

OPTN website focus groups

Actionable items to help members and patients

January 2020 – August 2020

Design & User Experience Team | Communications Department | UNOS

- *Summary: complaints*

- *Summary: needs and topics*

- *Objective*

- *Methodology*

- *Patients*

- *Transplant professionals*

- *Organ procurement professionals*

- *Policy and bylaws*

- *Patient education*

- *Professional education*

- *Proposed site navigation*

- *Proposed implementation schedule*

- *Summary: complaints*
- *Summary: needs and topics*
- *Objective*
- *Methodology*

SUMMARY: COMPLAINTS

Users can't remember the OPTN website address; they rely on Google or bookmarks to find it.

Make the web address more memorable: optn.gov

Search yields poor results that are neither relevant nor recent.

Invest in a new tool for improved search functionality.

Users can't find policies, bylaws or the evaluation plan easily.

Change navigation and test with users.

Toolkits are critical, but inconsistent.

Standardize contents and make information easy to understand.

Give me bullet points. Summarize.

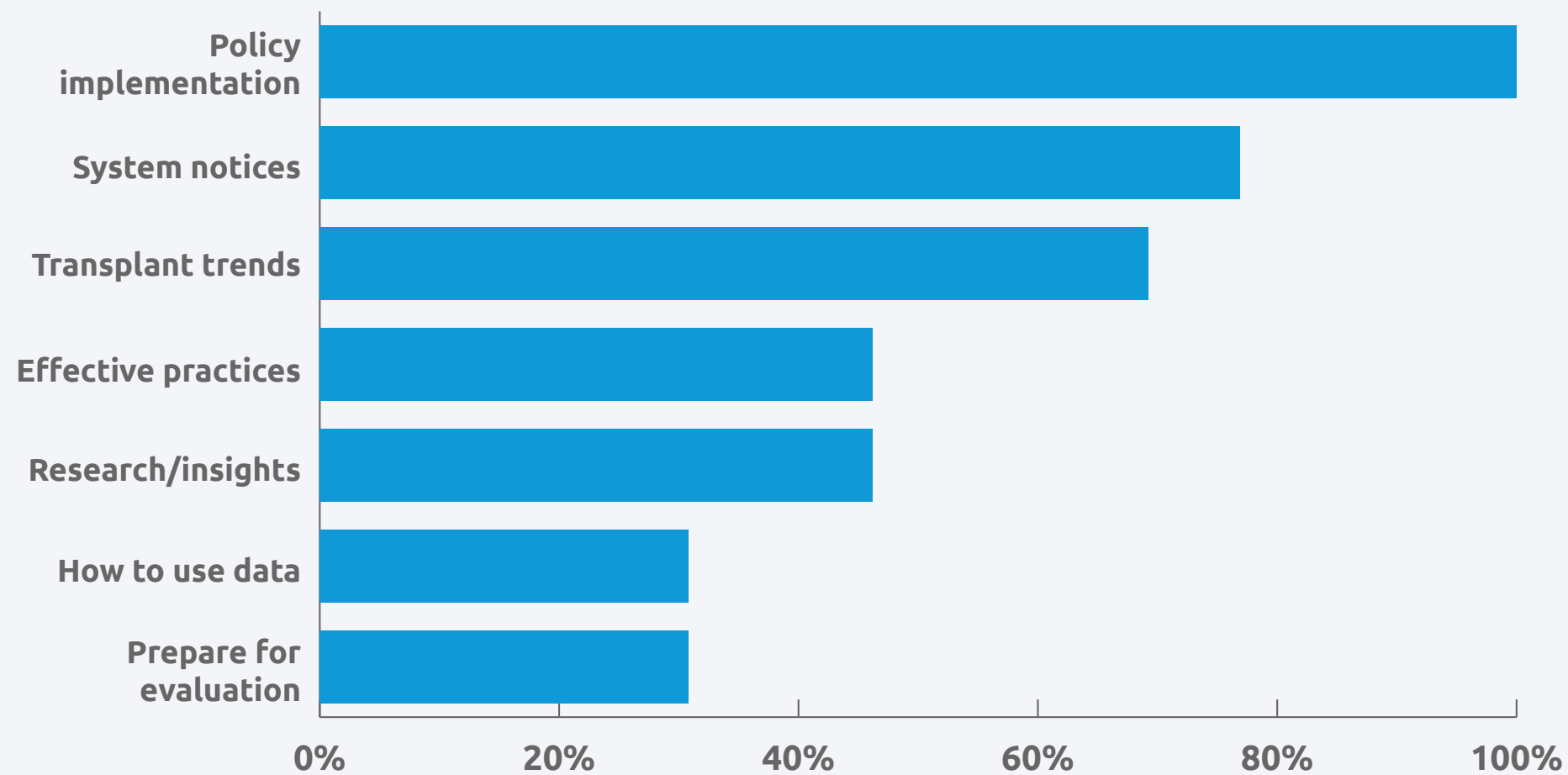
Use plain language. Use concise, relevant subheads.

“

To me, it's where's the policy?

SUMMARY: NEEDS & TOPICS OF INTEREST

What we want to find. Focus group questionnaire shows most frequently accessed topics:



Additional topics of interest mentioned during discussion:

- Policy
- Public comment
- MPSC stories
- Education paths for professionals
- Data tools: what's available and how to use

Objective

To understand the needs of visitors and improve the OPTN website, we conducted five focus groups and workshops in January and February 2020.

Our goals are to build trust among our members and strengthen the organ donation and transplant community.

Methodology

PARTICIPANTS

64 Patients and professionals from three regions and two committees

73 Professionals and patients tested the website navigation

Focus group *worksheet*

Your time is valuable as we are all working to save more lives. We appreciate your input. Information you provide here will be used to improve your experience on the OPTN website. We want to better understand you, your daily work schedule, your pain points and highlights working as a transplant professional.

How do you stay current on donation and transplantation news or policy updates?
 emails from UNOS and from transplant societies

What websites do you rely on for your job? (And with what frequency do you visit them?)
 ASTS, UNET, OPTN, SRTR at least weekly

What kinds of information do you access online most frequently?
 Effective practices Research / insights
 Policy implementation System notices
 Trends in transplantation How to use data
 Evaluation plans / preparing for evaluations

Preferred format when reading:
 long-form (articles longer than 700 words)
 digest
 bullets

What would you expect to find in a resource called 'online toolkit'?
 Bulleted and up to date "how to" for administration and clinical guidance

Guided discussion and questionnaire worksheets.



Card sorts and tree testing to evaluate current site information architecture and navigation.



Empathy mapping to understand patient and member challenges and goals.

- *Patients*
- *Transplant professionals*
- *Organ procurement professionals*

A day-in-the-life for the individuals who visit the OPTN website, based on responses during guided discussions

**See Appendix
for list of wants
and barriers**

Day-in-the-life of a **patient**

Today, as an waitlist candidate, I will:

- feel exhausted
- go to dialysis
- take time off from work
- worry about money
- make career and relationship decisions
- wonder if I'm listed at right place
- wonder where I am on the waiting list

“

*I'm running a marathon,
but no one told me the
distance.*

**See Appendix
for list of wants
and barriers**

Day-in-the-life of a **transplant professional**

Today, as a transplant coordinator, I will:

- see 50 transplant patients (pre- and post-transplant)
- respond to 400-500 emails
- respond to organ offers 24/7
- be repeatedly interrupted
- carry 3 or more devices (including pagers) plus batteries, chargers and more
- interact with many hospital systems and applications
- look up what happened to donor, share with staff

**See Appendix
for list of wants
and barriers**

Day-in-the-life of a **organ procurement professional**

Today, as an OPO coordinator, I will:

- carry a laptop, 2 phones, paper charts, a case box, educational materials, and medical equipment
- spend hours in my car
- look up the OUT report and SRTR's benchmark reports
- enter donor information into DonorNet
- feel pressed for time and have frequent interruptions
- frequently lose internet connectivity at hospital and have to switch from laptop to my cell phone to access records
- coordinate transportation for transplant

“

*Not an hour goes by
without a call.*

- *Policy and bylaws*
- *Patient education*
- *Professional education*
- *Proposed site navigation*
- *Proposed implementation schedule*

Policy and bylaws

Help me:

- easily find policy
- easily understand policy
- understand policy development

I want to easily find policy

Barriers addressed

Hard to find policies resources

Difficult to find policy, evaluation plan and bylaws.

Members “google” policies as many as 3x per day.

Need to access policies quickly in the OR. It’s an important discussion tool.

Actionable items:

- *Improve navigation to policies, bylaws, and evaluation plan*
- *Add a “Policy” section to main navigation*
- *Add a link to Policies.pdf in global navigation*
- *Rename “Governance” — users say it’s confusing*
- *Remove low traffic sections from navigation*
- *Simplify the policies page*
- *Less text*
- *In the summary list of new policies, add direct links*

I want to easily find and understand policy

Barriers addressed

Hard to understand what's new or changed

Must be able to see what a policy was a particular point in time

Actionable items:

1. *Improve the policies PDF document*

2. *Use highlights, underlines, strikethroughs and dates to indicate content changes. Users want to see:*

- *What's new (what's changed? What's new?)*
- *What's past (what was the policy on a given date?)*
- *What's gone (what policies no longer apply?)*

“

At the end of each policy, it tells you when the most recent part of it was updated. The last change that happened may only affect policy number 12 but the whole policy document date changes. It's just really hard to figure out, did I miss something?

I want to understand policy

Barriers addressed

Feeling overwhelmed

Lack of time to sift through lengthy web pages and documents

“

I feel overwhelmed and want a Cliff Notes version of what's new with this policy.

Actionable items:

- 1. Write in plain language*
- 2. Digest format: summarize and bullet points*
- 3. Remind me about upcoming policy changes*
- 4. Provide alerts*

I want to understand policy development

Barriers addressed

Communication style

Unaware of where a policy is in development

Actionable items:

Pre-implementation: Help me understand and prepare

- 1. Define what this policy will mean for the OPO world and for the transplant world*
- 2. List discreet steps to prepare my team*
- 3. Provide timelines whenever possible*
- 4. Make it visual: show where proposal is in the development lifecycle*
- 5. Be clear on what's going away and what's new*

I want to understand policy development

Barriers addressed

Communication style

Don't understand policy lifecycle

Site navigation issues

Actionable items:

Post-implementation: guide me

1. Write in plain language

2. Make it visual

3. Provide step-by-step guidance in policy toolkits

4. Help me access policies no matter where I am. Include link to policies document in global navigation.

Patient education

Help me:

- direct patients to helpful resources
- educate patients

I want to direct patients to helpful resources

Barriers addressed

I need resources.

I have to pull information from many sources; internal marketing teams have outdated content; time consuming

Actionable items:

- *Create a one-stop education shop for patients. Professionals need trusted, up-to-date resources that they can easily share with their patients.*
- *Create 1-page fact sheets in PDF format*

I want to educate patients

Barriers addressed

Low health literacy of patients

Actionable items:

Expand patient information about:

- *The entire transplant process — simply, quickly*
- *Understanding the waiting list*
- *Accepting PHS increased risk organs*

Professional education

Help me:

- find resources

I want to find resources

Barriers addressed

I need resources for both new coordinators and seasoned professionals

Actionable items:

- *Make toolkits more consistent in contents: include cheat sheets, quick summary of what classifications mean, templates for centers to adapt, share what's working at other centers*
- *Create learning modules and pathway for both new and seasoned professionals to better understand criteria for listing and exceptions, organ allocation, multi-organ matches*

QUOTES

“

One of the things we're starting to do is educate [new transplant coordinators] about what's happening on the OPO side or the donor side. They can kind of envision that they're trying to communicate to the surgeons.

“

I would like to have something that would be easy clicks for the coordinator to know the criteria for listing, the criteria for exceptions....

Proposed site navigation changes

Actionable items: (see page 26 for detailed navigation)



Tree testing

Evaluate findability of information on site using two navigation structures: existing and proposed

- *Create **PATIENTS** and **PROFESSIONALS** top-level navigation, replacing **LEARN** and **RESOURCES***
- *Rename **GOVERNANCE** section to **POLICY***
- *Rename **DATA** section to **DATA & CALCULATORS***
- *Create **ABOUT THE OPTN** section, housing items from **MEMBERS** section*
- *Add “Kidney paired donation” to **PROFESSIONAL** section to help people locate OPTN KPDP*
- *Create new subsection “Preparing for site visit”*

Proposed site navigation

Current navigation

- Home
- Governance ▾
- Members ▾
- Improvement ▾
- Learn ▾
- Data ▾
- News ▾
- Resources ▾

42%

Overall ability to successfully complete 14 tasks

Proposed navigation

- Home
- About the OPTN ▾
- Policy ▾
- Data & calculators ▾
- Professionals ▾
- Patients ▾
- News & events ▾

76%

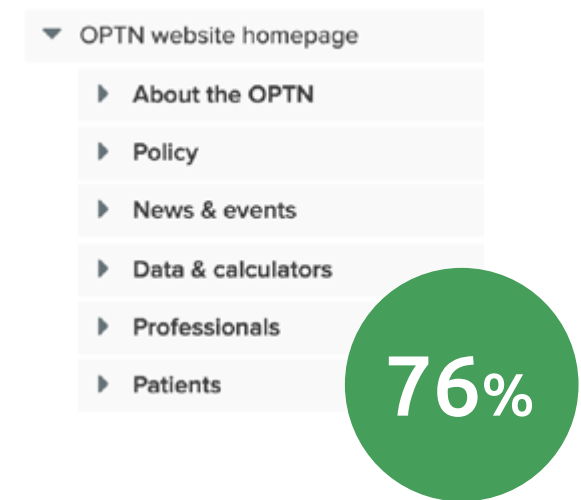
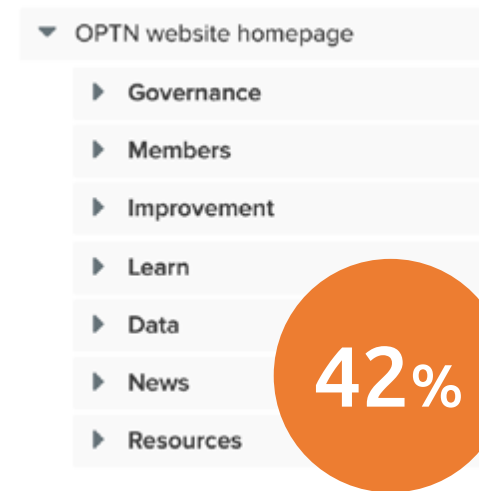
<p>What is the OPTN? OPTN History Bylaws Strategic plan</p> <hr/> <p>OPTN Membership Find a member Member actions</p> <hr/> <p>Board of Directors Committees Regions Review boards</p> <hr/> <p><i>How to get involved</i></p>	<p>Policies Policy notices Policy initiatives Public comment</p>	<p>About data View data reports Request data Citing data</p> <hr/> <p>ALLOCATION CALCULATORS</p> <p>CPRA EPTS KDPI LAS MELD PELD</p>	<p>BY ORGAN Kidney & pancreas Liver & intestine Heart & lung Vascular composite allograft</p> <hr/> <p>BY TOPIC Living donation Kidney paired donation Organ transport Pediatric transplant Informing patients Patient safety Ethics Guidance</p> <hr/> <p>PREPARING FOR SITE VISIT Compliance Evaluation plan</p> <hr/> <p>IMPROVEMENT About Impact Register</p>	<p>ABOUT TRANSPLANTATION How organ allocation works The transplant team Transplant process Pediatric transplants Multiple listing History</p> <hr/> <p>ABOUT DONATION Deceased donation Living donation Donor matching system</p> <hr/> <p>BY ORGAN Kidney & pancreas Liver & intestine Heart & lung Vascular composite allograft</p> <hr/> <p>Glossary</p>	<p>Newsroom Media resources Calendar of events</p>
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Tree test results

Overall ability to successfully complete tasks:

Test 1 *of existing navigation*

Test 2 *with revised navigation*



Task	OVERALL*	OVERALL*
You have an upcoming site evaluation. You want to prepare. Where would you look for guidance on how to prepare?	3 42% Success 58% Fail	4 49% Success 51% Fail
You want to read the policy related to kidney allocation points. Where would you look?	5 68% Success 32% Fail	10 95% Success 5% Fail
You want to find out who chairs the Heart Transplantation Committee. Where would you look?	6 74% Success 26% Fail	3 51% Success 46% Fail / 3% Skip

This overall score, out of 10 with an 8 or above considered well-performing, is a weighted average of the squares of success and directness. It favors success over directness at a ratio of 3:1, scaled to be a value out of 10.

Proposed site navigation

Task	Test 1	Test 2
	OVERALL*	OVERALL*
You want to find out what the acronym “GFR” means. Where would you look?	5 68% Success 32% Fail	4 57% Success 43% Fail
You need to find the time for the upcoming Living Donor Committee Conference Call. Where would you find this information?	3 42% Success 58% Fail	8 84% Success 16% Fail
You want to read more about how organ distribution policy may change. Where would you look?	3 42% Success 58% Fail	6 68% Success 32% Fail
You have thoughts on proposed policy change. Where can you share these thoughts?	5 68% Success 32% Fail	9 95% Success 5% Fail
You need to calculate a patient’s MELD score. How do you do this?	4 58% Success 42% Fail	8 89% Success 11% Fail
You need a kidney and want to understand how to receive a kidney from a friend. Where would you look?	3 37% Success 63% Fail	9 94% Success 6% Fail

This overall score, out of 10 with an 8 or above considered well-performing, is a weighted average of the squares of success and directness. It favors success over directness at a ratio of 3:1, scaled to be a value out of 10.

Proposed site navigation

Task	Test 1	Test 2
	OVERALL*	OVERALL*
You want to find a transplant center that participates in the OPTN Kidney Paired Donation Pilot Project. Where would you look?	1 0% Success 100% Fail	4 54% Success 40% Fail / 6% Skip
You want to find out how many people are on the waiting list for a kidney in Arizona. Where would you begin?	4 53% Success 47% Fail	7 74% Success 26% Fail
You want to understand how the kidney works and find major diseases that lead to the need for transplant. Where would you look?	2 0% Success 100% Fail	7 79% Success 21% Fail
You are the parent of a child in need of a transplant. Where would you look to learn more?	3 37% Success 63% Fail	8 84% Success 16% Fail
Your partner needs a liver transplant and you want to learn more about liver transplant procedures. Where would you look?	2 0% Success 100% Fail	9 95% Success 5% Fail

This overall score, out of 10 with an 8 or above considered well-performing, is a weighted average of the squares of success and directness. It favors success over directness at a ratio of 3:1, scaled to be a value out of 10.

Proposed implementation schedule

Tasks that are connected to site’s functionality are contingent upon upgrading the content management system which powers the OPTN website (currently Umbraco). We are presently defining business, technical and architecture requirements in order to upgrade the platform. **Dates below are contingent upon this needed upgrade.**

	Date	Page reference
Expand educational offerings for patients and professionals		
Online versions of patient brochures explaining policy	2021 or earlier	21 23
Standardize toolkits	ongoing	4 23
Enable users to print patient material easily	June 2021	20
Changes to navigation menu	2022 or earlier	25
<i>Note: Site navigation changes needed to improve user experience require rearchitecting the website, to include creating and managing hundreds of redirects to prevent broken links, and ensuring proper search engine optimization (SEO).</i>		
Improve findability of policy content	2021 or earlier	14 18 25
Simplify website name: Change domain name from optn.transplant.hrsa.gov to optn.gov	2021-2022	4
Improve search functionality	2023	4
Add direct links connecting people to policy	ongoing	14

Appendix

Additional information on needs and barriers

As a patient, I want to:

- Understand my status on waitlist
- Understand how the organ match happens
- Feel hope for my future
- Recover after transplant and stay healthy
- Be a part of improving the national system

Barriers

I don't feel well. Overwhelmed with information.

Conflicting information on the web.

Don't understand the technical language.

Understand data and feel empowered to make decisions.

Misinformation in the media. I don't know what's true.

Need trusted source where I can find information as my status changes.

I don't understand policy development process or how I can participate.

As a transplant professional, I want to:

- Increase transplants
- Be more efficient (improve process)
- Easily find policies
- Understand what's happening in public comment
- Easily share information with colleagues
- Provide easy-to-understand information to patients

Barriers

Low health literacy of patients

Too many systems, too much to do

Hard to find policies, bylaws, and evaluation plan

Hard to find public comment proposals (new and outcomes)

Limited time to summarize info to staff

Have to pull information from many sources; internal marketing teams have outdated content

As an organ procurement professional, I want to:

- Procure more organs

Barriers

Heavy caseload, connectivity issues and multiple system use (EHR and other health systems), potential donor family education

- Fully understand policy, especially complicated allocations

Policies are difficult to find. Lack of clarity and unreliable access in places such as hospital OR

- Train staff to comply with policy

Time. Unable to write bite-sized info for staff and maintain up-to-date onboarding materials.

- Coordinate transportation for transplant
- Increase transplants

Logistics, connectivity, time, communication