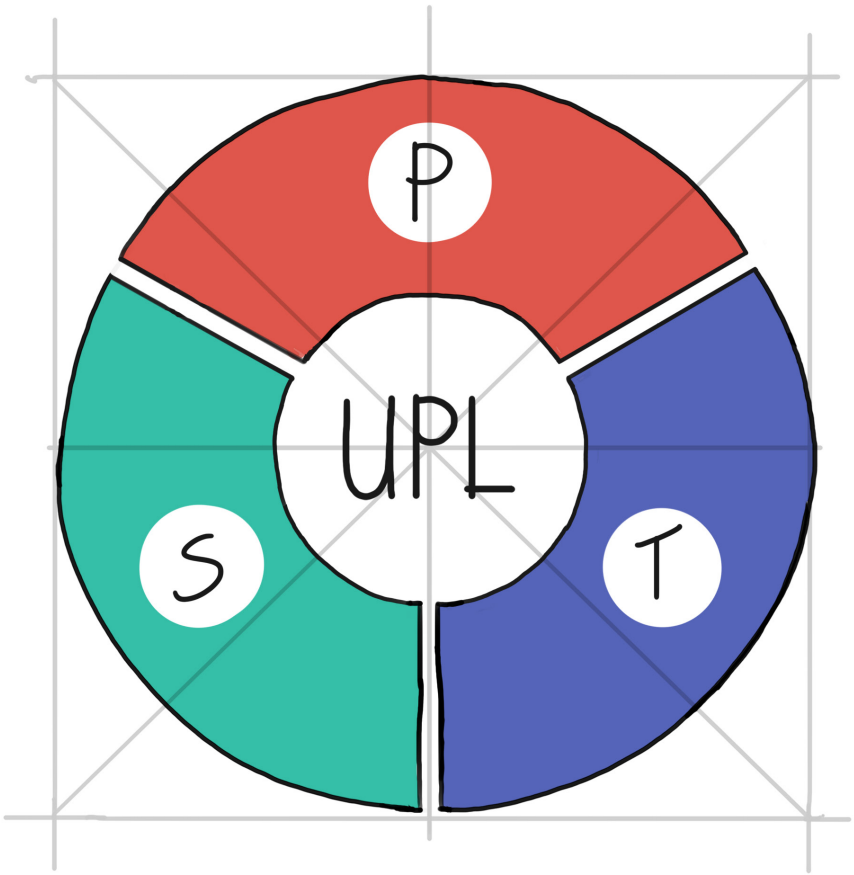
Statements of purpose, describing the UPL's intent and breadth. These were based on the themes we prototyped in co-creation.

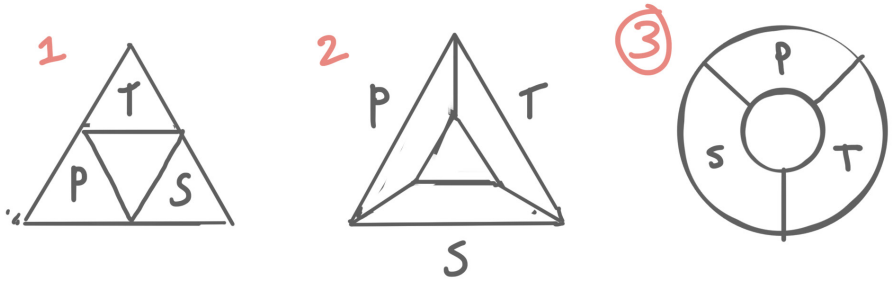
Tools

Resources helpful to those producing patient materials, so their communications can truly embody the Principles.

Stewardship

Processes and systems that facilitate the adoption and evolution of UPL.





The UPL Model in its early form

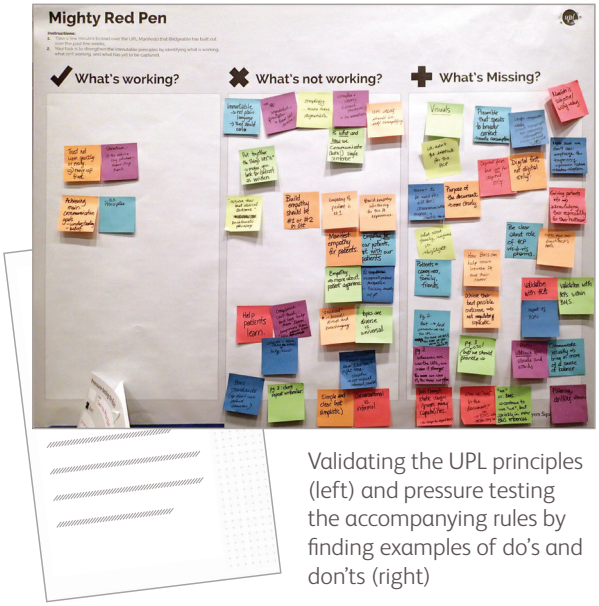
Co-Creation Session 2: **UPL Build Out**

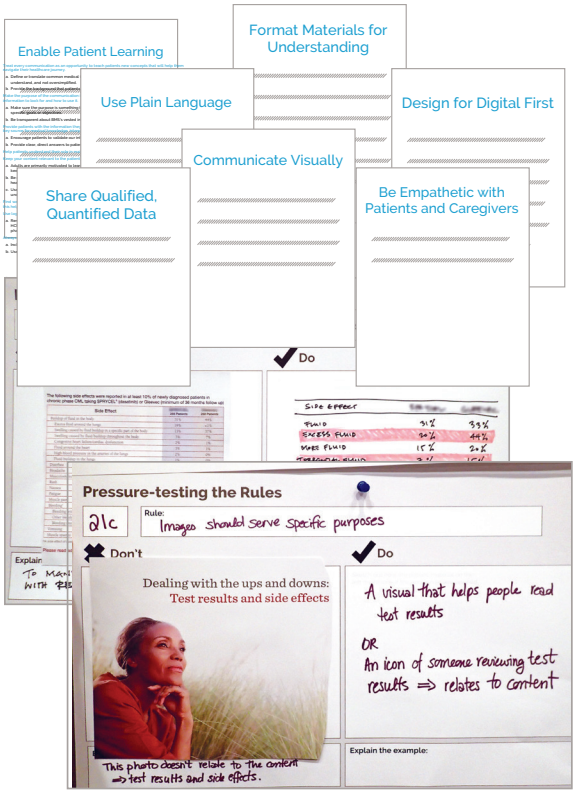
With a preliminary UPL architecture in hand, we assembled the group for a second co-creation session. The first part of the session focused on validating the prototype we had refined after the first session, with particular emphasis on the UPL Principles.

At this point, our ten themes had become seven principles, each with a paragraph of text. Our co-creation attendees spent an hour refining the Principles — identifying things that weren't working, and adding things that were missing. The balance of the co-creation session focused on co-creating UPL Tools. In advance of the session, we had prototyped one tool: a set of UPL Rules to support the Principles.

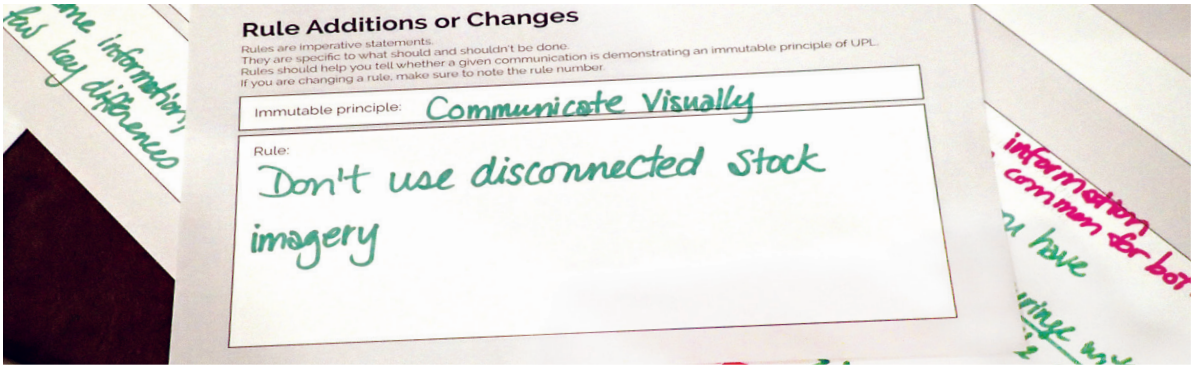
Our co-creators worked with us to define new rules and create examples of "dos" and "don'ts" to clearly illustrate what the rules meant.

On day two, our co-creators started to build their own tools from scratch. Groups acted out how people might use the Tools once they were created, and started making rough prototypes for the Tools themselves: tools for communicating data, tools for communicating visually, and tools for communicating in plain language.



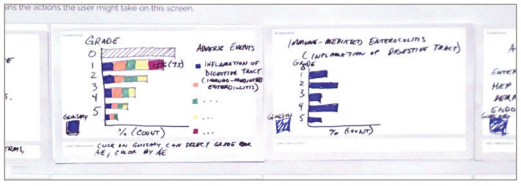


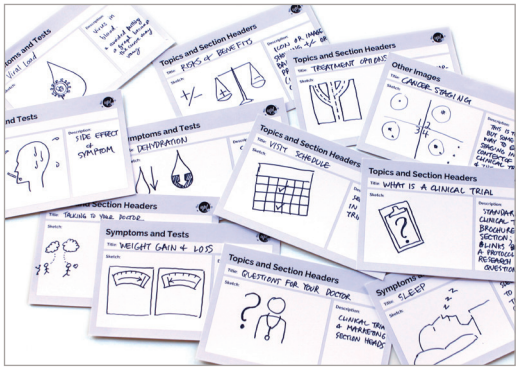
Validating the UPL principles (left) and pressure testing the accompanying rules by finding examples of do's and don'ts (right)



Pressure-testing the UPL Rules

One of the most important ideas to emerge out of this co-creation session was the notion that the UPL is "always ready, never finished." Patient communications are almost limitless in their potential scope. If we waited until we had something that was comprehensive enough to handle every possible patient communication, the UPL might never be put to use. Thus, we decided that after this co-creation session, the UPL would always be ready to be used in creating a new patient communication. However, the UPL might never be finished, in the sense that it would continue to grow and evolve as it was applied over time.





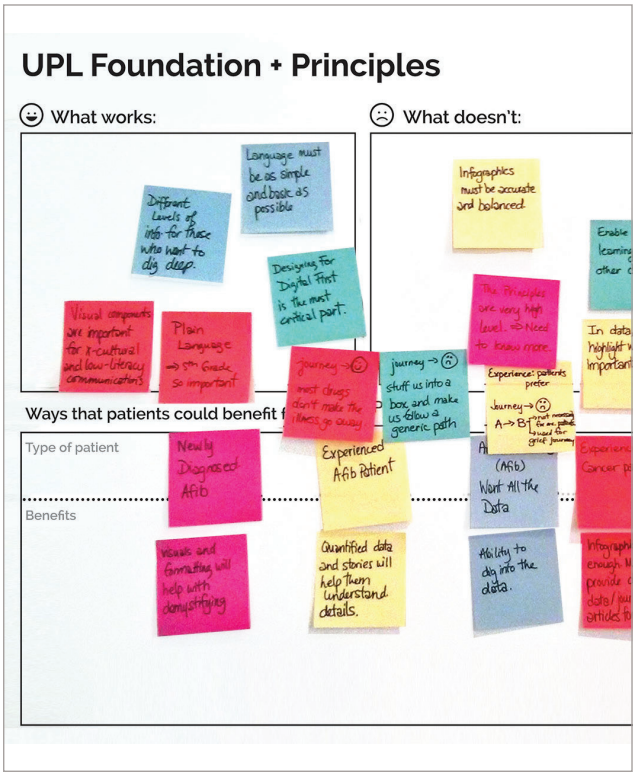
Prototype Validation with Stakeholders

After further developing, refining, and polishing the prototypes that came out of co-creation, we launched a series of validation sessions to get feedback on our prototypes.

Our first stop was a select group of internal stakeholders at Bristol Myers Squibb. With this group, we validated the UPL, focusing primarily on Stewardship within BMS. Through co-creation activities, we began to answer key questions:

- How do we maintain a high standard of consistency in the use of the UPL?
- How do we make using the UPL a norm at BMS?
- Are there existing processes or checkpoints that we could build on?
- How do we give people the opportunity to validate and get feedback on their use of the UPL?
- How do we measure the benefit of the UPL?
- Which scenarios, tasks, and common workflows at BMS are most relevant to UPL?
- How do we make it easy and interesting for people to learn how to use the UPL, and incorporate it into their day-to-day work?

Of course, many of these questions apply equally to UPL users outside of Bristol Myers Squibb, and our Stewardship work includes both internal and external stakeholders.



Next, we engaged with patient advocacy organizations. We invited them to join us and asked for their feedback on our Principles and Tools, with particular emphasis on the UPL Rules. Drawing on their experiences, the advocacy representatives were able to give us plenty of constructive feedback that helped us refine the UPL even further.

"I'm disappointed that I can't take these rules home!"

"I learned from seeing your stuff what we can do better as an organization."

"I think there will be a lot of trust built when patients see these materials."

– Patient Advocacy Groups

"The UPL has very solid foundations."

"This is definitely a glimpse into the future of healthcare."

"It is really great to see BMS supporting this kind of work — really focusing on the patient experience in a very tangible way."

– Expert Collaborators

The advocacy organization representatives were very enthusiastic about the UPL. They were impressed by the scope and ambition of the initiative, but, more importantly, they expressed their belief that the UPL will improve the patient experience while also reducing patient risk. Their enthusiasm and support was heartening — a valuable confirmation that the UPL's benefit is also clear outside of Bristol Myers Squibb.

Finally, we circled back with our original expert collaborators to get their feedback on how the prototypes had evolved since they last saw them. Our emphasis was on the various UPL Tools, since these had changed the most since our summertime co-creation sessions. However, our collaborators were also able to get a sneak peek at the first applications of UPL, which really made the whole UPL prototype come to life.

Future of UPL

Since the UPL is "always ready, never finished," the process of building the language is ongoing: adding new Tools, defining key Stewardship processes, and using the UPL in new ways.

Over time, in applying UPL more and more, we hope to enable a real transformation in patient communications — not only at Bristol Myers Squibb, but in the healthcare system overall.

This goal is a lofty one. In many ways, defining our seven UPL Principles was the easy part. The real challenge lies in making the UPL easy to use, and a resource that provides real value to anyone who communicates with patients.

Bristol Myers Squibb can't achieve our UPL goals alone. Our collaborative approach — grounded in co-creation, prototyping, and systems thinking — was essential to the initial development of the UPL, and will continue to be essential as the UPL evolves. Collaborating with others gives us a different perspective, and helps us have a more meaningful impact on patient experience. Moreover, we have found the collaborative process to be both effective and rewarding. Our collaborators have given us fresh insight and ideas which have fueled great excitement at Bristol Myers Squibb around the potential of this initiative.

We are looking forward to channeling that excitement into new initiatives as we put the UPL into practice, and as the UPL continues to grow and evolve.

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