OPTN
Modernization

Final Mapping Report

Contract Number: 75R60224D00042/75R60224F34001
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Deliverable Number/Product Name: Deliverable 3 / Final Mapping Report
Due Date: 06/18/2025
Date of Submission: 06/18/2025

Note

The Health Resources and Services Administration (HRSA) contracted Deloitte Consulting LLP (Deloitte) to conduct a review and mapping of current state communication services for the Organ Procurement and Transplantation Network (OPTN). This report provides a snapshot of the current state as of March 28, 2025.

Deloitte received some OPTN contract documentation (i.e., OPTN Communications Plan, OPTN Website Plan, OPTN Branding Plan), but was not provided with other contractor internal documentation (e.g., incumbent communications processes) or direct access to incumbent personnel. Additionally, many communication processes were informal and did not have established standard operating procedures (SOPs), which resulted in Deloitte not being able to map certain processes.

Table of Contents

Executive Summary

This Final Mapping Report[1] provides a study of the current state of Organ Procurement and Transplantation Network (OPTN) communication services. It is based on the information gathered from interviews with 29 OPTN stakeholders,[2] meetings with the Health Resources and Services Administration (HRSA) Health Systems Bureau (HSB) and Office of Communications (OC) leaders,[3] OPTN communication plan documents,[4] and other sources outlined in the Methodology section. This report distills the information and provides current state process maps where requisite information was available.

This report includes process maps for:
- Responding to media inquiries received by:
  - HRSA OC
  - The OPTN communication vendor
- Developing website content
- Creating communication plans
- Reviewing publications and materials for conferences

Additionally, this report provides key OPTN communication findings from the analysis of current state processes and engagement:

Figure 1: Final Mapping Report Key Findings

1	Lack of Clear Processes	2	Limited Audience Segmentation
3	Minimal Tailored Communications	4	OPTN Brand Confusion
5	Inconsistent Messaging Across OPTN	6	Limited and Reactive Information

This report serves as the foundational work for the Final Re-Engineering Report, which builds on these findings and provides HRSA with initiatives for consideration to transform OPTN communication processes and practices.

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[1] Appendix P includes a PowerPoint version of this report.
[2] Appendices G-K include summary notes from OPTN Stakeholder interviews.
[3] Appendix L includes summary notes from meetings with HRSA.
[4] Appendices A-C include OPTN communications plan documents.

Methodology

The Final Mapping Plan guided the information gathering, analyses, and documentation for the Final Mapping Report. The Final Mapping Plan details three phases of discovery to gather information necessary to map various OPTN communication processes. The phases and activities completed under each phase are listed in Figure 2.

Figure 2: Mapping Plan Phases and Activities

① Discover and Capture	**② Analyze**	**③ Document**
Deskside research and stakeholder identification	*Stakeholder engagement and deliverable analysis*	*Process mapping and gap identification*
• Researched available communication materials and requested all additional relevant materials • Determined and validated key audiences • Identified points of contact to engage • Conducted interviews with key stakeholders • Mapped communication channels and touchpoints	• Captured and analyzed available materials • Held interviews and review sessions • Reviewed existing communication channels and materials • Identified metrics and trends	• Summarized insights • Developed process maps • Validated process maps with key stakeholders • Identified and tracked key insights, pain points, and potential areas for improvement

Discover and Capture

External Resources

The report analyzes the following public-facing OPTN materials:

- OPTN websites developed for patients and professionals[5]
- Samples of newsletters published by HRSA and the OPTN contractor regarding OPTN processes and policies
- Samples of e-mail blasts ("e-blasts") between OPTN stakeholders
- OPTN-related social media channels, specifically channels owned by Health and Human Services (HHS), HRSA, the United Network for Organ Sharing (UNOS), and the Scientific Registry of Transplant Recipients (SRTR)[6]

The analyses include a review of key messaging, reading level and accessibility of web elements, products, publishing cadence, and perceived audiences for each channel.

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[5] Appendix E includes a summary of OPTN website readability test results.
[6] Appendix F includes an analysis of HHS, HRSA, and UNOS accounts, focusing on OPTN mentions.

OPTN Stakeholder Engagement

Interviews with OPTN stakeholders, including individuals from patient advocacy organizations,[7] professional organizations,[8] Organ Procurement Organizations (OPOs),[9] transplant centers,[10] and the OPTN Board of Directors (OPTN BoD),[11] helped expand the set of perspectives used to inform this report.

Figure 3: OPTN Stakeholder Interview Breakdown

OPTN STAKEHOLDER ENGAGEMENT

This analysis includes interviews with a total of 29 stakeholders. Interviewees were drawn from the OPTN BoD, patient advocacy organizations, transplant centers, professional organizations, and OPOs.

- Patient Advocacy Groups
- Professional Orgs.
- OPOs
- Transplant Centers
- OPTN BoD
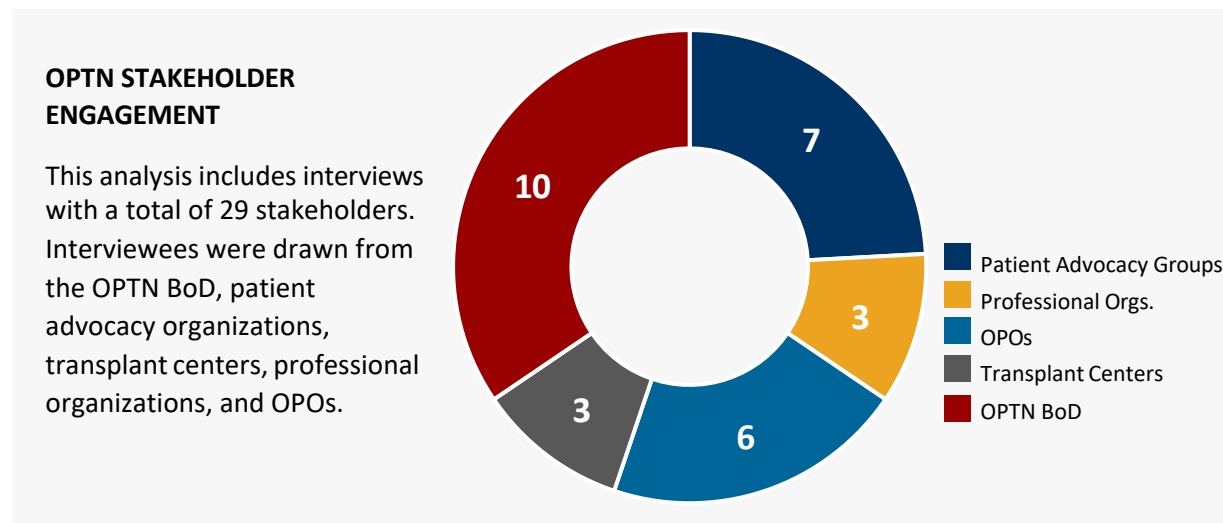
Below is a breakdown of the rationale used to select the stakeholders to interview:

- Patient advocacy groups are instrumental in providing education, outreach, support services, and community engagement to the transplant community.
  - Seven individuals were interviewed. They were selected based on the range of services their organizations provide.
- Professional organizations provide opportunities to collaborate and share experiences to advance transplantation care through research, education, and advocacy.
  - Three individuals were interviewed. They were selected based on the size and composition of their organization's membership base (e.g., a range of transplant professionals who actively engage in the science and clinical practice of organ transplantation).
- OPOs are a crucial link between organ donors, donors' families, and patients awaiting transplants. These organizations facilitate the donation process by identifying donors, recovering organs, and delivering procured organs to transplant centers. OPOs are involved in public education about organ donation and work with families to provide support before, during, and after a donation or transplant. They are required to follow national policies and report key data to the OPTN to enhance the quality of donation and transplant processes as well

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[7] Appendix G includes summary notes from interviews with patient advocacy organizations.
[8] Appendix H includes summary notes from interviews with professional organizations.
[9] Appendix I includes summary notes from interviews with OPOs.
[10] Appendix J includes summary notes from interviews with transplant centers.
[11] Appendix K includes summary notes from interviews with OPTN BoD members.

as the safety of donors and recipients. Additionally, OPOs collaborate with transplant centers to develop donation policies and provide education to providers.

- o Six individuals were interviewed. They were selected based on their OPO's geographic region, size, and community needs.

- Transplant centers provide direct care for patients throughout the entire transplantation process, using a comprehensive approach with different levels of expertise and specialties to address the complex needs of transplant patients. These centers include multidisciplinary teams that conduct research, leverage leading practices, and provide education and support to patients and their families.
  - o Three individuals were interviewed. They were selected based on their center's geographic region, size, academic affiliation, types of transplants performed, and populations served (e.g., rural, Veterans).

- The OPTN BoD is the governing body that develops policies and procedures for the OPTN. Its members come from various backgrounds, including those with lived organ transplantation experience, transplant professionals, and non-transplant professionals.
  - o Ten individuals were interviewed. They were selected based on their involvement in communication activities within the OPTN, prior engagement at the OPTN BoD meeting in Detroit, Michigan, and recommendations from other interviewees.

HRSA Coordination

The report considered inputs from meetings with nine individuals from HRSA, including the HRSA Health Systems Bureau (HSB) Associate Administrator, the HRSA HSB Executive Officer, two HRSA HSB Senior Advisors, the Director of HRSA Office of Communications (OC), the HRSA HSB Deputy Director of Policy and Public Affairs, a HRSA HSB Senior Health Advisor, and HSB Contracting Officer's Representative (COR). During these meetings, HRSA shared information on internal processes and their perspective on the current state of the OPTN, as well as goals for the future state.

OPTN Vendors

The OPTN is supported by multiple vendors that fulfill different roles tied to communications. Below is a breakdown of vendor support:

- *OPTN Project Management Office (PMO) Vendor:* The vendor, Summome Native Ventures LLC, shared the OPTN Stakeholder Engagement Report and supporting materials that they developed.[12]
- *OPTN Contractor:* The HRSA HSB Deputy Director of Policy and Public Affairs shared information regarding historical OPTN contractor (i.e., UNOS) communication processes and identified opportunities for improvement.[13]
- *OPTN BoD Support Vendor:* The vendor currently supporting the OPTN BoD, American Institutes for Research (AIR), shared their role within OPTN, as well as their perspective on the OPTN communication current state and opportunities for improvement.[14]

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[12] Appendix D includes the stakeholder engagement report and supporting materials.
[13] Appendix M includes the summary notes from the information HRSA shared regarding the OPTN contractor.
[14] Appendix N includes the summary notes from a meeting the OPTN BoD support vendor.

- *Scientific Registry of Transplant Recipients (SRTR) Vendor*: Chronic Disease Research Group of the Hennepin Healthcare Research Institute, the vendor supporting SRTR[15], provided and explained SRTR's management of scientific research for the OPTN. This includes collaborating with the OPTN and OPTN vendor staff to create the annual OPTN data report, supporting analytics and reports, and developing materials for the OPTN website and social media (e.g., educational infographics.[16]

Analyze

After aggregating insights from the "Discover and Capture" phase, the "Analyze" phase focused on identifying common themes and performing a leading practice qualitative analysis to uncover key insights. Additionally, mapping current state OPTN communication processes in the "Document" phase allows for revisiting the process analysis to identify more key insights and validate previous findings. An initial list of key findings was validated with HRSA HSB leadership, gaining further insight on the needs expressed by HRSA HSB leadership for the future state of OPTN communication services. The understanding of current state processes and key findings was continuously validated with HRSA HSB throughout this process.

Document

The information gathered was used to map current state communication processes, as highlighted in the Process Review and Mapping section of this report. Additionally, the analyses revealed findings on the current state of OPTN communications and corresponding key findings, which are presented in the Key Findings section of this report.
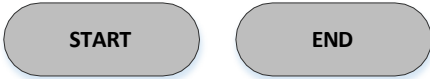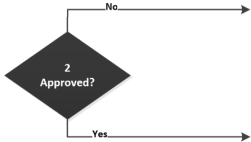
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[15] Appendix O includes the summary notes from a meeting the SRTR vendor.
[16] Appendix O includes the summary notes from a meeting the SRTR vendor.
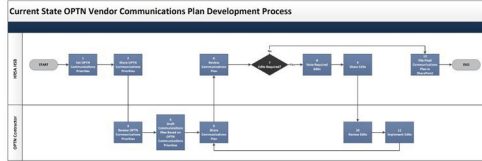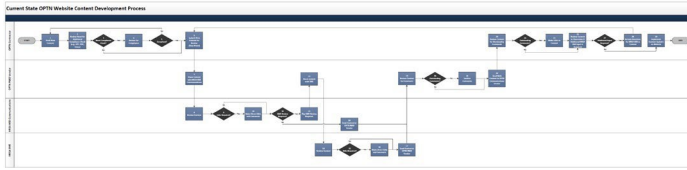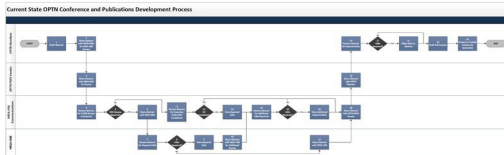
Process Review and Mapping

The activities outlined in the Methodology section of this report informed the development of the current state OPTN communication process maps. A process map is a visual representation of the steps involved in a particular process, illustrating the sequence of activities, decision points, and roles and responsibilities for each task. Process maps can help readers better understand and analyze workflows, identify inefficiencies, and serve as a basis for re-engineering. Table 1 includes a description of the graphic elements used to visualize the processes.

Table 1: Process Maps Key
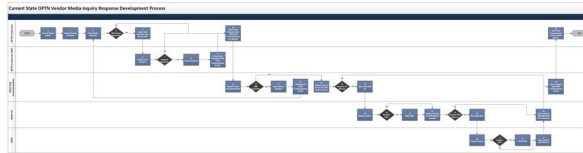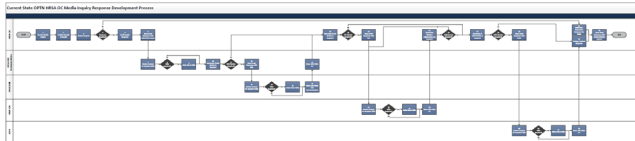
Graphic Element	Visual Example	Description
Swim Lanes	Role or Responsible Party	Sections that group activities by the roles or departments responsible for them.
Start and End Indicators	START END	"Start" and "End" icons indicate the start and end of the entire process, respectively.
Standard Process Steps	1 Draft Content	Depicted by rectangles, showing the tasks or actions taken.
Decision Points	No 2 Approved? Yes	Represented by diamond shapes, indicating where a choice must be made.

The Task Order outlines a variety of communication processes for mapping in this report. Five current state communication services processes are documented in Table 2 based on available information gathered during the "Discover and Capture" and "Analyze" phases.

Table 2: Process Maps Descriptions and Files

Process	Description
Developing Communication Plans	This process includes the steps that HRSA HSB and the OPTN contractor take to develop and review the annual OPTN communication plan. The process map file is embedded below.[17] Current State OPTN Vendor Communicatio
Creating Website Content	This process includes the steps that the OPTN contractor, OPTN PMO vendor, HRSA HSB Communications and HRSA subject matter experts (SMEs) follow to develop, review, and publish content on the OPTN website. Unless otherwise noted, most OPTN communication development and review processes follow the same, or a similar, process to what is mapped out for website content. The process map file is embedded below. Current State OPTN Website Content Deve
Reviewing Publications and Materials for Conferences	This process includes the steps that OPTN members, the OPTN PMO vendor, HRSA HSB Communications, and HRSA SMEs follow to review and update OPTN members' conference materials or publications. The process map file is embedded below. Current State OPTN Conference and Publi

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[17] Appendix Q includes larger images of each of the five current state OPTN communication process maps.

Process	Description
Responding to Media Inquiries	There are three scenarios for media inquiries, based on who receives the media inquiry: • *Vendor Media Inquiry:* This is the process if the OPTN contractor receives a media inquiry, specifically highlighting the roles of the OPTN Contractor and their SMEs, HRSA HSB Communications, HRSA OC, and the American Society for Public Administration (ASPA). The process map file is embedded below. Current State OPTN Vendor Media Inquiry • *HRSA OC Media Inquiry:* This is the process if HRSA OC receives a media inquiry, specifically highlighting HRSA OC, HRSA HSB Communications, HRSA OPTN SMEs, the Immediate Office of the Administrator (IOA), and ASPA. The process map file is embedded below. Current State OPTN HRSA Media Inquiry F • *OPTN BoD:* When the OPTN BoD receives a media inquiry, they draft a response, send the response back to the media point of contact, and then share the response they sent with HRSA HSB for awareness.

Key Findings

An analysis of collected documentation, stakeholder engagement, research, and consultation with HRSA HSB leadership revealed six key findings, as noted below.

LACK OF CLEAR PROCESSES

The OPTN has few formal communication processes …

The lack of formalized, written communication process documentation, such as standard operating procedures (SOPs), can create confusion about roles and responsibilities, lack of accountability, and delays in processes. Additionally, it can lead to misaligned objectives, increased errors, and inefficiencies in communication product development.

> *A lot of processes are word of mouth […] clearances are often done on an ad-hoc basis.*
>
> **– HRSA**

> *I had to make a report about an organ transportation vendor and called the Patient Services Line. They sent me to a Patient Safety Portal where I made the report but didn't hear any follow up on the report. I eventually got a response back, but it wasn't very insightful and didn't tell me if there were any outcomes or repercussions from the report.*
>
> **– OPO**

… which can hinder the quality and timeliness of communication products.

Clear processes and well-defined roles and responsibilities foster alignment on expectations, paving the way for more efficient and effective processes.

LIMITED AUDIENCE SEGMENTATION

The OPTN has a limited understanding of its audience and their information needs …

While HRSA has expressed an understanding of key stakeholders in the OPTN ecosystem, the OPTN does not have documented understanding of its audiences' communication and information needs or an audience segmentation approach.

> *Have the patient perspective lead conversations or communications. Try to get former patients in the room when it comes to creating messaging and validating messaging.*
>
> **– Patient Advocacy Organization**

… which limits effective audience segmentation and tailored communication strategies.

Audience segmentation and personas enable organizations to develop communication strategies and focused plans to more effectively raise awareness, engage audiences in impactful ways, and drive action.

MINIMAL TAILORED COMMUNICATIONS

There are limited tailored and accessible OPTN communications …

Many OPTN information sources are long, complex, and intended for all audiences in one format. This requires readers to sort through information that may not be relevant to them and can be difficult for those without clinical backgrounds to understand. For example, some webpages intended for patients use technical and clinical terminology with high-reading levels (e.g., the OPTN Modernization web page has a reading level of 12.8, whereas the HRSA OPTN Modernization Style Guide suggests a "5th to 8th grade reading level").[18]

> *Even if you read it, you might not understand it. Especially for our patients, some of whom haven't even gotten out of grade school.*
>
> **– OPTN BoD**

… which reduces the OPTN's ability to reach and engage target audiences.

The organ donation and transplantation processes can be complex for patients and providers alike, and many OPTN audiences are busy and may be in stressful situations. Clear and concise communications delivered to audiences how they need (e.g., right channel, right language) helps to strengthen messaging and increase awareness of key OPTN information about news, policy, or donation processes.

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[18] Appendix E contains additional examples of OPTN website readability scores, including methods used to capture these scores from OPTN website content.

OPTN BRAND CONFUSION

The unclear and inconsistent use of OPTN branding …

OPTN branding and logo are used inconsistently on the OPTN website and in communication materials. This can cause confusion about who authored the information and contributes to the notion that the OPTN vendor, UNOS, is one-and-the-same as the OPTN.

> *We get UNOS-branded information and OPTN-branded information, but nurses don't always understand the difference between HRSA, UNOS, and the OPTN.*
>
> **– Transplant Center**

> *Some information is branded as UNOS and some is branded as OPTN. They need to be different now that they are separate.*
>
> **– OPTN BoD**

… contributes to confusion about the distinct roles and responsibilities of UNOS, OPTN, and HRSA.

Clear and consistent branding enhances recognition and mitigates misinformation. Distinguished branding between different organizations can also help audiences quickly and easily identify the author of provided information. In the long term, maintaining a consistent brand identity can help build a stronger reputation and foster trust.

INCONSISTENT MESSAGING ACROSS THE OPTN

The messaging from HRSA and the OPTN members is often not aligned …

Some OPTN audiences are receiving different information from OPTN sources. This includes inconsistent key messaging as well as varying availability and depth of information. While some variation in communications can be expected, the current differences create confusion and knowledge gaps for some audiences (e.g., patients at smaller transplant centers).

> *How we talk about modernization matters. We need the sides to work together and have that be explicit.*
>
> **– OPTN BoD**

… which can create confusion and information disparities.

Aligned messaging on key topics across all parties of an organization validates that the information is reliable and trustworthy. Additionally, turnkey products that can be shared by stakeholders across the network can help close information disparities.

OPTN
Modernization

LIMITED AND REACTIVE INFORMATION

Limited OPTN information …

There is a lack of regularly updated information on OPTN channels explaining how key elements of the OPTN (e.g., modernization) will impact healthcare providers, patients, families, and the public.

Public trust in the organ donation system matters, and patients need reassurance that modernization will help them.

– Patient Advocacy Organization

… paired with reactive messaging …

There have been instances in which information has been shared with key stakeholders with short notice or after-the-fact.

We get more timely and detailed information from one-on-one texts with our industry connections and peers than from formalized OPTN communications.

– OPO

… contributes to confusion and ultimately undermines trust in the system.

Proactive and readily available messaging helps build trust, reduce confusion, and enable individuals to make informed decisions.

Conclusion

To develop a comprehensive understanding of OPTN communications services and resources, the Final Mapping Report set out to research, review, and map existing processes, laying the groundwork to advance future communications and, as a result, improve the lives of patients and their families. This report provides an overview of methodology and inputs, as well as current state process maps, based on information gathered from the Discover and Capture, Analyze, and Document phases.

The activities conducted in developing this report led to six key findings: lack of clear processes; limited audience segmentation; minimal tailored communications; OPTN brand confusion; inconsistent messaging across OPTN; and limited and reactive information. By addressing these findings, HRSA can improve internal collaboration, increase efficiency, and more effectively engage key audiences (e.g., donors, their families, and other OPTN stakeholders).

Insights from this report informed the Final Re-Engineering Report, which includes four transformative initiatives. Together, these initiatives can support a commitment to excellence and innovation, driving toward a future where organ transplant communications are not only effective but also life-saving.

Appendices

Appendix A: OPTN Communication Plan (as of July 31, 2024)

The PDF document embedded in this appendix details the OPTN communication strategy as executed by the current OPTN contractor and includes the objectives of OPTN communications, the schedule of deliverables and milestones, and the approach to developing and disseminating communication products.

3.10.1-A174_OPTN
Communication Plan_

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Appendix B: OPTN Website Plan (as of July 31, 2024)

The PDF document embedded in this appendix details the plan for updating and maintaining the OPTN website, as executed by the current OPTN contractor. This plan includes requirements for OPTN website content, the objectives of overarching website content, the timeline of necessary updates and audits, and the approach to executing updates.

3.9_A171_Annual
OPTN website mainte

Appendix C: OPTN Branding Plan (as of July 31, 2024)

The PDF document embedded in this appendix details the OPTN branding plan (as executed by the current OPTN contractor) and includes the purpose of effective branding, as well as their approach to branding OPTN-related materials.

3.10.2-A176_OPTN
branding plan_ 07.31.

Appendix D: OPTN PMO Stakeholder Engagement Report and Supporting Materials

The documents embedded in this appendix detail several layers of stakeholder engagement analyses completed by the OPTN PMO that informed discovery work for this Final Mapping Report. Decisions regarding which stakeholders to engage to complete discovery work for this Final Mapping Report leveraged these initial assessments by the OPTN PMO team.

FINAL_OPTN
Stakeholder Engagem

OPTN Stakeholder
Engagement Report C

FINAL_Vendor Office
Hours Q&A_11.19.202

FINAL_User Research
Focus Group Protocol

FINAL_Stakeholder
Segementation Mapp

OPTN Stakeholder
Segmentation & Map

Data Management
and Analysis Vendor E

Data Management
Workbook_Template_

Appendix E: OPTN Website Content Readability Test Results

This appendix details three resources for determining readability for communication materials: Flesch Reading Ease Score, Flesch-Kincaid Reading Level, and presence of passive voice in language depicted on the pages.

Flesch Reading Ease Score:

The Flesch Reading Ease Score is a calculation of reading ease (RE) based on average sentence length (ASL) and average words per page (AWS), where RE = 206.835 - (1.015 * ASL) - (84.6 * ASW). Microsoft Word's reading ease calculator was applied to the body copy of the websites described in Table E.2: OPTN Website Page Readability Test Results. Higher numbers on this rubric indicate that a passage is easier to read, while lower numbers indicate that it is harder to read.

Flesch-Kincaid Reading Level:

The Flesch-Kincaid Reading Level incorporates data from the Flesch Reading Ease equation to approximate the U.S. grade level that is most likely to comprehend the passage as it is written.

Table E.1: Flesch-Kincaid Reading Grade Level based on Flesch Reading Ease

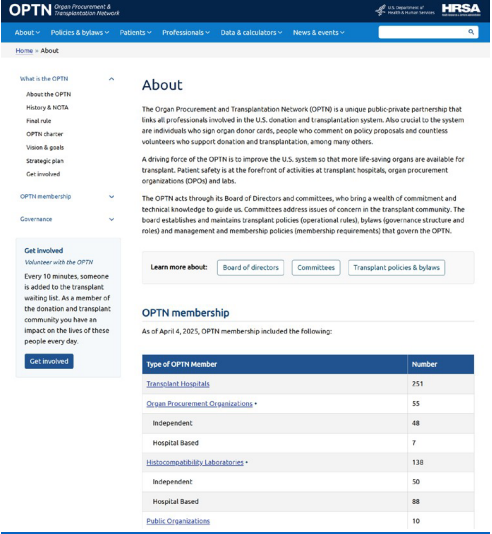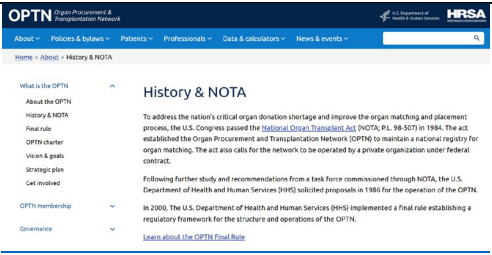| Reading Ease Score	U.S. Grade School Level
91-100	5th grade
81-90	6th grade
71-80	7th grade
61-70	8th and 9th grade
51-60	10th-12th grade
31-50	College student
0-30	College graduate

Passive Voice:

Passive voice, as defined by www.plainlanguage.gov, is a communication technique that "obscures who is responsible for what." Communication practices under the Associated Press (AP) Stylebook prioritize active voice, which "makes it clear who is supposed to do what." An excerpt from www.plainlanguage.gov that further explains this concept reads, "In an active sentence, the person or agency that's acting is the subject of the sentence. In a passive sentence, the person or item that is acted upon is the subject of the sentence. Passive sentences often do not identify who is performing the action." The passive voice scores below indicate how much of the content on the identified webpages is written passively without clear identification of which organization or individual is responsible for an action.
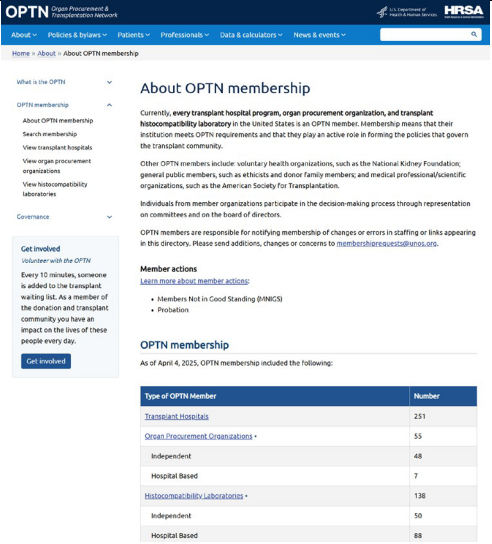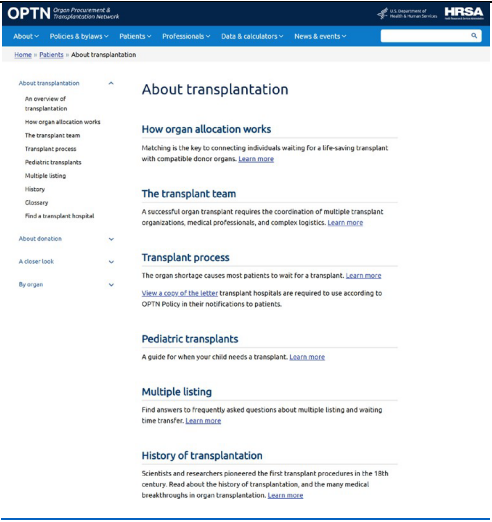
While the Plain Language Act of 2010 does not define specific reading metrics to inform leading practices for government writing, an analysis of the OPTN/UNOS web pages centered on organ transplantation and modernization show that communications, while designated for multiple audiences, still hold high reading scores according to Flesch-Kincaid readability tests. For example, the two pages with the highest reading ease score, and thus easiest content to read, score approximately 52 on the scale, meaning they are written on a "10th to 12th grade reading level," with the most difficult page scoring a reading ease of 21, meaning the content is written to be best understood by college graduates. While Reading Levels across pages average out around high school education (9th-12th grade in the U.S.
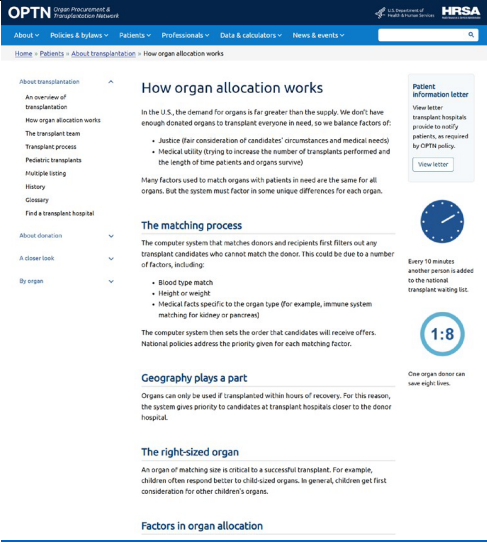
school system), most of the OPTN background information pages (e.g., "About OPTN Membership" and "What is the OPTN: History and NOTA") are written for college students and graduates with a reading level above 12th grade.
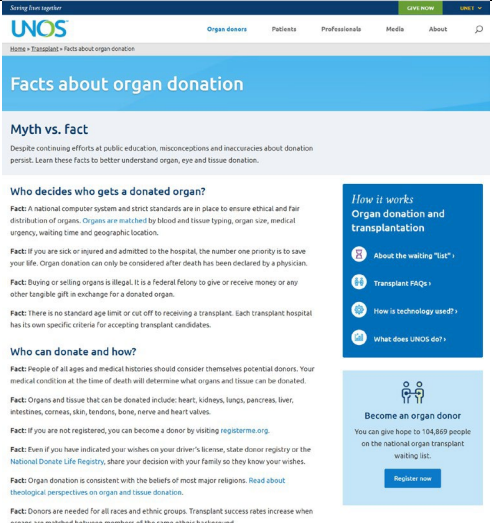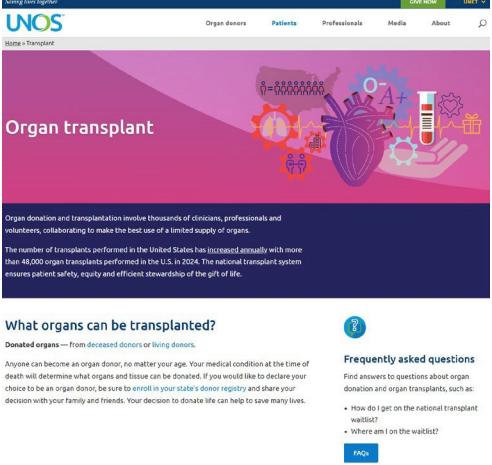
Most pages analyzed on HRSA, OPTN, and UNOS websites show more than 20% passive voice present on the pages, creating potential confusion for readers on who the acting part is for an action on the page.

Table E.2: OPTN Website Page Readability Test Results

Website Page	Link	Readability Test Results
OPTN What is the OPTN: About the OPTN	 https://optn.transplant.hrsa.gov/about/	Flesch Reading-Ease Score: 30.4 Reading Level: 13.9 Passive Voice: 23%
OPTN What is the OPTN: History and NOTA	 https://optn.transplant.hrsa.gov/about/history-nota/	Flesch Reading-Ease Score: 25 Reading Level: 14.8 Passive Voice: 20%

Website Page	Link	Readability Test Results
OPTN OPTN Membership: About OPTN Membership	 https://optn.transplant.hrsa.gov/about/about-optn-membership/	Flesch Reading-Ease Score: 21.1 Reading Level: 14.5 Passive Voice: 25%
OPTN Patients: About Transplantation	 https://optn.transplant.hrsa.gov/patients/about-transplantation/	Flesch Reading-Ease Score: 36.2 Reading Level: 11.6 Passive Voice: 12.5%

Website Page	Link	Readability Test Results
OPTN Patients: How Organ Allocation Works:	 https://optn.transplant.hrsa.gov/patients/about-transplantation/how-organ-allocation-works/	Flesch Reading-Ease Score: 51.5 Reading Level: 9.1 Passive Voice: 25%
HRSA OPTN Modernization webpage	 https://www.hrsa.gov/optn-modernization	Flesch Reading-Ease Score: 34.5 Reading level: 12.8 Passive Voice: 15.7%

Website Page	Link	Readability Test Results
UNOS Organ Donors: About Organ Donation	 https://unos.org/transplant/facts/	Flesch Reading-Ease Score: 47.3 Reading Level: 10.1 Passive Voice: 26.3%
UNOS Patients: About Transplant and Waiting List	 https://unos.org/transplant/	Flesch Reading-Ease Score: 51.7 Reading Level: 9.5 Passive Voice: 25%

Appendix F: OPTN Social Media Presence on HHS, HRSA, and UNOS Channels

The OPTN does not have its own social media channels, but information about organ donation and transplantation can be found on HHS-, HRSA-, and UNOS-owned social media channels. Below is an analysis of these social media accounts, including a summary of the number of relevant posts, topics, and perceived audiences. This analysis included a thorough read-through of each post on each designated channel, beginning with posts published on Nov. 2, 2024, and ending with posts published by close of business on March 28, 2025. Analysts flagged posts that mentioned any part of the organ donation or transplantation process, paying particular attention to posts and graphics that mention the OPTN, outright.

While each account mentions organ donation, procurement, or transplantation at least once, most of these mentions were for organ-related observances (e.g., Blood Donor Awareness Month, National Kidney Month) or testimony from donor families and transplant recipients. There were no updates on the progress of modernization or events/actions accompanying modernization (e.g., responding to public comment, attending specific webinars).

Table F.1: Social Media Presence on HHS, HRSA, and UNOS Channels

Channel, Followers, and Cadence	Number of Relevant Posts	Primary Topics	Perceived Audiences
Facebook			
HHS 527k followers Daily, ~3/day	3 of 288	Content varies from observances, health statistics, vaccination promotion, health enrollment open season, general health tips Posts about organ donation/transplant reference observance months, but not modernization	• General audiences • Hospital staff • Health advocates
HRSA 51K followers Daily, ~6/week	1 of 118	Content includes observances and patient engagement toolkits Posts about organ donation/transplant reference observance months/testimonies, but not modernization	• General audiences • Hospital staff • Health advocates
UNOS 61K followers ~1/week, doubled in cadence in March	24 of 24	A mix of statistics, requests to Congress, donation success stories, and observances Posts about organ donation/transplant do not mention modernization	• Patients on the waiting list • Living donors • Caregivers • Transplant professionals • Donation advocates
Instagram			

Channel, Followers, and Cadence	Number of Relevant Posts	Primary Topics	Perceived Audiences
HHS 202k followers Daily, ~2/day	2 of 186	Content varies from observances, health statistics, vaccination promotion, health enrollment open season, general health tips Posts about organ donation/transplant reference observance months, but not modernization	• General audiences • Hospital staff • Health advocates
HRSA 8,344 followers ~4/week	2 of 70	Content includes observances and patient engagement toolkits Posts about organ donation/transplant reference observance months/testimonies, but not modernization	• General audiences • Hospital staff • Health advocates
UNOS 8,192 followers Ad hoc, about once every two weeks or as content is available	10 of 10, although no posts mention modernization	Highest performing post (i.e., largest number of likes and comments) was a collaboration with Donate Life America (DLA), with triple digit engagement Average video length was 10-20 seconds	• Patients on the waiting list • Living donors • Caregivers • Transplant professionals • Donation advocates
LinkedIn			
HHS 843k followers Daily, ~2/day	2 of 174	Highest number of likes and comments on posts related to observances (e.g., Martin Luther King Jr. Day) and messages from HHS leadership	• General audiences • Hospital staff • Health advocates
HRSA 46k followers Daily, ~5/week	3 of 95	N/A	• General audiences • Hospital staff • Health advocates
UNOS 26k followers Ad hoc, about once a week or as content is available	Of 46 posts, 1 mentions OPTN and 1 mentions modernization	Highest performing posts mention successful legislation/policy or are collaborations with DLA Several success stories also received high engagement	• Patients on the waiting list • Living donors • Caregivers • Transplant professionals • Donation advocates
X/Twitter			
HHS 1.5M followers Daily, ~5/day	1 of 514	Content varies from observances, health statistics, vaccination promotion, health enrollment open season, general health tips	• General audiences • Hospital staff • Health advocates

Channel, Followers, and Cadence	Number of Relevant Posts	Primary Topics	Perceived Audiences
		Posts about organ donation/transplant reference observance months, but not modernization	
HRSA 40.8k followers Daily, ~6/week	16 of 151	Content includes observances and patient engagement toolkits Posts about organ donation/transplant reference observance months/testimonies, but not modernization HRSA posts more organ donation-related content on X than on other platforms	• General audiences • Hospital staff • Health advocates
UNOS 12.9k followers Ad hoc, about once a week or as content is available	Of 49 posts, 1 mentions OPTN specifically and 1 mentions modernization	A mix of statistics, requests to Congress, donation success stories, and observances Posts about organ donation/transplant do not mention modernization Mostly organic content, with reposts consisting of quote posts with thoughts included	• Patients on the waiting list • Living donors • Caregivers • Transplant professionals • Donation advocates
YouTube			
HHS 140k subscribers 793 videos Video with most views: 3.8M, Spanish shorter videos (<31 sec) have highest views Ad hoc as events/updates occur	0 of 154	Webinars/briefings, PSAs for observances, short informational videos for relevant health issues	• General audiences • Hospital staff • Health advocates
HRSA 13k subscribers 817 videos shorter videos	11 of 22	Webinars, informational videos, telehealth 101, and additional health-related information	• General audiences • Hospital Staff • Health Advocates • Donation advocates

Channel, Followers, and Cadence	Number of Relevant Posts	Primary Topics	Perceived Audiences
(<31 sec) have highest views Ad hoc as events and updates occur			• Transplant professionals
UNOS 908 subscribers 79 videos shorter videos have higher views, on average Ad hoc as events/updates occur	*No new posts since January 2024*	N/A	N/A

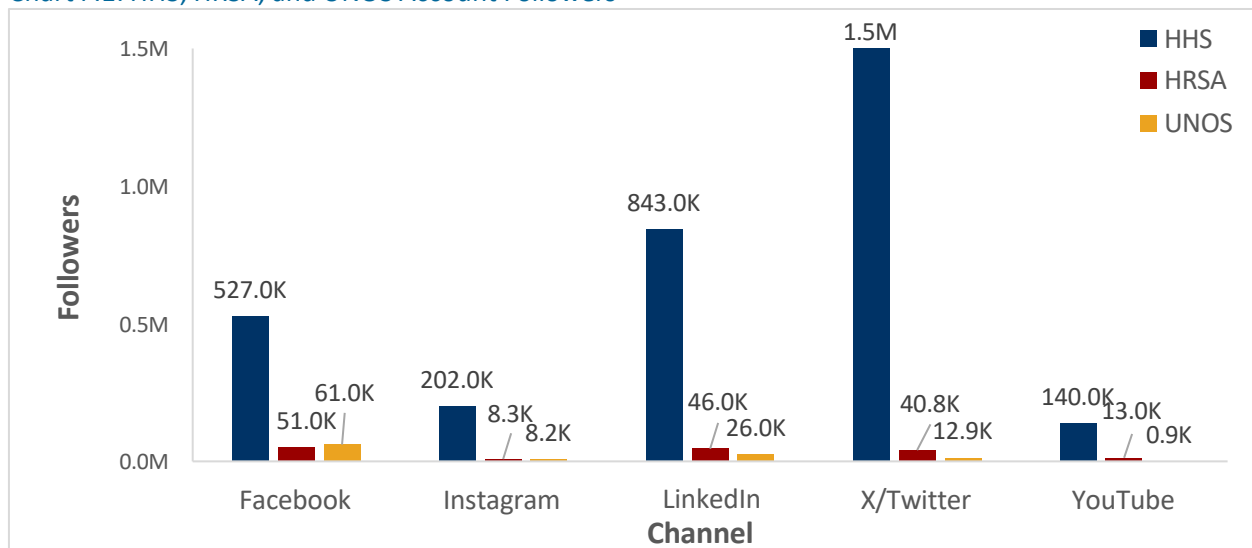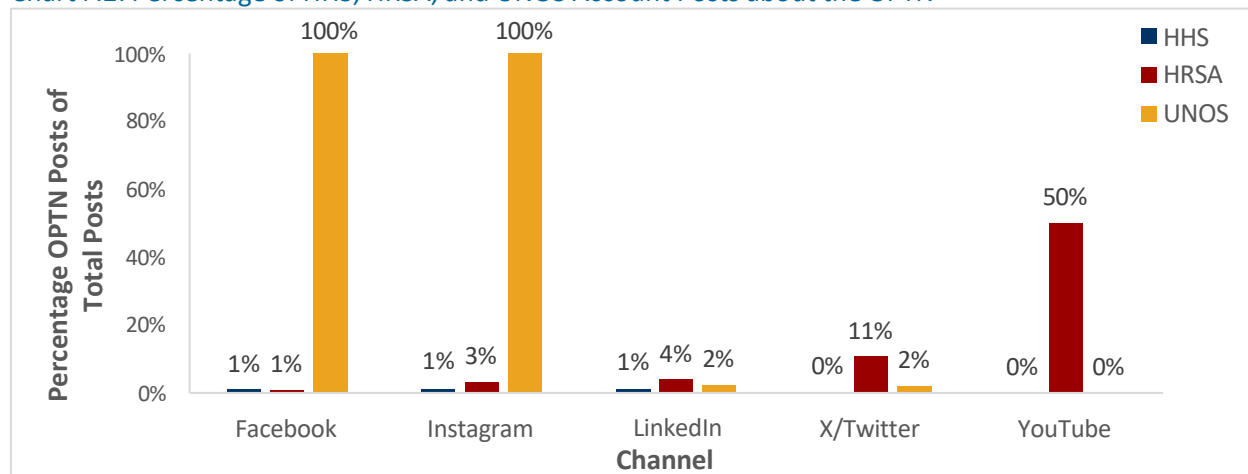Chart F.1: HHS, HRSA, and UNOS Account Followers

OPTN
Modernization

Chart F.2: Percentage of HHS, HRSA, and UNOS Account Posts about the OPTN

UNOS has not posted any YouTube videos in this timeframe

Appendix G: Patient Advocacy Organizations Engagement Notes

This appendix details the patient advocacy organizations interviewed during stakeholder engagement, the number of individuals present in the interview from each organization, and an aggregation of feedback and recommendations from the interviews.

Table G.1: Patient Advocacy Organization Engagement Count

Organization	Number of Individuals
Transplant Families	• 1
Organize	• 2
American Association of Kidney Patients	• 2
Global Liver Institute	• 1
National Kidney Foundation	• 1
Total	**5 organizations, 7 individuals**

Notes

- Participants suggested that HRSA go directly to patient advocacy organizations and provide these organizations with the key OPTN information to share with their members
    - HRSA's communications often are not in plain language and are not specific, especially around modernization activities. Example: an individual mentioned the February 2024 Special Election Webinar was not clear and did not address the community's concerns about the special election process and the Transitional Nominating Committee.
    - Patients do not understand how they will be impacted by modernization and are not getting the same level of information from HRSA and the OPTN that was previously provided since modernization started.
    - Donors do not understand how modernization will impact them – some questions that arose included, "*should I go to a new transplant center?*" and "*should I continue with the donation process?*"
    - It is important to include providers in updates and information sharing, as many do not understand the full picture of what is going on in the modernization process or how the transition from a single vendor to multi-vendor environment will impact them and their patients.
- A reactive approach to messaging and communications from HRSA and the OPTN has resulted in misinformation and decreased public trust. Specifically, individuals mentioned that:
    - There is a shared feeling that trust is lost between the replacement of the OPTN BoD and lack of communications around how modernization is going to affect patients and donors.
    - The OPTN needs to dispel some of the misinformation circulating about the current organ donation landscape. The misinformation includes:
        - Wait times to receive a transplant have increased.
        - Providers on the current OPTN BoD are part of a "conflict of interest" causing some patients to wonder if they should seek care from a different provider or transplant center.

- A sentiment among donors that the transplantation system is "corrupt," leading them to reconsider donation.
  - *"Public trust in the organ donation system matters, and patients need reassurance that modernization will help them."*
- Individuals stressed the importance of creating a cohesive brand to speak as "one voice" for the OPTN that is differentiated from UNOS.
  - *"Currently the OPTN and UNOS are viewed as 'one and the same' which contributes to misunderstandings and lack of clarity around branding and messaging."*
  - Many stakeholders (e.g., clinicians, the public, the larger transplant community) are not familiar with how UNOS and HRSA support the OPTN and the broader organizational structure.
- There is an unclear governance process around communications within the OPTN and HRSA.
  - *"It needs to be determined who decides what is communicated and what time period and what mechanism."*
  - *"I've participated in quality reviews where I've audited OPTN web products and deliverables for adherence to OPTN final rule, but I don't see any follow up, such as a response or impact after submission."*
- One individual shared that there is an opportunity to connect innovation teams to the OPTN.
  - There is no process or path in place to engage new groups and integrate with the OPTN, resulting in missed opportunities for further modernization and engagement (e.g., biotech companies, innovation centers).
- Patients should have "a seat at the table" so that decisions and policies do not appear to be geared towards transplant professionals exclusively.
  - This includes listening to patient feedback *"There needs to be an ability to listen and to hear – if it was great we wouldn't be here."*
  - It is important to leverage the Patient Advisory Boards and patient committees on issues, messaging, and decisions that impact patients.
  - *"Have the patient perspective lead conversations or communications. Try to get former patients in the room when it comes to creating messaging and validating messaging."*
- UNOS regional meetings are a good source for OPTN updates and an opportunity for face time with other members of the community.
  - However, regional meetings are geared towards transplant professionals and are not "patient-centric" or "patient-friendly."
  - These meetings are valuable in-person, but also nice to have a virtual option.
- There is limited information on the use and purpose of the Patient Services Line. Specifically, when asked, individuals state:
  - *"I have never heard of it."*
  - *"I don't think I have used that before or know about it."*
- Educational materials are not tailored for OPTN audiences (e.g., patients, families, and other OPTN stakeholders) and are challenging to find and navigate across different OPTN systems. Specifically, the following was described:

- o Patients need to go to a lot of different places (e.g., websites, transplant centers) to get information about transplantation. It would be beneficial for patients to have a centralized hub for patient education to increase and streamline access to all materials.
- o The OPTN distributed a provider guide at one point, as well as a patient guide, but these guides do not apply to all patient needs and situations. Several individuals mentioned that these guides cost money, and this is an added challenge for patients or hospitals who are not able to purchase.
- o Most of the OPTN education materials are policy-based, which can create confusion for those who are not policy experts.
- o Transplant centers are overburdened and understaffed and looking at processes or solutions to remove some of the burden from transplant centers to generate patient communications and education. There is a feeling that this is an opportunity that should be explored.
- There is a desire to have HRSA/OPTN representatives speak at trainings and conferences, so transplant professionals and patients get an opportunity to engage with leaders and to increase awareness and education for the community.
- Donation/transplant is a niche medical topic, as it is the only type of specialty medical process that exists because of the generosity of people donating organs.
  - o *"How do we allocate this precious resource ethically and maximize the process?"*
- There needs to be a connection and communication between all the steps of the organ donation and transplantation process. This includes connecting OPOs with transplant centers. One individual shared:
  - o *"Having worked on the donation and transplant side, I have experienced all the roles. But there needs to be seamless communication between donor hospitals and OPOs. Also need a tool or mechanism for OPOs to communicate with transplant centers. The primary stakeholder is the patient, we need to make sure that fits into the entire process."*

Appendix H: Professional Organizations Engagement Notes

This appendix details the professional organizations interviewed during stakeholder engagement, how many individuals were present in the interview from each organization, and an aggregation of feedback and recommendations from the interviews.

Table H.1: Professional Organization Engagement Count

Organization	Number of Individuals
American Society of Nephrology	• 2
American Society of Transplantation	• 1
Total	**2 organizations, 3 individuals**

Notes

- People would like more transparency into OPTN modernization.
  - Institutional communications from HRSA need to be consistent, thoughtful, and considerate.
    - Patients are curious about what updates like the multi-vendor environment or the OPTN BoD special election mean for them.
  - *"While change is happening, people are still hungry for information and want to feel like the OPTN is doing everything they can to inform people and hear their perspectives."*
  - Interim communications may be helpful outside of actionable updates.
    - *"We know information is scarce, but here is what we can say."*
  - HRSA has put out "monthly" updates, but a lot of updates across the OPTN get rolled together. Consider updates on a more predictable schedule so patients, their families, and other OPTN stakeholders know what day to look for information.
    - On current communications, individuals think, "What do you think triggered this?" instead of recognizing that information shared is proactive and consistent.
    - *"I'd like to know that I can click on this website on this day and get all the updates I need on a consistent basis."*
  - On public comment periods, *"People want to put comments in, but you have to be alert and looking for it to find it."*
- While they have noticed improvements in communications, individuals have noted a lot of jargon in some of the updates and recommend emphasizing plain language in future communications.
  - *"Folks build up stories in their head, like 'I don't know what this means, so what are they hiding?'"*
- OPTN communications should find a way to better understand the everyday patient's perspective through feedback and on advisory boards.
- There are different types of patients, "professional patients" who are well-informed about transplantation and speak up frequently, and the "everyday patient" who may not be as informed and may not have as much time to get involved as a professional patient.

- o *"The everyday patient may not be comfortable speaking to a doctor, but we need to give these patients their voice back somehow."*
  - o *"We need relatable people as well. Not just the patient with all the money to take care of their bills and all the time to recover after their transplant. We need more of the people who may struggle with finances or struggle to find the time to educate themselves while working every day."*
- Individuals had several suggestions for additional channels for the OPTN to consider for their audiences:
  - o Leverage donation influencers on social media as the OPTN is building its own presence.
    - ▪ Influencers have a dedicated following and cross-promotion can increase awareness and engagement with OPTN products.
    - ▪ These influencers can also be student-run organizations, such as the Student Organ Donation Advocates, with a strong social media presence.
  - o Consider opt-in text blasts to reach more audiences.
    - ▪ These texts can have short blurbs that encourage others to click into web resources.
- Transplant centers could also use some communication products, *"even if it's just a flyer telling people who to contact and when,"* as most patients see them more frequently.
- Individuals have shared information about the Patient Services Line in their duties.
  - o One organization compiles resources from various sources and shares with their audiences. A handout on the Patient Services Line is one of those resources.

Appendix I: Organ Procurement Organizations Engagement Notes

This appendix details the Organ Procurement Organizations interviewed during stakeholder engagement, how many individuals were present in the interview from each organization, and an aggregation of feedback and recommendations from the interviews.

Table I.1: Organ Procurement Organization Engagement Count

Organization	Number of Individuals
Life Connection of Ohio (Maumee, OH)	• 1
Mid-America Transplant (Saint Louis, MO)	• 1
Louisiana Organ Procurement Association (LOPA) (Covington, LA)	• 1
Arizona Donor Network (Tempe, AZ)	• 1
LifeNet Health (Virginia Beach, VA)	• 1
Southwest Transplant Alliance (Dallas, TX)	• 1
Total	**6 organizations, 6 individuals**

Notes

- Individuals get a lot of information from emails sent by UNOS, but report that the content is lengthy and can be difficult to find key insights. They shared the following:
  - *"They're really long, but I appreciate the portions at the top that say who the information is intended for in the email or update."*
  - *"The regular emails and updates from OPTN/UNOS are informative, but it takes a lot of time to find the key information."*
  - *"I prefer to be able to understand in 30 seconds, but it takes a little longer to get to the meat of it."*
- Individuals shared varied responses about regional meetings, including that the format and content is not always centered for OPOs. The following was stated:
  - The regional meetings are not always beneficial since they can be more transplant center-oriented, not OPO-oriented.
  - The meetings do not always address the "big topics" or "real issues," like de-certification and organ allocation.
  - UNOS regional meetings were an opportunity to get OPTN updates and have face time with other members in the OPTN, such as transplant surgeons.
  - These meetings are valuable in person but also nice to have the virtual option to accommodate schedules.
- It is challenging to commit to all possible OPO improvements related to policies and processes because there are government requirements that need to be met for OPOs to stay open. This is challenging for smaller OPOs as they shared they need to prioritize where to put their energy and resources. To support prioritization, interviewees shared the following:
  - Stakeholders would appreciate some more information around requirements to be able to act more efficiently and proactively.

- o Stakeholders would benefit from guidance on what's being said around timelines and requirements for OPOs.
- Several individuals suggested the OPTN should consider alternate technology pathways to communicate and manage information/data. The following ideas were discussed:
  - o Text updates for news and policies are a good way to reach rural communities that may have issues accessing broadband/internet.
  - o Using similar text messaging models that were successful for the COVID-19 vaccine initiative could also be used for modernization and transplantation network updates (e.g., text notifications and messaging).
  - o There is an opportunity to use machine learning and/or artificial intelligence (AI) for organ allocation algorithms "to push more relevant data models" and improve workflows for OPOs.
  - o Application Programming Interface (API) was mentioned by several individuals to match organs better and to pull data and information from the OPTN website to improve efficiency for report development.
  - o *"The OPTN website is not user friendly, you would have to know what you're doing to find stuff you need."*
- One OPO emphasized the importance of having individuals on the OPTN BoD that are not all technical professionals from major metropolitan areas and, instead, include rural communities so they can be part of the decision-making and information gathering process.
- OPOs would like to see more transparency and proactive communications into processes around policies and requirements. Specifically, interviewees shared the following would be beneficial:
  - o Clear timelines, when individuals are allowed to provide feedback/public comment and when policies will be implemented in the OPOs.
  - o OPOs would like to see more opportunities to provide feedback on the messaging and on policies that are being reviewed or implemented by the OPTN.
- The following was stated about modernization and reform:
  - o Modernization and reform are opportunities for improvement across OPOs.
  - o Reform and modernization will give *"opportunities to patients that every community deserves."*
  - o Modernization is an opportunity for OPOs to communicate more directly with HRSA leadership.
  - o OPOs appreciate having more face time with HRSA leadership, and hope this good presence also leads to good reform and representation in future OPTN BoD.
- Two-way communications with OPOs and the OPTN around changes that impact systems from a staffing and cost perspective would be beneficial (e.g., liver allocation policy changes).
- OPTN and HRSA have an opportunity "*to educate the transplant community and the public that they're consumers in this process."* Specifically, it was noted there are opportunities to educate patients on topics about "*where do I get listed?"*
  - o *"There is no overarching communication campaign that talks about donation, how patients can get listed for transplants, how to navigate the donation process…or how to empower people with the information that is available."*

- OPOs indicate that it is difficult to stay updated on the most important information, but the following channels and processes were shared as the most used to receive information:
  - Public letters and comments have valuable information, but it is challenging to stay up to date on recent information regarding public comments as the information changes frequently.
  - Press releases give the most information about modernization and OPO teams tend to pull these manually from OPTN/HRSA websites or through other media channels.
- An OPO mentioned that there should be better alignment between OPTN committees to reduce inefficiencies and improve transparency around processes and new policies.
  - OPTN committees that are supporting OPTN membership and OPTN governance have alignment challenges at times.
  - *"Sometimes it is difficult to figure out what committees are working on and what projects are being developed."*
- There is an opportunity for knowledge sharing between OPOs with HRSA and the OPTN, specifically around challenges with implementing new policies and requirements.
  - *"For the OPO community, we never get a sense of what is happening across the other OPOs and if we are all experiencing the same patterns."*
  - *"Our OPO looks at policies and doesn't understand the feedback loop, so it would be helpful to have engagement with other OPOs to gain a greater understanding of policies."*
- One OPO described that their organization has reported events to UNOS but have never heard back and describe the process as *"a bit of a black hole."*
  - Specifically, this event was related to a kidney that was lost during transport. The individual reported that they did not learn if the kidney had ever been located, if the transplant center reported the event, or any outcomes following the reporting.
- There should be more communications about transportation of organs and the technology that can be leveraged to improve organ transportation.
  - For example, one OPO identified a process for transporting necessary kidney pumps during a kidney transport. They were able to wave airline fees and improve efficiency. This information can be shared with other OPOs, along with other opportunities for knowledge sharing.
- *"We have forgotten the procurement side and the donor family. We need to honor their gift, and we don't have systems that support that. Communications can honor this and set policies. Honor the gift with better communications."*
- OPOs report that there is adequate notice of new policies and IT updates which allows for planning and preparation within organizations to navigate downtime procedures and planned Information Technologies (IT) outages.
  - Example: scheduled computer downtime/outages, which are also described as "short and planned."
- The data reports available on the OPTN website are helpful for informing staff at OPOs on key metrics.

- Several OPOs reported that it would be helpful to know who in their organization receives OPTN emails around updates and policies to avoid duplication of sending additional emails and preventing information gaps.
  - Example: Sharing the users within an organization who are part of the database or distribution list would help with visibility.
- A tracking system or database for OPTN policies would be beneficial to help with communications and knowledge gaps.
  - Example: when an organ allocation changes, they need to search through emails and locate the information.
  - It would be beneficial to see a repository of changes (e.g., what changed, when it changed)
  - This includes an archive of newsletters/email communications that were sent from the OPTN to the community and stakeholder groups.
- *"OPTN Regional Meetings are a huge part of how OPOs move,"* and OPOs have concerns over their cancelation. OPOs shared the following:
  - *"Virtual meetings don't work as well as in-person meetings."*
  - *"Hybrid meetings are the "worst of both worlds," but at least you get access."*
  - *"These meetings are where individuals can share information and best practices, and something is lost when you're not doing these in person."*
  - *"It was great to meet with transplant center colleagues twice a year to share advice and settle information gaps."*
- There is a shared feeling that OPOs are underrepresented on the OPTN BoD and the transplant community and that transplant centers are heavily represented which impacts OPOs voices to be heard on pertinent issues.
  - *"It [the OPTN BoD] almost feels 'anti-OPO' and the new OPTN BoD won't have sufficient OPO representation either."*
  - *"I think of it like a bicycle wheel, you have the transplant program or center in the middle because they are aligned with survival and metrics and the OPOs are the spokes and if they do not align, they will not spin."*
- HRSA does donor awareness and has a website for it, but it does not always seem well-coordinated with industry efforts or the OPTN. For example, there is no overarching donation campaign that HRSA/OPTN supports.
  - *"The OPTN and HRSA are the national voices we have, so they should be in lock step with Donate Life America to promote donation."*

Appendix J: Transplant Centers Engagement Notes

This appendix details the hospitals and transplant centers interviewed during stakeholder engagement, how many individuals were present in the interview from each organization, and an aggregation of feedback and recommendations from the interviews.

Table J.1: Transplant Center Engagement Count

Organization	Number of Individuals
University of Arkansas Medical Center: Little Rock	• 1
Cedars Sinai Hospital System	• 1
University of Minnesota	• 1
Total	**3 organizations, 3 individuals**

Notes

- Education for patients primarily exists within transplant centers or through dialysis centers where materials are provided.
    - There is a need to educate patients before they get on the transplant list, letting them know transplantation is an option and making sure they know how to get referred to a transplant center.
    - This education process can be started in dialysis centers or in other outpatient settings.
    - *"It feels like there's tension between transplant centers and dialysis centers, so is there a way to facilitate those referrals into the transplant system?"*
    - To reach members of the community, transplant centers have native Spanish-speakers to help with their Spanish-speaking patients in clinics to educate on key transplantation topics.
    - Nurse educators know what resonates in their community and what's going to be effective in terms of meaningful dialogue.
    - *"What doesn't work is getting technical."*
    - *"Our patients don't spend a lot of time online. As soon as you require a log in, you're locking your patients out. What works for us is to get patients on the phone or educate face-to-face."*
    - Patient education materials with pictures are crucial since literacy can be low in some communities.
- OPTN emails are the primary source of information for providers as well as regional meetings.
- The governance structure of HRSA and the OPTN is challenging to navigate, and the ambiguity makes it difficult to find information and to determine where communications and information come from.
    - *"Who is responsible for what? How does HRSA fit in with OPTN, CMS, SRTR? What's the OPTN in charge of? What's the mission? Who are the stakeholders? Who is calling the shots?"*
- Constant policy changes are hard to keep up with, especially around allocation.
    - Keeping up with allocation changes has gotten especially difficult over the past few years because of out-of-sequence allocation.
- When looking for policies and updates, vetting against UNet and the OPTN policy site is the current practice. It would be helpful to have all the updates in one place to decrease efforts and improve efficiencies.

- Organizations feel confused between UNet and the OPTN site and if the information has the same and most up-to-date information. Specifically, it was noted that:
    - UNet and the OPTN website don't always "sync up," so they need to visit both sites to get all the information.
    - *"I am pretty sure that patients are even looking for information from the OPTN/UNOS on UNet or the OPTN website."*
- Transplant centers provide handouts to patients with the UNOS contact information, but patients do not receive this handout until post-transplant.
- Transplant centers are also giving instructions to patients on how to get to the SRTR website because that is a requirement, but unclear if patients regularly access the website.
- UNOS does a good job of putting information on the website and via email, but there are a lot of emails and not enough time to look at all the information.
- When calling the UNOS help desk it takes a little longer to get responses and you can't track the status of your request.
    - Example: a portal works well instead of talking on the phone all the time because it would be helpful to be able to screen share with the UNOS support team calls.
    - After routing the call, the ticket is marked as completed, even if the issue has not been fully resolved.

Appendix K: OPTN BoD Engagement Notes

This appendix details how many members of the OPTN Board of Directors (OPTN BoD) were interviewed as a part of stakeholder engagement, which communities in the overall organ transplant community they represent, and an aggregation of feedback and recommendations from the interviews.

Table K.1: OPTN BoD Engagement Count

Engaged Board Member Representation	Number of Individuals
Patient Advocacy Groups	4
Transplant Center	5
Histocompatibility Lab	1
Total	**10**

Notes

- One of the biggest concerns during leadership calls with the OPTN BoD is around communications.
  - *"How left hand will talk to right and how will this be strategically done so it will not disrupt taking care of patients."*
  - *"Modernization is an area for opportunity for everyone to start thinking how to communicate, educate, and reach out to the broader community about what this modernization truly looks like and how it is going to happen."*
- There is a sense of "information fatigue" around too many emails and several individuals shared that streamlining the information can improve processes and how to obtain information.
  - General problem with communication email, sometimes becomes "white noise."
- Individuals report that the public does not currently have a good perception of the OPTN.
  - *"Patients and families are being used as political ploys back and forth -- there needs to be a come-to-Jesus meeting within the community, and what needs to be done is making it all better, not politicizing it."*
  - Patients and donor families on the OPTN BoD feel disheartened and concerned about being called "conflicted" by HRSA.
  - *"Put blood sweat and tears into policies and products – when you're put into corner like that it's disheartening."*
- SharePoint is used to share information between OPTN BoD members, although it is not set up effectively and efficiently, which makes it difficult to locate information to prepare for meetings and vote on policies.
- There is a shared feeling that there is a lack of transparency and limited communications from HRSA as an OPTN BoD member. The following was shared:
  - *"When it comes to communications, we're the last to know on things."*
  - *"Relying on HRSA's website is a horrible way to communicate within the OPTN community -- not the most robust way in my opinion. There are definitely better ways to communicate with all of us more effectively."*
  - *"One example is the Expeditious Task Force is indefinitely on hold but audiences don't know what that means or what OPTN is doing about it."*
  - *"If there are delays or ethical concerns, those should be clearly outlined."*
  - *"Lots of thought behind decisions, but public doesn't see that."*

- Current understanding is that the OPTN cannot have its own social media page, all channels must go through HRSA (but HRSA social media is limited).
  - *"If there was a way for the OPTN to communicate to the broader community through social media, a lot of the communication issues could be diffused."*
  - *"Social media would really help the OPTN reach their target audience."*
- Patient education is always evolving and there are opportunities that the OPTN can leverage to improve patient education. The following examples were shared:
  - The OPTN can help with patient education around waitlist times and transplant care follow-up.
  - General information about the state of transplant in the U.S. can be an OPTN communication opportunity, but patient-specific information and transplant center processes need to come from their provider.
  - Transplant centers and other organizations provide most of the patient education and communication needs with communities, but the OPTN has the opportunity to have a footing in patient education and outreach.
  - There are audience segments that need more communications and have specific or special education or communication needs (e.g., rural populations, non-English speaking patients, pediatrics, patients with low literacy levels).
  - *"There need to be better processes for communications to be approved in a timely manner so patients can have updated information without too much delay."*
- These challenges of reaching certain audience segments mirror the same problem that healthcare has in general in terms of social determinants of health.
  - There are areas that are still missed in terms of underserved communities that are not receiving adequate information.
  - It is important to simplify communication for disadvantaged groups and provide patients with clear and understandable information.
- Public perception of the OPTN is currently poor and the following examples were shared:
  - The media impacts the public perception of the OPTN. The OPTN and HRSA should do more "myth busting" to dispel rumors.
  - The poor public image has potentially led to a decrease in the number of individuals on donor registries as individuals do not want to register as organ donors because of distrust in the system.
  - *"Again, it's time to show what the OPTN and the transplant community are actually doing -- currently one-sided story right now."*
  - *"There are numerous volunteers and donors that put in blood, sweat and tears, don't get paid. We're volunteers for a reason. We're either touched by transplantation or in medicine, and this is our way to give back to the community and that story needs to be told as well -- we need to start showing humanistic piece of transplant -- we see the medical side, but what is missing is the humanistic side of transplantation -- can help show altruism of transplant."*
- The OPTN website is difficult to navigate and find information. The following information was shared:
  - *"HRSA micromanages everything that goes on there, using 'cover yourself' policy language and legal language."*
  - *"Even if you read it, you might not understand it. Especially for our patients, some of whom haven't even gotten out of grade school, which is hard."*

- - The OPTN website does not have valuable information for patients like "where am I on the list?"
  - *"The historical information and records of meetings, open comments, and policy updates are on the website and have been preserved, but the lack of ability to access that information easily inhibits people's ability to understand historical context."*
    - *"We should better document things that OPTN has tried and not pursued or failed and include the why behind it."*
    - *"If we don't know our history, we're doomed to repeat it."*
    - *"There's no place for people to fact check information on policies or committees that end and why they ended."*
- UNOS as the contractor sends emails out to the community frequently on policy change, policy implementation, letters about modernization, and surveys, but high volumes of information can be overwhelming to audiences.
  - *"People working in the system are immune to these -- need to provide different ways to show these [content updates] so they don't get overloaded and are flooded."*
  - *"For the past year or so emails have not been going to the right audiences, something is off with the distribution list."*
  - *"There is a need for an OPTN-specific brand that can support communications and is identifiable by the public."*
  - *"There is a need for a differentiation in UNOS and OPTN branding so that it is very obvious who communications are coming from."*
- Limited resources and HRSA approval processes make it challenging to develop content and new channels.
  - There are many layers of approval for anything to happen, and it takes a long time for content to get approved or delivered.
  - There needs to be a better process for things to get approved and for resources to make it to publication.
  - Money and resources are huge limitations for developing content and creating new channels.
- To provide appropriate information for audiences, individuals who have a background in health literacy should be developing content.
  - "*Every policy going out there should have someone with health literacy to review to make sure patients will be able to understand the information."*
- An individual noted that HRSA/the OPTN use very reactive communications, with no apparent engagement strategy.
  - A member suggested improving communications by using blogs, social media, and forums to drive collaboration and transparency for patients and the community.
  - There is a need for a more receptive feedback mechanism for patients and families between the OPTN.
- One individual stated that *"what has made UNOS work is that support staff is always extremely willing to get data, answer questions, time and resources they've invested into.*"
- Pediatrics is identified as a vulnerable population, and an OPTN BoD member is worried that efficiency *"is going to cause pediatrics to get pushed to the sidelines, because every step of the pediatric transplantation process takes more time."*

- When patients are removed from the National Transplant Waitlist, they are supposed to get a letter or a phone call, but some do not get the communications that they have been removed from the waitlist and this contributes to a lack of trust in the transplantation system.
- The OPTN website is challenging to navigate and often has repetitive information.
  - UNOS may update things more quickly, but HRSA takes more time to review.
  - If UNOS and OPTN websites have different information and transplant centers also have information – it comes down to who the patients trust more.
  - On websites, if you go into patient education material, it's not linear. (There is no pathway or playlist, or the available playlist doesn't make sense).
- There are helpful publications like "Everything that patients should know about transplant" and "What every parent should know about pediatric transplant," but these resources are not free and are not written at accessible reading levels.
- The transplantation community is familiar with UNOS as a contractor, so they're familiar with communicating through UNOS.
  - *"This is a well-oiled machine. These are folks who have been involved and have the experience." (about UNOS)*
  - *"Talking to people is fine, but stakeholders don't know how HRSA is going to replace all this institutional knowledge of people who have been doing this for years."*
  - Respect for the depth of what they're doing and why they're doing it is so deep and not easily transferable.
  - *"Communication has to come from the heart, and folks don't know where that heart is coming from if the people they are familiar with leave. It's not just an email or a meeting invite, it's why."*
  - *"OPTN leaders are some 'of the top in the nation' and because of the time, effort, and love they've put into it…got to respect that. If you don't have that background, it's not a thoughtful communications."*
  - An individual mentioned that they felt that UNOS staff kept them informed about committees and OPTN BoD work and initiatives.
- There needs to be more context in intra-organizational communications between HRSA, the OPTN BoD, and contractors.
  - Example: OPTN BoD support vendor has sent OPTN BoD members an email accompanied with a calendar invite, but no other information about the meeting or context, which increased confusion among OPTN BoD members.
- Timeliness is very important for reviewing policies and meeting materials.
  - Some OPTN BoD members said they felt it is not considerate to send content for review at the last minute when members have other commitments and considerations.
  - The policies that require review from OPTN BoD members involve a lot of focus and attention as they have a large impact on patients and families.
  - *"For patients on the OPTN BoD they're either actively going through the process, up for transplant, or waiting for another. Doing this with a full-time job and life."*
  - *"The best thing we can do for our patients and our volunteers is to respect their volunteerism. Don't send them items at the last minute if you want their perspective."*
- To increase trust and transparency with the OPTN community, communications should foster partnership.

- o *"Modernization is being communicated as a hostile takeover instead of a strategic partnership. How we talk about modernization does matter. We need the two sides to work together and have that be explicit."*
  - o This includes good communications around policy and technology changes.
- Town halls are a good opportunity to learn more about upcoming policy, "*but you get what you put into it."*
  - o There are different opinions and feedback depending on the region, which is good to consider for discussion.
  - o Programs who are interested in transplantation policy gain a lot of information and value. However, if these were more patient-focused, they would potentially be more well-attended.
  - o *"We don't say thank you enough to the patients. A lot of meetings get very technical, which is hard on the patient representatives involved. Sometimes with so many confident technical voices in the mix, the non-technical voices may not feel as comfortable speaking up."*
  - o If they aren't a technical person, they don't care a lot about technicalities.
  - o In-person makes a difference, but virtual is beneficial because people can join and leave a stream whenever they want.
- Stakeholders would love to see the OPTN "hone in" on tailored messaging (e.g., what practitioners need to know, the administrator/quality person needs to know).
  - o For current communications, subject lines on emails may not be specific or informative.
- There is a policy that the transplant center must provide a specific letter to waitlisted patients about the Patient Services Line that describes how to report problems or concerns.
  - o There is ambiguity about how this phone line is used because many patients use the service to call and ask about specific personal information or information related to their waitlist status.
  - o *"Items that are public-facing need to be tailored to lower health literacy and simple messaging. A lot of the words we use [on the website], people don't know what they mean. Don't make it too complicated."*

Appendix L: HRSA Meeting Notes

This appendix details the number of HRSA staff present during information gathering sessions and a summary of participant feedback. Participants were from HRSA offices and an affinity group.

Table L.1: HRSA Engagement Count

HRSA Engagement	Number of Individuals
HRSA Office of Communications (OC)	1
HRSA Health Systems Bureau (HSB)	6
Organ Transplantation Affinity Group (OTAG)	2
Total	**9**

Notes

- Participants discussed the current state of HRSA and OPTN communications, including:
    o Currently HRSA and the OPTN contractor make updates to the OPTN modernization webpage to correspond with updates in policy or actions stakeholders should be aware of regarding modernization.
    o HRSA is aware that OPTN audiences have varying perspectives on the modernization efforts. Communications can help address questions and needs from different audiences.
    o OPTN BoD contributes to policy updates and stakeholders would appreciate more time to contribute to public comment on policy changes.
    o The OPTN contractor currently makes updates to various pages on the OPTN website after sharing proposed changes with HRSA/HSB or HRSA OC.
- Only certain individuals within HRSA have access to the review portal. Establishing back up personnel may help HRSA continue review and development processes if the primary point of contact is out of office or unavailable.
    o SME and inter-office reviews within HRSA sometimes seem out of sequence.
- HRSA has a congressional affairs team that collaborates with HRSA OC to establish and verify key information for Congress.
    o Different offices within HRSA provide different levels of detail for deliverable review. HRSA Congressional Affairs and HRSA OC are working together to determine a baseline for appropriate detail.
- HRSA highlighted the need for clearer delineation between HRSA and OPTN roles in communications, including who will lead communication responsibilities, approval processes, and identifying key players.
- Many stakeholders have built trust in the individuals who they communicate with most frequently in current state communications, so transferring information will be essential to maintain the flow of processes.
- The OPTN Strategic Plan will need updating based on new communication structure and new actionable parties.
- HRSA will need a feedback mechanism to gather input on OPTN and its supporting communication, as most of the current feedback (e.g., patients, OPOs, transplant centers) funnels through the OPTN contractor.
- HRSA shared some initial goals for the future state of OPTN communications:
    o Factoring trust into communications is a priority and focus for HRSA leadership.

- o More consistent communication will give the OPTN more visibility and allow audiences more insight into operations and key changes.
  - o Positive, patient-centered communication can help build an understanding of and trust in the system without underplaying the challenges and the risks associated with it.
  - o OPTN's voice will be owned by anyone who is communicating on behalf of the OPTN, so it should have a consistent branding, style, etc., that is established by HRSA.
  - o Stakeholders would like to hear from HRSA more in future communications to build HRSA's voice in the OPTN.
  - o Social listening tools could be used to gather audience sentiment and feedback on OPTN operations and communications.
- HRSA discussed the importance of speaking to the OPTN BoD for insights into existing processes, challenges, and opportunities for growth, including OPTN functions and the needs of different populations within the OPTN community (e.g., transplant centers, patients, OPOs).
- HRSA discussed five potential communications strategic shifts, including:
  - o Defined audiences to inform strategy
    - ▪ HRSA HSB leadership discussed which communications and topics should be managed by HRSA, the OPTN BoD, or OPTN vendors, as seen in Table L.2.

Table L.2: OPTN Topics and Channels by Responsible Party

Topic and Channel	Suggested Responsible Party	Additional Notes
OPTN Modernization	**HRSA** should communicate to audiences	• Modernization should be communicated by HRSA, but there will be interdependencies • Priority item for proactive communication strategy
Policy	**OPTN BoD** should communicate to audiences	N/A
OPTN Operations	**OPTN vendors** should execute **HRSA** should provide oversight	• HRSA mandates that certain infrastructure and operations exist, then OPTN vendors execute
Website	**HRSA** should set the infrastructure for OPTN KPIs **OPTN BoD** and **OPTN vendors** should help make sure operations meet these expectations	• HSB leadership is interested in a public-facing scorecard/dashboard that tracks OPTN KPIs to increase transparency of OPTN operations and functions • Want to make sure that HRSA is communicating to the public the benefits of modernization relating to operations and overall performance (e.g., outcomes, processes)
Critical Actions/Comments	**HRSA** should communicate to audiences	• Priority item for proactive communication strategy
Hill Messaging	**HRSA** should be responsible for messaging to the Hill	N/A
Patient Services Line	**HRSA** should be responsible for hosting the technology that supports the back end of the Patient Services Line.	• HRSA has yet to determine who will be responsible for managing the phone line and providing patient service representatives to address live questions • Consider whether the line will have an options tree or calls will be sent directly to patient service representatives

- o Proactive communications strategy
  - This can include a future communication strategy that focuses on patient-centered communications from HRSA and the OPTN, including weekly meetings with the OPTN BoD to help improve communication deficits.
- o Recognizable and cohesive OPTN and HRSA brands
  - This can include OPTN/HRSA brands that identify HRSA as the government oversight entity of the OPTN.
  - The OPTN vendors will be responsible for executing operations and consistently implementing HRSA-established branding and voice.
    - The OPTN Executive Director role will focus on working with staff and volunteer groups as part of the OPTN and may amplify communications (e.g., attending conferences, monthly updates).
- o Standard processes for tailored communications
  - This can include a system where HRSA oversees OPTN communications and catalyzes the system through communications, collaboration, strategic partnerships, and evaluation.
  - Creating a patient satisfaction survey to help inform where the OPTN needs to go and give insight into patient pain points could help the OPTN grow.
- o Consistent and transparent communications that foster trust
  - This could include positive, patient-centered communications for the public to understand and trust the transplantation system without underplaying the challenges and risks associated.
  - Establishing OPTN ambassadors may help build trust.
- HRSA emphasized the importance of transparency and user-friendly communications products. This includes websites with public-facing dashboards that track OPTN KPIs to increase transparency on OPTN operations and functions.
  - o Establish tools and resources that get people the information they need for a range of users with varying levels of interest and involvement.

Appendix M: HRSA-Shared Insight into OPTN Contractor Services

This appendix captures OPTN communication current state information shared by HRSA after the HRSA HSB Deputy Director of Policy and Public Affairs met with the OPTN contractor (i.e., UNOS).

Note

- Media inquiries, requests, and responses follow a standard process as outlined in Appendix Q.
- The current process for content review includes a portal for contractual requirements (e.g., website development, news items) and there is a protocol and approval process with HRSA before the OPTN contractor proceeds with publishing content.
  - The OPTN contractor creates news items with an in-house SME pool, then the OPTN contractor uploads news items to the portal for HRSA review.
- The OPTN contractor communication team determines news item topics and when to push out communications based on community needs.
  - There are multiple factors that the OPTN contractor uses to consider communication needs with the community such as committee activity, governance activity, patient safety, health safety, educational needs, policy changes, and data collection.
  - In times of change, more communication can help build community awareness and trust. OPTN audiences have expressed a desire for more information.
- The OPTN contractor emails OPTN members via Salesforce.
- There historically was a backlog of items awaiting approval from HRSA for OPTN website content; however, new HRSA staff have worked through the backlog and provide timely reviews.
- OPTN members want to hear more about modernization, and it is important to consider that the type of information they want to receive depends on their role and expectations.
  - For example, a kidney coordinator who is more front-and-center in the process will have different information expectations than an administrator working behind the scenes.
- Different communities have different communication needs (e.g., the pediatric community versus the adult community, rural versus urban). A one-size-fits-all communication approach will not be effective for OPTN audiences.
- The feedback that is received is primarily anecdotal and is provided to the OPTN contractor staff who directly engage with audiences, instead of the communications team.
- The OPTN contractor uses Google Analytics and industry standards (e.g., open rates/click rates.)
- The OPTN contractor does not use A/B testing to optimize email marketing.
- Some current senders of communications have relationships with audiences that they have developed over many years. Audiences know they can trust that information because of who it is coming from.
- OPTN members are often more likely to read information if it is coming from a trusted source.
  - Even if the information cannot come first-hand from a trusted source, a hand-off from a trusted source to the new source can help establish that new source as reliable.

Appendix N: OPTN Board Support Vendor Meeting Notes

This appendix captures notes from a discovery meeting with the current OPTN BoD support vendor, including an aggregation of feedback and recommendations from the meeting.

Table N.1: OPTN Board Support Vendor Attendee Count

Meeting Attendees	Number of Individuals
American Institutes for Research (AIR)	1
Total	**1**

Notes

- The participant noted that there is a need to create a "communications arm" of the OPTN as a structural system with better access to information.
- Defining roles and responsibilities for OPTN communications can enhance transparency and efficiency.
  - For example, defining what vendors are responsible for in terms of communications, HRSA's role as the oversight, the OPTN BoD, and the Executive Director of the OPTN.
- Stakeholder engagement has many entities within the transplantation ecosystem and there are no regular communication channels that support stakeholders in receiving information.
  - Creating regular channels can foster relationships and increase public awareness and education.
  - Looking at additional platforms (e.g., social media) is an opportunity for "anyone to receive OPTN communications" and for the OPTN to clarify messaging.
  - Stakeholders report experiencing a "void of information" related to the OPTN and there are missed opportunities for the OPTN to share "all the good work the OPTN does" with the public.
- Developing an external affairs strategy including media relations, legislative affairs, crisis communications, and addressing reputational damage are key areas of focus for vendors when discussing challenges with OPTN BoD members.
  - It was shared that there are not a lot of opportunities for experts to provide insights on external facing public comments.
- Public awareness campaigns, crisis communication plans, and leveraging social media and media relations are critical ways of reaching audiences with the information they need.
  - These strategies should be rooted around human-centered design while also including decision making authority.
- Transparency and user-friendly communications can increase trust within the transplantation community.
  - Communication that is tied with trust and transparency should align with the key goals and mission of the OPTN.
- Conversations discussed the following communication challenges:
  - Inconsistent messaging creates a void, as well as "different narratives" of messages.
  - Branding around the role of the OPTN in the organ donation field and confusion between UNOS and HRSA is apparent when interacting with the OPTN BoD and other

stakeholders. Developing a brand strategy that is no longer intertwined with UNOS might alleviate this confusion.

- ▪ *"For example, we will receive emails that say, 'I am on the UNOS committee' and she will respond, 'Thank you for continuing with the OPTN committee.'"*
  - o There is limited clarity into the current communication processes.
  - o Lack of information is closely related to decreased trust and transparency.
- There is an opportunity to engage global partners and look at international strategies for leading practices and successful models.
  - o The OPTN can establish international relationships to foster collaboration as appropriate.

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Appendix O: Scientific Registry of Transplant Recipients (SRTR) Vendor Meeting Notes
This appendix captures notes from a discovery meeting with the SRTR vendor.

Table O.1: SRTR Vendor Attendee Count

Meeting Attendees	Number of Individuals
Chronic Disease Research Group (CDRG) of the Hennepin Healthcare Research Institute	1
Total	**1**

Notes

- The SRTR vendor discussed the structure of its organization, including the overview and history of the organization, as well as key responsibilities that are described below:
    - Manages the scientific research coming into the OPTN
    - Publishes performance reports every six months for "program-specific reports" or "OPO-specific reports"
    - Develops annual data report alongside OPTN and UNOS staff that addresses key trends
    - Supports OPTN policy making committees when they need analytics done
    - Handles some of the mandatory reporting that falls under the OPTN final rule
- Conversation participants reviewed the SRTR website and the SRTR patient-facing website that was recently developed.
- The SRTR vendor worked with patient advocacy groups to develop tailored information for the patient-facing website: Preview.srtr.org

Figure O.1: SRTR Website Screenshot
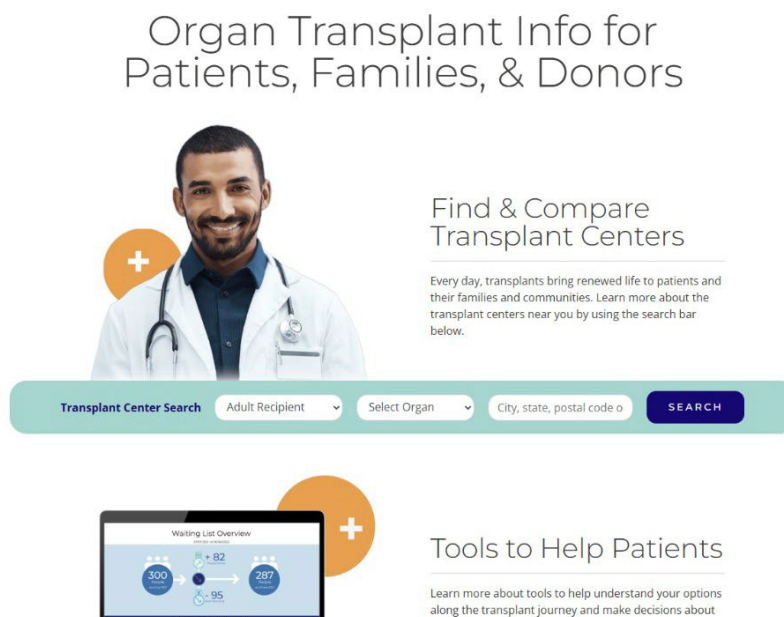
- The SRTR vendor uses social media to post infographics, reports and other relevant publications (they partner with Donate Life America, National Kidney Fund, and other organ donation organizations to elevate messaging).

- o YouTube is where their educational videos live, which are mostly geared towards transplant professionals, but a bit for patients as well.
- OPOs have dedicated "data people" on staff who maintain the data for SRTR.
- SRTR has a secure site that OPOs and transplant centers can use for generating quality improvement reports and tracking metrics.
- The SRTR vendor runs data quality check reports to see data and make sure it's accurate before being made public.
- SRTR has an infographic of the organ transplantation journey *(see below).*
  - o SRTR brought this infographic to a conference to orient their discussions. They kept the resource since it got positive feedback.
  - o This infographic has been a cover image for transplant journals and publications.

Figure O.2: SRTR Organ Transplantation Journey Infographic
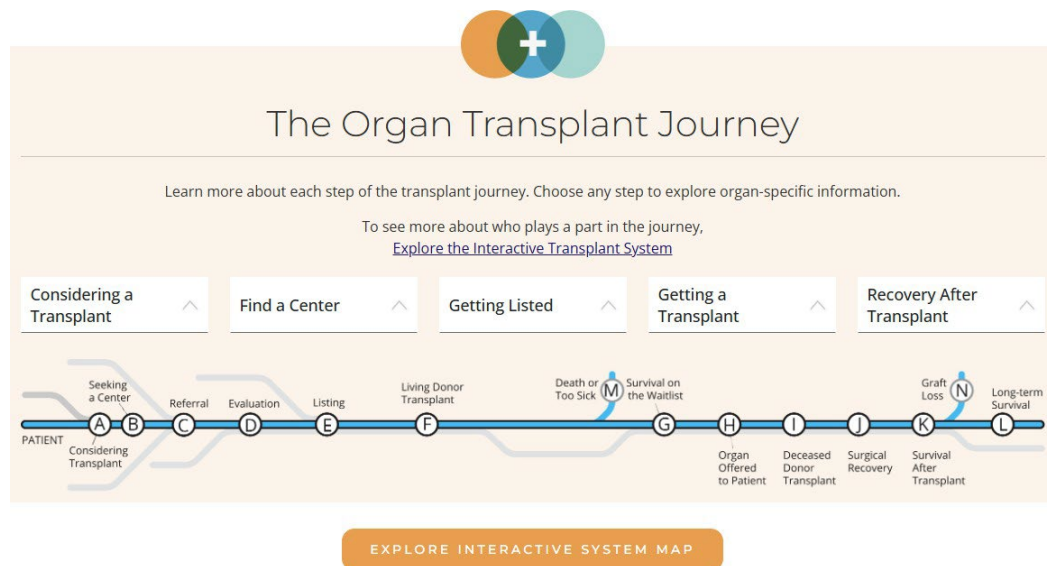
Appendix P: PowerPoint Version Report Summary

The PowerPoint slides embedded in this appendix summarize the Final Mapping Report and supporting study.

HRSA OPTN_D4 TO
Final Mapping Report

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Appendix Q: Images of Current State OPTN Communication Process Maps

This appendix provides images of the five current state OPTN communication process maps included in this report.

Figure Q.1: Current State OPTN Vendor Communication Plan Development Process
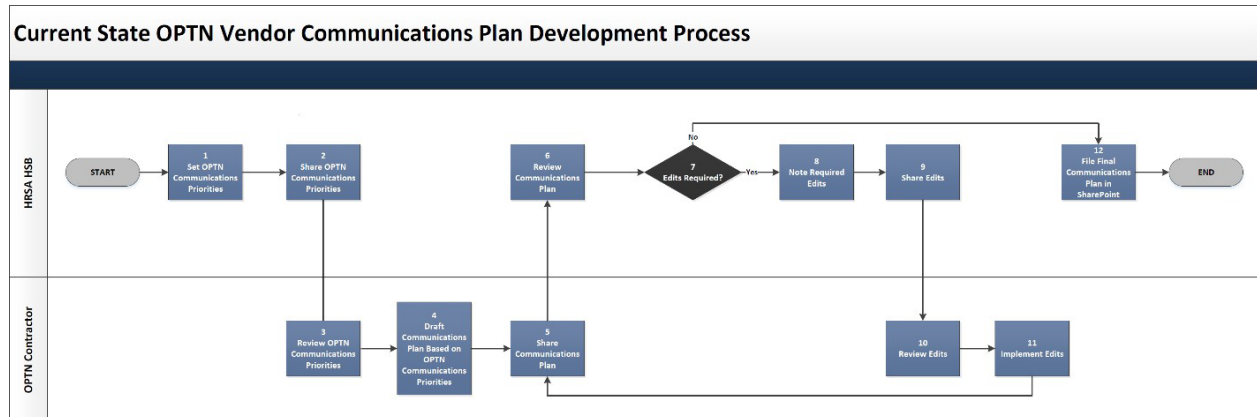
Figure Q.2: Current State OPTN Website Content Development Process
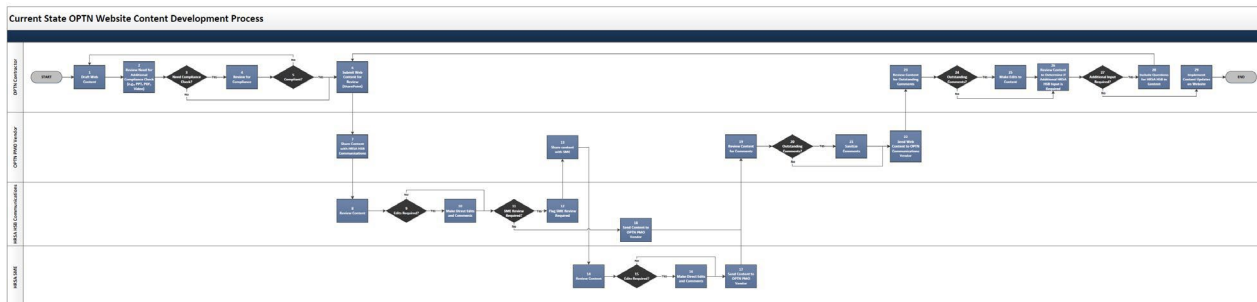
Figure Q.3: Current State OPTN Conference and Publications Development Process

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Figure Q.4: Current State OPTN Vendor Communication Development Process
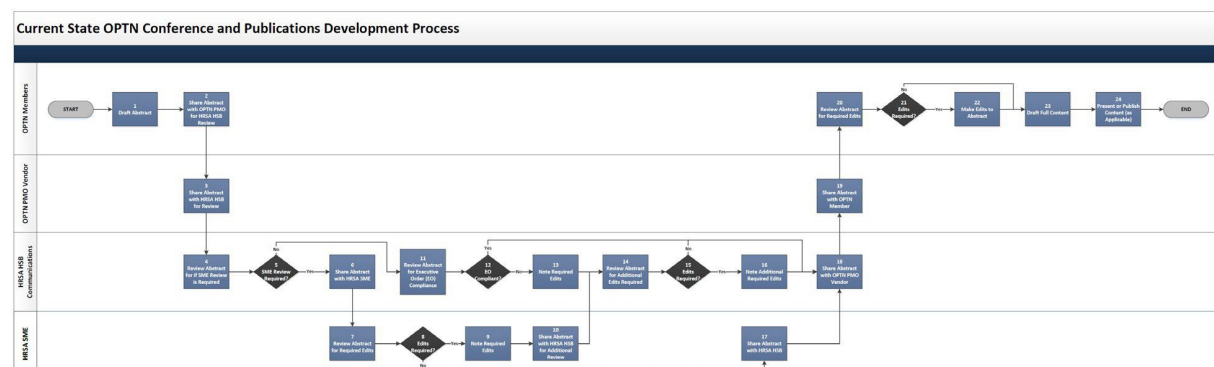
Current State OPTN Vendor Communications Plan Development Process

Figure Q.5: Current State OPTN HRSA OC Media Inquiry Response Development Process

Current State OPTN HRSA OC Media Inquiry Response Development Process