UNOS Member Survey 2011

Open-ended Comments
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Final Additional Suggestions
UNOS Member Survey 2011- Open-ended Comments

Informational Needs of patients, living donors, or non-transplant health professionals

Question: Are there informational needs of patients, living donors, or non-transplant health professionals that are not currently being met? If so, please explain.

1. Appropriate explanation of SRTR data and what it means at a simple patient level. Dramatic disclaimer for payors and the why to use SRTR data and what to use it form
2. .
3. A help desk or useful (available to transplant centers) phone number for 24 hour needs.
4. ability to breakdown data by DCD donors would be helpful
5. Brochures are on back order frequently
6. Brochures in Vietnamese would be helpful.
7. data! more self-serve report capabilities should be implemented.
8. Educational DVDs by organ
9. explanation of ECD, DCD and CDC high risk donors in pamphlet form
10. financial resources for living donors
11. more discussion on proposing reimbursement for living donors
12. history and archival of polices and procedures so you can research practice changes
13. I am not aware of any
14. I am not sure
15. I cannot identify a need at this point
16. I do not currently access this type of data.
17. I find very little educational material on Pancreas transplant.
18. I would like to see more in person support groups for deceased donor families, transplant recipients and living donors. I live in a rural area where all recipients have to travel for their transplant and then when they get home there is no formal support group type setting for them to interact with other transplant recipients. Same for bereavement support for the deceased donor families there is no support group for them. There is no support group type setting for folks who are listed for transplant or beginning the living donor process either...bottom line is more information and more support is needed.
19. I would recommend that UNOS develop a letter, similar to the one transplant centers are required to reference and include in all candidate patient correspondence, for donors. I would also recommend UNOS provide centers with another HIPAA memorandum so that we can get information easier from the recipient and donor PCPs.
20. Info about chain donation
21. Information needs are being met.
22. Information regarding international transplants
23. make it easier to find info. If I didn't know where to look, it would be very difficult to find various resources that are available online (e.g., thru the OPTN site). Policy and bylaws are difficult to navigate because some info is in less-than-obvious sections.
24. material on Paired Exchange is needed
25. more information available in Spanish
26. More information for living donors would be beneficial. Also success/outcomes at various centers should be easier to find.
More standardized information for patients would be helpful. Topics such as high risk donors, HLA typing/matching, etc would be helpful.

Need a review of all these resources I didn't know about.

Need EASY TO USE web page with patent, donor, and professional information.

N

need English as second language VERY basic transplant information - lots of pictures & basic simple information.

can use this for pediatric, MRDD, low literacy patients as well

need for various languages other than Spanish- ex: Russian

need more info about good Samaritan donation

Need standardized education info for What a High Risk Donor Is and ECD SCD donors.

Need Vietnamese language materials.
Opposite - In the interest of communication, UNOS/OPTN is requiring too much of the transplant center.

Paired Exchange patient information for patients at low health literacy - grade 4

Patient information hand outs are often on back order for long periods of time.

Patients do not know that they have a say in policy development. Most are so stressed when coming for evaluation, it may be difficult to explain the process, but UNOS should have an easy to read (8th grade level) section that explains policy development and how the patient can take part.

Some of the above I did not know about so I will be using these tools in the future.

Staff member that are in management may not directly work with patients. It seems that the best coverage and utilization of knowledge would be to send representatives that actually are involved in the transplant setup from listing, transplant, and post-operative care.

That living donors receive priority on the transplant list - this is crucial information and particularly for those who donated prior to the extra points policy going into effect.

The importance of following up with the transplant center or licensed professional after donation for a live donor.

The inventory levels of the online store has presented challenges throughout the year. There never seems to be enough to meet the need. Especially living donor and What Every Patient Needs To Know.

the system is hard to navigate

The UNOS information packets that are wonderful should be made available in Spanish-- you have all the books - just need to package with the letters.

The website needs to be simplified for persons from a nonmedical profession.

There could be some emphasis on the role of the HLA lab once in awhile, or a story on it.
There's a lot of information but I feel like it takes a while to locate it and/or navigate the databases.

They are met. I always refer my patients to review the UNOS website and I have no complaints so far.

Transplant Center level statistics regarding compliance on living donor follow up requirements, as well as break out detail on complications, morbidity and mortality.

Unknown

updated information about data on live donor risk and mortality

We need to have final UNOS guidelines to establish the evaluation, acceptance criteria and exclusion criteria for living donors with the intent to enforce those across all living donor programs is US.

We struggle for our non-English, non-Spanish-speaking patients to try and get them all educational materials translated.

When adding living donors to UNOS, I would like to see the UNOS ID and match ID be written in larger letters. They are difficult to see, and there is plenty of room on the screen.

It would be nice to connect with other transplant social workers, also I have had a difficult time accessing information about transplant for children. The info I’ve found is for young children who are themselves going through transplant but not much for those whose parents or grandparents are undergoing transplant.

Would like more education regarding Living donation for both recipient and potential donor.

Would like to have teaching materials in several languages for donors and recipients.

Would love to see “self survey” or “self audit” tools provided to transplant administrators to practice or self audit their center to improve compliance with living donor care, vessel storage and recipient compliance. Feel like this would allow programs to be more proactive in their compliance than react to the negative findings from an audit.

yes

yes

Yes, need some pediatric specific material

Yes, the web site is easier to find things than it was a couple of years ago

Yes. Stop informing me about the donor number and match run number during organ offer calls. I just want to press the button, go to the computer, and then go back to bed.
**Regional Meetings**

**Question:** What do you find most useful about the regional meetings?

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<table>
<thead>
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<tbody>
<tr>
<td>1</td>
<td>1. Receiving update from UNOS leadership on strategies and goals for the upcoming year for UNOS</td>
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<tr>
<td>2</td>
<td>2. Receiving updates from Regional Reps on UNOS Committees</td>
</tr>
</tbody>
</table>
| 3 | All aspects of the meetings  
Any topic that is current: live donor exchange was the most recent I attended and it was very informative. However if you are sending staff from an organ specific program it's helpful to have the most applicable topics presented to make the meeting the most useful to clinical staff.  |
| 4 | Being a part of the public comment process and hearing from other centers about how policy may or does affect them.  |
| 5 | Being able to meet with the region  
Bringing back pertinent information, packages of material, new/updated rules and regulations  |
| 6 | brings back current issues  |
| 7 | Can't answer because I've never attended a regional meeting  |
| 8 | Chance to ask questions of committee members and the councillor.  |
| 9 | change to keep up to data on issues  |
| 10 | Changes in policies that affect our institution.  |
| 11 | Clinical updates, and the business meeting  |
| 12 | Collaboration & sharing of ideas  
collaboration and information sharing  |
| 13 | explanation and intent of policy  |
| 14 | Collaborative session and organ specific sessions  
Collaborative sessions (day before meeting in Region V), organ-specific updates, UNOS update  |
| 15 | Committee reportas as well as UNOS speakers to discuss upcoming issues and answering questions  |
| 16 | committee reports especially on voting items  |
| 17 | committee reports, and opportunity to provide feedback on issues  |
| 18 | Committee reports, OPO meetings (when they occur) and information shared  |
| 19 | Committee reports; policy discussions; President presentations.  |
| 20 | Committee updates - what's happening  |
| 21 | Committee updates and discussion of public comment items  |
| 22 | committee updates and UNOS priorities. Also networking opportunities  |
| 23 | Committee updates  |
| 24 | Explanations of proposals  |
| 25 | committee updates, chance to network with other OPO/transplant center staff.  |
| 26 | Committee updates, etc.  |
| 27 | Committee updates, networking.  |
| 28 | Connecting with others  |
| 29 | Connecting with regional leaders in the field, access current info and policy development  |
| 30 | current changes and on-going learning  |
Differences between other centers and ours and how they differ/same
Discussion
Discussion among centers
Discussion of items out for public comment
discussion of policy out for public comment/other center issues with policy
discussion of policy with regional members
Discussion of proposals and networking opportunity
Discussion of public comment proposals. Updates on UNOS statistics
discussion of topics in and out of meeting
discussion re new policies
Discussion re policy interpretation/management trends
Discussions about the many regulatory requirements.
Discussions among other regional members
Discussions of proposed policies
Discussions regarding upcoming policy changes or implementations
Do not get the opportunity to attend
Does not pertain to my job at this moment
Don't know. Never get reports
education day
education portion,
the spats between docs are entertaining (this is confidential right?)
Examples of how programs had a solution for common problem. Collaboration with others
Feedback on bylaws interpretation
Forums
General information sharing
General information. Sometimes for Administrators the discussions are too clinical, but
good to hear the conversations.
General sharing of information
General UNOS Operational Update with National Trends and review of issues.
Committee Updates
General update re; policy changes, what's going on, etc.
get an update on policy changes
get messages to the UNOS reps and the CMS people - and hope they hear it.
getting an overview about trends within the region. Networking.
getting the points of view of other transplant centers and OPO's regarding issues
Getting updated general ideas about what is going on and discussing about new policies.
Good forum for discussing, evaluating, and planning for changes. Helps institutions remain
compliance and permits members to influence policy direction.
Good opportunity to see what is going on in the various committees. I enjoy the committee
reports and the proposal discussions
great to keep up to date on what is happening, changes in the organization.
Great updates on policy and a good time to meet with other OPO staff.
handout summaries of proposed changes
Having a representative involved in policy discussions
Heads-up on potential policy changes.
Hear about policies we didn't know existed - also learn about new policies coming down the
pike.
Hearing about relevant issues concerning Tx
Hearing about the different organs and what the committees are doing
Hearing from persons from several organizations who face the day-to-day challenges of implementing OPTN/UNOS regulations. People are very candid in the informal environments.

Hearing the information shared by specialists represented in the room.

Helps me better understand the thoughts behind policy changes.

HLA committee meets separately, then main meeting catches you up to what other committees are working on.

I am not the representative from our center, so I do not attend the meetings and have no input.

I am the representative for my institution. I find the meetings informative about policy in general and I gain insight into issues in other organ areas as well as my own.

I appreciate real examples of what other centers have experienced. Networking is very helpful. I appreciate reviewing new policies and open forums to discuss how others have implemented the change.

I attended the most recent one and found the person from UNOS giving an update about what is going/coming etc. very useful.

I do not really hear anything about them from the attending staff members.

I don't attend. Not sure if someone else does.

I don't know, I never go.

I have not attended for many years but plan to attend the next meeting.

I often learn new information or I am able to understand, in a bigger context, the information being considered at the national level.

I only attend the regional education forums which are usually excellent.

I personally have not attended.

I think the networking aspect is critically important.

I usually don't hear back about the meetings. Is there a summary online or a handout to give attendees so they could bring it back to dept so everyone is aware of what occurred at mtg?

Identification of best practice and new strategies for development.

I do not really hear anything about them from the attending staff members.

Networking with my fellow regional OPO representatives.

Learn about common issues across organs.

Learning about policies open for comment.

Learning about the proposed changes to policy or hearing about the latest controversies is better in person than reading it online or in an email.

Meeting other representatives.

Most current information and hearing other neighboring programs views.
National overview. Public comment sessions, Networking with OPTN/UNOS staff and other centers, labs and OPO

National unos updates

Committee updates

- Discussion of policies in development
- National updates from committees, networking in our region
- Network with other transplant professionals
- Networking
- Networking with other transplant professionals
- Networking
- Networking
- Networking
- Networking
- Networking
- Networking
- Networking
- Networking
- Networking & updated info of committees presented
- Networking and committee reports.
- Networking and discussion of regional challenges
- Networking and organ specific breakouts
- Networking and the UNOS update by a UNOS representative or officer
- Networking and updates on policy information/changes
- Networking for best practices
- Networking opportunities
- Networking opportunities. Ability to discuss potential changes.
- Networking with colleagues and discussions on topics
- Networking with colleagues in the industry; Learning from other colleagues.
- Networking with other centers
- Networking with other Transplant Professionals
- Networking with other Transplant Professionals
- Networking with peers, getting updates from our OPO and UNOS.

Review of upcoming UNOS activities and proposed policies

Networking opportunities

SRTR

Networking, clinical forum

Networking, committee updates

Networking, discussions

Networking, opportunity to have input into policy development
never attended UNOS meetings
New information, updates about the transplant practice.
new policies
New policy discussions and coming to regional opinion.
ew policy info
new tools, updates, resolutions to UNET situations in collaboration with our systems, etc.
News and policy updates
no idea, no feedback comes to my level from the person(s) who attend
Open discussion about proposals
Open discussion.
Opportunity to connect with regional partners.
Opportunity to dialogue with colleagues
opportunity to provide some feedback and vote on some policies, though not all
Opportunity to remain current with policy changes, networking with other transplant professionals
organ specific policy changes and discussions. networking with professionals from other areas of the region.
Our representative did not share with us the information.
Our Surgeons attend MAPB meetings. I am not sure of what information they bring back to the rest of the professional staff.
Our transplant nephrologist (UNOS rep) attends and enjoys updates, networking,
discussion, although he doesn't always share information.
Overview of public comment proposals. Additional information about complying with new policies that come out.
paired exchange policy updates
Participation in the process
participation, being heard, networking, lobbying
peer to peer interaction and policy discussions
Personally, never attended. Those attended usually don't talk much about their experiences at the meeting
Placing a face behind the voice/email.
policy discussion
Policy discussion and networking
Policy discussion, proposed changes, networking within the region and across with other region (recently Region 3 and !! met together) and I enjoyed it very much.
Policy discussion, voice in process
Policy discussions
Policy discussions
Policy discussions - networking
Policy reviews
Policy updates
policy updates
policy updates
policy updates
Policy updates and discussions and the chance to see and Ali to other members.
policy updates and impending changes; committee activity reports
Policy Updates
Face to face meetings with colleagues
Policy updates

Networking

Policy/future policy updates
Potential policy changes related to Kidneys.
Powerpoints and discussions in the business meetings; networking.
Presentations from committee leaders
Presentations re: OPO performance for our region
Proposal discussion
Proposals, policy updates
Proposed policy changes are reviewed, Committee Updates
Presentations re: OPO performance for our region
Proposal discussion
Proposed policy changes are reviewed, Committee Updates
Quick updates
Receiving info about current news in transplantation and networking with other transplant programs
Regional and national policy updates
Regional committee updates, national updates
Regional representation and networking opportunities.

Collaborative meeting the day prior to the business meeting.
Representative attend; I do not attend
Representative goes
Review of the proposals.
Review proposals
Seeing and meeting the other transplant individuals from the region.
Seeing colleagues, hearing policy descriptions. Mostly, they are very dry and the reports just read the UNOS staff's slides. Often, the slides are in UNOS-speak and difficult to really understand.
Shared information from all disciplines
sharing information, educational component
sharing of information and practices
Stay current with our region and the presentations etc.
Staying up to data on liver, heart and lung practices and policies as we don't have transplant programs in our service area.
Talking to the other people about their experiences. Hearing what is happening at our transplant centers in the region.
Talking with staff from other centers, ie networking
The collaboration between professionals at different centers and the chance to communicate offline with the OPOs.
The collaboration of all aspects of donation & transplant that generates so much discussion on every aspect. I find interesting the passion and "stubbornness" that can be displayed often from transplant surgeons on behalf of their recipients and what the surgeons feel is "the only way to do things". It often generates very lively discussions that can result in great ideas for moving forward.
The discussion relative to policy changes that are up for board approval
The discussion surrounding proposed new policies.
The educational offerings.
the general thoughts about what is happening in the region and the country
the information discussed and presented there; the networking
The interaction between members and updates on policies.
The knowledgeable discussions about policy proposals and the UNOS updates
The most useful part of the meetings is talking about new issues in transplantations.
The opportunity to air the unique needs created by our location.
The opportunity to meet with peers face to face.
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<tr>
<th>Number</th>
<th>Description</th>
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<tbody>
<tr>
<td>231</td>
<td>the organ specific break out sessions</td>
</tr>
<tr>
<td>232</td>
<td>The organ specific updates</td>
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<tr>
<td>233</td>
<td>The overall updates by UNOS senior management. The representative does not share information from the Regional meetings with transplant staff</td>
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<tr>
<td>234</td>
<td>The UNOS general update about BOD plans/actions</td>
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<td>235</td>
<td>The updates on UNOS activities and the policy discussions</td>
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<tr>
<td>236</td>
<td>tying into Regional collaborative meet and sharing best practices and networking</td>
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<td>237</td>
<td>updates on policy</td>
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<tr>
<td>238</td>
<td>Understanding the positions UNOS takes on issues and activities of the UNOS committees</td>
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<tr>
<td>239</td>
<td>Unknown</td>
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<tr>
<td>240</td>
<td>UNOS by law updates</td>
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<td>241</td>
<td>UNOS staff presentations</td>
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<tr>
<td>242</td>
<td>UNOS update; discussions that give other prospective.</td>
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<tr>
<td>243</td>
<td>Unsure if a representative attends.</td>
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<td>244</td>
<td>Update and discussion of policies.</td>
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<td>245</td>
<td>Update and discussions with transplant colleagues</td>
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<td>246</td>
<td>Update on current issues</td>
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<td>247</td>
<td>Update on current policies and discussion of current proposals.</td>
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<td>248</td>
<td>Update on current UNOS initiatives. Discussion with other centers</td>
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<td>249</td>
<td>update on regional data</td>
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<td>250</td>
<td>Updates</td>
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<tr>
<td>251</td>
<td>Updates / current information / upcoming issue / policy change / networking</td>
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<td>252</td>
<td>Updates and networking with regional transplant staff and UNOS representative.</td>
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<tr>
<td>253</td>
<td>Updates and the opportunity to comment on UNOS policy issues.</td>
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<tr>
<td>254</td>
<td>Updates from committees, policy updates</td>
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<tr>
<td>255</td>
<td>Updates from the UNOS committees on policy and by-law changes, the interaction with my Region and my UNOS Rep, the opportunity to speak freely and give input on organ and tissue donation in my state, region and for the future of the U.S.</td>
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<tr>
<td>256</td>
<td>Updates on bi-laws and changes in polices.</td>
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<td>257</td>
<td>Updates from the various committees</td>
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<td>258</td>
<td>Updates from UNOS leadership and committees</td>
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<td>259</td>
<td>Chance to meet those from other centers</td>
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<td>260</td>
<td>Updates on new or proposed policies</td>
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<tr>
<td>261</td>
<td>Updates on new policies, chance to verbalize concerns/issues regarding DonorNet</td>
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<tr>
<td>262</td>
<td>Updates on policy changes and committee activities</td>
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<tr>
<td>263</td>
<td>updates on information</td>
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<td>264</td>
<td>updates on UNOS changes and pro &amp; cons to proposed by-laws</td>
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<tr>
<td>265</td>
<td>Updates on what is to come in the transplant world updates regarding current happenings; committee updates; policy updates and proposed changes; networking with regional colleagues.</td>
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<tr>
<td>266</td>
<td>We always send representative(s) to the regional business meeting; we have regionalmanagement True or False?</td>
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<tr>
<td>267</td>
<td>Updates, collaboration, networking</td>
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<tr>
<td>268</td>
<td>Voting on current issues before the transplant community</td>
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<tr>
<td>269</td>
<td>Very little</td>
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<tr>
<td>270</td>
<td>Very little, other than voting on specific policy issues.</td>
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<tr>
<td>271</td>
<td>Voting on current issues before the transplant community</td>
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<tr>
<td>272</td>
<td>We always send representative(s) to the regional business meeting; we have regional management True or False?</td>
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</table>
education primarily by webinars due to travel, cost, staffing, etc, so it has been helpful to get more staff exposed to information

275 We rarely get feedback from the meetings
276 whole thing
277 Will attend my first at the end of this year.
278 Wish we could attend-
279 Yes
280 yes
281 yes
Regional Meetings—Suggestions

**Question:** What are your suggestions for improving regional meetings?

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<th>Response Text</th>
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<tr>
<td>1</td>
<td></td>
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<td>2</td>
<td>?</td>
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<td>3</td>
<td>A few more updates on the DDC and registry progress along with the Paired Exchange program progress</td>
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<tr>
<td>4</td>
<td>ability to do live web if we cannot travel</td>
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<td>5</td>
<td>Ability to get followup from UNOS on issues raised at these regional meetings. Afternoon session tends to lose attendees therefore I would recommend a working lunch with networking at the end of the meeting. Allow for more non physician participation. Many times only physicians are acknowledged in the meetings and others ignored</td>
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<td>6</td>
<td>allow live meeting or conf call-have meetings near airports</td>
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<td>7</td>
<td>Allow many personnel to attend from host center. An introductory activity so you get to meet and greet so you know who is attending and from where. Also required attendance for all transplant centers.</td>
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<td>8</td>
<td>appreciate the current format/agendas</td>
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<td>9</td>
<td>Back in the day, I enjoy the all day seminars.</td>
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<tr>
<td>10</td>
<td>Betsy Region 2 does a great job with a feisty audience!</td>
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<tr>
<td>11</td>
<td>better food</td>
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<tr>
<td>12</td>
<td>Better meeting facility, more time for discussion</td>
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<td>13</td>
<td>better representation at the meetings</td>
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<td>14</td>
<td>Breakaway sections to discuss your organ specialty</td>
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<td>15</td>
<td>Broaden the topics. The meetings are very specific and have a narrow focus.</td>
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<tr>
<td>16</td>
<td>Can't answer because I've never attended a regional meeting</td>
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<tr>
<td>17</td>
<td>CEPTC / education component tied into it.</td>
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<tr>
<td>18</td>
<td>changes times of year-go back to March/October- it is really hard to travel in December</td>
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<td>19</td>
<td>Committee presentations often could be condensed more effectively.</td>
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<td>20</td>
<td>Continue to rotate locations across the region</td>
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<tr>
<td>21</td>
<td>Develop the collaborative meeting prior to the business meeting. These might benefit from a stronger focus on policy and regulatory requirements and process improvement. The material seems to be 'recycled' a lot and becomes less engaging. There needs to be a balance between these current 'best practice' presentations and more traditional business improvement strategy. How about engaging the region prior to the meeting to see what THEY want to see/learn about?</td>
</tr>
<tr>
<td>22</td>
<td>Do it online through an internet meeting protocol.</td>
</tr>
<tr>
<td>23</td>
<td>Do more by live meeting. Travel time is wasted time.</td>
</tr>
<tr>
<td>24</td>
<td>Does not pertain to my job at this moment.</td>
</tr>
<tr>
<td>25</td>
<td>Don't combine 3 &amp; 11 again.</td>
</tr>
</tbody>
</table>
30 find ways to improve attendance.
31 focus on quality
32 Geographically difficult to get to
33 Have a limited open forum period to discuss current regional issues/concerns
34 Have proposed policy changes written in English. Written by someone who writes using the English language as opposed to lawyer or government jargon.
35 Having the President there is excellent and sends a strong message of support.
36 host a 30-45 minute best practice presentation - highlighting a OPO and a TX Center unique approach to anything....more to stimulate best practice conversations and share ideas
37 I am not the representative
38 I attending the transplant forum held in Richmond for the transplant centers. Is there anyway to do the same thing for the OPO's? I would be happy to volunteer to help as would many others.
39 I cannot identify a need at this point
40 i could care less about the OPTN business etc. We are there to discuss policies and vote
41 I don't have any new suggestions, I think Shannon Edwards does a great job setting them up and organizing things
42 I don't have any special requests at this time.
43 I dont know
44 I have no suggestions. I like them as they are.
45 I haven't personally attended the meeting.
46 I liked it when the educational forums were presented twice a year, which is no longer the case. It was a good way to network and to obtain CEPTCs.
47 I liked the old 2 day regional meetings where the first day was an educational component and the 2nd day was the business meeting. Offer MD and RN CEUs and CEPTCs.
48 I think our meeting run pretty well
49 I think our region 4 meetings are handled well. Sometimes the committee reports at the end are a bit rushed, but I can't think of a way around that.
50 I think that the meetings are very well organized and scheduled appropriately so as to allow travel in a single day.
51 I usually don't hear back about the meetings. Is there a summary online or a handout to give attendees so they could bring it back to dept to distribute so everyone is aware of what occurred at mtg?
52 I would like to see the meeting more balanced by representing topics on both transplantation and donation.
53 I would recommend a meet and greet - something formal so newcomers can feel welcome and get to know transplant staff from other centers.
54 It is always held on the same place. It will be helpful to rotate in the cities of member institutions
55 It is mostly geared towards the OPO's, a little more information regarding transplantation would be nice.
56 It would be helpful if it were possible to fly in and out on the same day.
57 Keep rotating the location
58 Keep topics and discussions focused: continue associated educational opportunities
59 Keeping them on time
60 Keeping to agenda, updating issues on all organs (not just single organ dominance of any meeting)
61 Keynote speaker on a transplant topic....CME, CEU maybe the night before or at lunch
62 Less Paper, more digital.
Less redundancy. More Dynamic presentations. I can read the powerpoint myself. Most presenters read verbatim what the slides say. Yawn.

Limit the amount of time for each committee representative to present materials - stay on point.

Live meetings so that more can attend by teleconference and web link.

Make physicians act like adults. Sorry. Just the way I see it.

make region 3 smaller

Make sure slide sets get sent out after the meeting. Timely distribution of the minutes.

Make sure they are easy to travel to, and keep the agenda focused.

make them more accessible to more staff

Make travel worthwhile. Would try to add an educational component, or have committee members give more detailed background on committee thoughts and actions.

Maybe adding one break out session. This allows regional topics to be addressed without it having to be at a national conference. For instance, we'd be happy to talk about air/ground transportation best practices - and there may be 15-20 people that want to hear that, but would not be able to at a national conference.

more educational opportunities

More informed staff available for public comment items.

More meetings with Regions 3 and 11 combined as was their history.

More opportunities to discuss regional issues

more regional initiatives

Move through the information more quickly.

N/A

n/a

N/A

n/a

n/a

N/A - have not attended

NA

NA

NA

NA

NA

need the ability to have better teleconferencing for members that can not attend due to financial or on call responsibilities.

Need to be sure there are enough materials. At the most recent meeting I attended, there were several attendees who did not get the meeting materials.

needs to be more time for dialogue and not just presentations

No

no

No concrete suggestions, meetings seem fine.

No opinion

No problems

No recommendations.

no suggestions, satisfied with time frame and meeting content.

none
UNOS does a good job of condensing a lot of information into a small chunk of time. Also appreciate the 2 meetings face-to-face and 2 meetings using technology. Best use of time without losing the value of face-to-face interaction.

Our location in Region 10 is not desirable but it is what the members wanted.

Our regional meetings run very well - no suggestions at this time.

Personalize slides to Region, or have the person reporting out have a better understanding of the slides.

Please have a meeting in Washington, DC prefer face to face meetings rather than conference calls since in person meetings generate more discussion and dialogue

Provide policy review first to allow ample time if needed and some informational presentations at the end

Provide some financial support so more organizations may attend. Too many member organizations see attendance at UNOS meetings as the first budget item to cut.

Provide the opportunity for more people on the “front lines” who actually work on allocation and with the recipients to attend the meetings. I realize this is mostly up to the OPOs; however, I don’t believe it is conveyed to the general OPO staff that they may attend the meetings as a public forum.

Region 4 is run well...no complaints.

Representative goes

rotate location

Rotate meetings to different sites again

Rotating meeting sites if possible

rotating the venue to allow better proximity periodically might help

See above.
seems to always be on a Friday which may be good for many but maybe sometimes on a Monday.

Sharing more information on Best Practices and methods to increase utilization shorter

skip some of the unimportant committee updates, or figure out a way to limit them to a prescribed timeframe. Listening to someone blather for >10 minutes about the multicultural affairs committee is not a good use of anyone's time. Some of the policy info is boring and time consuming-- maybe have a teleconference for this-- so more could attend.

stay focused
the chair of specific committees should participate by phone when important policies are up for voting.

The meetings are pretty dry. Could one get CEUs for it?

The pre meeting dinner was an excellent idea!
the recent merge of regions 3 and 11 was very good as there was good discussion on how proposed changes impact the regions

There could be more data about how our region compares with others / suggestions from other regions about how to improve our performance. We should hear more about waitlist trends; discard rates (kidneys), deaths waiting for transplant

There must be a way to mandate that all attendees stay to the end of the meeting. One suggestion would be to put the organ specific committee reports at the end of the agenda with Kidney/Pancreas last.

They have significantly improved over the past years and I found the last meeting very informative on ethics

Unsure if a representative attends.
Use the full day. We are often rushing through important topics so that people can fly out in the late afternoon.

Use the regional meetings for a standard ongoing training about UNOS policy and regulation. Each transplant hospital is required to maintain staff competency and continuing education. It would be helpful if UNOS facilitated a more easily accessible training program staff could attend or participate by webcast to maintain ongoing competency regarding UNOS / OPTN regulation.

Utilize webmeetings to conduct regional meetings to keep cost down.

Vary location and day of week.

Videoconference

Webcasting

When offered as webcate or there is listening opportunities we try to be involved

Will attend my first at the end of this year.
### Evaluation Plan—Usefulness

**Question:** What do you find most useful about the evaluation plan?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The extent of the information</td>
</tr>
<tr>
<td>2</td>
<td>Resource for how to remain in compliance.</td>
</tr>
<tr>
<td>3</td>
<td>Thoroughness.</td>
</tr>
</tbody>
</table>
| 4      | The hyperlinks are beneficial for supplemental and supporting information.  
the ease of finding information and the way that it is set up to distinguish OPO from TX Centers |
| 5      | N/A |
| 6      | N/A |
| 7      | easy to follow and understand |
| 8      | outlines exactly what needs to be done to meet the requirement in a concise wayl. |
| 9      | Keep up with regulatory changes |
| 10     | Interpretation of guidelines, what surveyors are looking for. |
| 11     | comparing expected rates vs transplantation rates  
I had to pull it up to refresh myself on it. I have not looked at it in some time. I tend to access policies and bylaws when I need questions answered. However, I review changes when sent, but to be honest don't remember receiving 2011 updates. |
| 12     | Update |
| 13     | n/a |
| 14     | Well organized, easy to use, accessible and current |
| 15     | very specific description of how to comply.  
Love that is separates how the policy applies to the different estates (OPO, vs Transplant); |
| 16     | Very useful guide. I reference it all the time. |
| 17     | N/A |
| 18     | Everything that you need to know to run a transplant program. |
| 19     | current updates that link to policies |
| 20     | Changes highlighted in blue.  
Very helpful to understand up front the expectations for participation so that we can align our practice consistent with good patient care and compliance |
| 21     | Clarity of the rules |
| 22     | Good guidance for demonstrating compliance with policy. |
| 23     | Allows updating of policies to maintain compliance.  
I really liked the "Overview of Policy Modifications/Board Actions and Affected Professionals summarization that used to be sent out right before the evaluation plan. |
| 24     | Good reference |
| 25     | Great reference when needed |
| 26     | the changes are highlighted  
The policy pages that delineate whether the policy applies to the OPO, HLA lab or Transplant Center |
| 27     | How we will be evaluated and the specifics |
| 28     | Areas relating to OPOs. |
| 29     | understanding how auditors will be evaluating compliance issues. |
| 30     | I do not use it personally our manager does |
It is important to know exactly what the transplant center is responsible for updating section from last plan publication date.

Compliance monitoring

I appreciate the policies each give suggestions on how to be in compliance. This has been helpful.

SUMMARY CHANGES AND LINKS TO THE POLICIES

Reviewing the information to determine if we are meeting requirements.

the information about what is needed to comply

Used as reference for some standards

As a QA Director of an OPO, it serves as a guide to me for ensuring our staff understands the specific expectations of UNOS for members to remain in compliance; it helps me identify when we are out of compliance.

Way too long and hard to follow.

The changes are highlighted in blue, hyperlinks are provided.

i read the evaluation plan

I like that it's online.

self explanatory... we have a plan

Reading it after doing this survey

Help with maintaining compliance with regulations

it helps guide policies/QAPI

the detail and explanation

That we have one.

Nothing useful.

Compliance

The summary of policies and updates

changes to the policies and how to be compliant with these

Easy to find needed information

red highlighted changes and 1 page overview of how to comply

Keeps our performance expectations in the forefront of our minds.

Guidelines for allocation

assists with QAPI

Summarizes key requirements

i have looked at it, but haven't done much more than that.

The plan is fairly straightforward to follow allows for a uniform policy with which to follow.

The description of how to comply

Links to actual policies.

ability to search the document electronically

it keeps me up to date with current policy and regulatory "best practice"

Validating understanding of requirements.

Help us keep our processes compliant with CMS/UNOS requirements.

Guidelines for compliance with OPTN policies

All updates- Would like more input on how to search the data- Not too familiar

having access

NA

Its comprehensive nature.

Policy guidelines

formulating changes to policy or practice to be in sync with OPTN in a timely fashion

helps operationalize most policies.

information on the most common areas of non-compliance

searchable - thank GOD!
didn't know about it
provides overall easy to use summary
The information provided on exactly how to comply with policy
Provides detailed info regarding policy implementation
Every aspect of it
It provides some insight & guidance
Survey preparation/internal policy review
Help us understand what we need to focus on
Answers the day to day questions that arise regarding waitlist management
Our center uses this plan to make sure we are following policy and it helps when prepping for audits.
Refer to it frequently for updates and for guidance.
It is simpler to read/ navigate than the policies & bylaws
The section for each policy that tells us how to compliance will be measured.
Overall mimics the guidelines we use as an OPO.
Knowing where the emphasis is in our community or professionals.
being able to reference rules and expectations
Again - really does not apply to me as I am a living donor.
Updated policies and implications for transplant center practice. Unfortunately, do not reference often enough and get behind.
format
Good place to go for updates, like that they are highlighted
No opinion
highlighted changes
Everything
Supplement to UNOS policies
clear expectations
Helps interpret vague OPTN policy language
Updated Information
Explains the process for policy development and implementation
Format and comprehensive nature of it. It is applicable and helps to clarify questions regarding UNOS expectations.
More in depth means necessary to maintain compliance.
It helps with internal policy and protocol development.
helps with compliance
expanded explanations
It outlines each policy clearly and the member responsibilities as well as how DEQ will assess for compliance
It tells you exactly what to expect from an audit and how to comply with policies
All of it.
Summary each quarter of policy changes.
Sections 4 and 5 of each policy.
Highlighted changes and links to bylaws and policies
Policy Updates
Good
good guideline
 Identified changes
Easy to read - quick 1 to 2 page guides
Being able to access it on-line
Clearly noted updates each quarter.

How compliance will be measured

Explanation about how compliance is measured

It details how specific components will be evaluated

What specifically is being evaluated.

It is a document that we can refer when we have questions.

new updates are highlighted

confirming that we are in compliance

This was a recent introduction and I find it very helpful in trying to insure compliance with all the necessary requirements my different departments in our facility

The plan is clear and concise the fact that items are highlighted is a plus.

They provide a framework for day-to-day transplant center operations and UNOS site survey preparation

The explanation of how to comply is straight to the point allowing centers to conform while maintaining a flow to patient care and not causing disruption to a center unlike Medicare.

organized way of checking

policy changes highlighted in blue

To double check that we are doing the appropriate things

Knowing key items to address...good summary.

protocols,

n/a

Very specific in terms of what surveyors look for as evidence of policy compliance

actionable item
## Evaluation Plan—Suggestions for Improvement

**Question:** What are your suggestions for improving the Evaluation Plan?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>A summary of what is new each quarter, and maybe these exist because my quality department does pull it for me.</td>
</tr>
<tr>
<td>2.</td>
<td>Assists in revision of policies and procedures.</td>
</tr>
<tr>
<td>3.</td>
<td>At times the language is vague and lacks authoritative position - which is frustrating for Transplant Centers. We will follow the rules - we just need clarity about what those rules are.</td>
</tr>
<tr>
<td>4.</td>
<td>Better table of contents with specific policy on specific page of document. Chang the layout of the evaluation plan so that it can be used as an audit tool. Currently the plan has to be converted. Make it in a format that would allow for policies and bylaws to be sorted by member type for ease of finding.</td>
</tr>
<tr>
<td>5.</td>
<td>Create two evaluation plans, one for OPOs and the other for Transplant Centers, a document of three hundred and something pages is a little ridiculous. Another suggestion may be to split it by policy or bylaw section and subsection so centers/OPOs may print what is applicable to them.</td>
</tr>
<tr>
<td>6.</td>
<td>Define evaluation delineating the changes more clearly and as a total unit, so you don't have to go to other places to review what the changes are.</td>
</tr>
<tr>
<td>7.</td>
<td>Do not use it. Freda Wilkinson put out a &quot;quick tip/guide&quot; for patient notification letters (great!!!). I think more &quot;quick tip guides&quot; as well as some best practice examples would be VERY helpful.</td>
</tr>
<tr>
<td>8.</td>
<td>I am embarrassed to say although very involved with national policy I really only very recently started using the evaluation plan. Think we are all so focused on CMS final rule and the interpretive guidelines it gets hard to keep reviewing other regulatory references and you end up dwelling on the CMS ones.</td>
</tr>
<tr>
<td>9.</td>
<td>I am on the pre-side primarily, but think this is good info all coordinators need to know. Perhaps presenting a webinar as to usefulness from a nurse perspective would be helpful.</td>
</tr>
<tr>
<td>10.</td>
<td>I don't personally use it but my Quality and Safety officer does.</td>
</tr>
<tr>
<td>11.</td>
<td>I like it just as it is. I think it works very well. The instances of non-compliance that I'm aware of have not been because of lack of clarity in the evaluation plan.</td>
</tr>
<tr>
<td>12.</td>
<td>I think the name is confusing. I'm too embarrassed to say what it means I think it's a great tool. I'd like a similar document that is comprehensive of all policies &amp; bylaws. Perhaps the 'rewrite' project will accomplish this.</td>
</tr>
<tr>
<td>13.</td>
<td>If possible and needs to be shorter. We are regulated to death.</td>
</tr>
<tr>
<td>15.</td>
<td>Is there a way to condense it? It's hugely long and not easy to find information. I would like an easier way to identify revisions, updates, or clarifications.</td>
</tr>
<tr>
<td>16.</td>
<td>It is too long, but not sure how to fix that. It's a very large document - put links within the document that can take you from the table of contents to the specific policy section you are interested in.</td>
</tr>
<tr>
<td>17.</td>
<td>It's so large, that it is difficult to navigate. Just looking at it now? 398 pages? How could this possibly be necessary? What are the key points?</td>
</tr>
<tr>
<td>18.</td>
<td>Large plan - sometimes difficult to find information.</td>
</tr>
<tr>
<td>19.</td>
<td>Lengthy. Needs to be bulleted so that it can be more easily read/skipped.</td>
</tr>
</tbody>
</table>
29 Links do not always match up to where you need to go.
30 make date effective more clear
31 make is accessible to download as a "write" document
32 Make it easier to find policy
33 make it more user friendly
   Make it part of the general training of new members and also make sure all centers are
34 training staff on the availability of these tools
   Make it readable - less than one page. Again, get someone to write it in concise English.
   Currently it is not readable by normal human beings. Once it is put into concise English and
35 made readable there could be actual suggestions for improvement.
36 Make it shorter
37 Many minds greater than mine are working on this.
38 Make an electronic compliance tracking checklist
39 More direct and specific
40 More usable index
41 N/A
42 n/a
43 N/A
44 N/A
45 n/a
46 NA
47 NA
48 NA
49 Needs to be easier to read. Need a better process to highlight changes.
50 No suggestions
51 None
52 none
53 None
54 none
55 none
56 none
57 none
58 None
59 None at this time
60 None at this time.
61 None at this time.
62 none for now
63 None.
64 Not sure
65 organization- difficult to find things. Have to refer to multiple policies to get all the answers.
66 Overall, it's hard to find what I'm looking for.
67 perhaps a summarized version
   Plain english & brevity - not necessarily a "9-9-9" plan, but a damn decent effort at it would help. (I know I'm talking to the wind...)
68 Please, please consider drafting a template for centers to follow so that common areas for non-compliance (ABO verification) could meet both UNOS and CMS. We have been audited recently and even with a change in either UNOS or CMS policy, things that were acceptable at one audit are now no longer acceptable. This would make things so much easier for centers to be compliant rather than guessing and expending an inordinant amount of effort trying to do things correctly only to find we are not.
seems that opo and transplant are mixed together, separating them would be helpful
shorten
Simplify it - streamline it, it's too large. Improve table of contents or searching for a specific topic.
Some of the wording is not as stated in the policy.
Sometimes confusing what is under revision and what is current
Standardized forms, such as ABO verification prior to surgery, would be GREAT.
Streamline the document
The plan needs to match what all regulatory people require of transplant programs.
There needs to be a "table of contents" or something that allows you to quickly find the section you are looking for and skip to it. I find the current format difficult to navigate
To soon for me to make any recommendations-
Too large. I would just like to see policies that pertain to transplant centers and I would like them grouped by categories that are easy to navigate. I feel like we're always discovering policies that we never knew existed.
Too large...wish it were a bit more user friendly.
UNOS and CMS should use the same tools to ease the tremendous burden on centers
**UNOS Website-Usefulness**

*Question: What do you find most useful about the redesigned UNOS website?*

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Access to data/statistics</td>
</tr>
<tr>
<td>2</td>
<td>Access to our listed population lists</td>
</tr>
<tr>
<td>3</td>
<td>Accessibility of organ offers and ABO verification</td>
</tr>
<tr>
<td>4</td>
<td>actually, I use it much less often because a lot of what I need was moved.</td>
</tr>
<tr>
<td>5</td>
<td>ah that explains it...</td>
</tr>
<tr>
<td>6</td>
<td>all of it</td>
</tr>
<tr>
<td>7</td>
<td>As useful as the previous one</td>
</tr>
<tr>
<td>8</td>
<td>automatic transfer</td>
</tr>
<tr>
<td>9</td>
<td>Best practice articles are hard to find!!</td>
</tr>
<tr>
<td>10</td>
<td>Better designation of UNOS role to the OPTN</td>
</tr>
<tr>
<td>11</td>
<td>Better organized than before.</td>
</tr>
<tr>
<td>12</td>
<td>central location</td>
</tr>
<tr>
<td>13</td>
<td>centralization</td>
</tr>
<tr>
<td>14</td>
<td>clarity has improved</td>
</tr>
<tr>
<td>15</td>
<td>Clear and happy vibrant colors.</td>
</tr>
<tr>
<td>16</td>
<td>Clear delineation of areas of responsibility</td>
</tr>
<tr>
<td>17</td>
<td>data</td>
</tr>
<tr>
<td>18</td>
<td>data, policies and bylaws</td>
</tr>
<tr>
<td>19</td>
<td>data reports</td>
</tr>
<tr>
<td>20</td>
<td>data reports</td>
</tr>
<tr>
<td>21</td>
<td>Data resources</td>
</tr>
<tr>
<td>22</td>
<td>data retrieval</td>
</tr>
<tr>
<td>23</td>
<td>Didn't really have much effect on my practice.</td>
</tr>
<tr>
<td>24</td>
<td>donor net</td>
</tr>
<tr>
<td>25</td>
<td>dont usw</td>
</tr>
<tr>
<td>26</td>
<td>don't know</td>
</tr>
<tr>
<td>27</td>
<td>Don't like the redesign at all. Much easier to use when both UNOS and OPTN content were in the same place.</td>
</tr>
<tr>
<td>28</td>
<td>don't use it</td>
</tr>
<tr>
<td>29</td>
<td>dropdown menu of frequently used pages</td>
</tr>
<tr>
<td>30</td>
<td>Ease of finding where to go on the site.</td>
</tr>
<tr>
<td>31</td>
<td>Ease of navigation</td>
</tr>
<tr>
<td>32</td>
<td>Ease of use</td>
</tr>
<tr>
<td>33</td>
<td>Ease of use</td>
</tr>
<tr>
<td>34</td>
<td>ease of use</td>
</tr>
<tr>
<td>35</td>
<td>Easier access to updated information</td>
</tr>
<tr>
<td>36</td>
<td>Easier to find data.</td>
</tr>
<tr>
<td>37</td>
<td>Easier to find information</td>
</tr>
<tr>
<td>38</td>
<td>Easier to navigate</td>
</tr>
<tr>
<td>39</td>
<td>easier to navigate to where I want to go to find the information I desire</td>
</tr>
<tr>
<td>40</td>
<td>Easier to navigate, clear, resources easy to find</td>
</tr>
<tr>
<td>41</td>
<td>Easier to navigate. Good links.</td>
</tr>
</tbody>
</table>
Easier to read
Easier to read and find the information you need.
Easier to see what you are looking for
easier to track down data
Easy access to direct support.
ey link to the OPTN website to access policies
Easy to find data quickly.
Easy to find what I'm looking for.
easy to navigate
easy to navigate
easy to navigate
Easy to navigate
ey to navigate
ey to navigate and data access.
Easy to navigate and find what is needed.
Easy to navigate where you want to go
Easy to navigate.
Easy to navigate.
Easy to use
ey to use
ey to use
ey to use
Easy to use-
ey to use and find information
ey to use, able to jump directly to what I need rather quickly
Easy to use.
Excellent resources to patients and public
fairly easy to navigate
Format is much clearer
getting quick statistics
Gives access to various information.
Hadn't noticed.
Have all necessary info in one site
Haven't noticed the redesign.
haven't used it enough to know
I can find what I am looking for in a very rapid manner.
I can get right to the data I need faster
I did not use the site before 2011.
I did not use this site before the redesign
I didn't realize it had changed.
do like that for customers (patients all the policy information is taken off the UNOS website)
I don't have a hard time finding anything
I don't spend that much time to assess this.
I don't use the public one often so I have to search for things
I find the website to be more cumbersome now as it is laid out than previously.
I had some trouble navigating the new site but I'm getting used to it.
I always found this confusing and it was not well explained to me when I started in this
industry years ago by my OPO; the separation that the re-design brought about was helpful,
especially for newer industry folks, to connect the dots.
I have not recently used the website.

I haven't really used this site.
I like the links to the OPTN website so I don't have to figure out where to go next for information I seek.

I like the policy/bylaws moved to OPTN contractor section
I liked it better the other way. It was easier to get all the info at one site.
I love the transplant trends section. It puts into perspective how many people are really waiting for an organ and it is a powerful tool to aid in educating the public about becoming an organ donor.

I sometimes find it difficult to find things. For the most part I like it.
I still can't find a darn thing!
I think it is more user friendly and easy to surf

It finally has a google search tool
It has taken me almost this whole time to realize I have to go to OPTN to find data.
Remembering the "unos.org" URL was much easier.

It is easier to locate information

It is easier to navigate

It is easier to navigate and more appealing visually

It is easy to navigate

It is more streamlined and easier to find items I am looking for.

It is very easy to find what you are looking for

It was very difficult to access the OPTN site due to its name. While the separation was essential for corporate structure, it made it difficult for those of us who accessed UNOS policies for daily allocation to find the policies. It took a lot more clicks and searches to find what we needed. The OPTN site is/was not very user friendly in contrast to the prior UNOS site which was very user friendly. Also, the

It works. I use it mostly for data and policy review
It's pretty, but I have such a hard time finding things.

Less clutter

less cluttered

less confusing about what is where and if you have the correct site for information

like the old one better

links and available information

Love the quick links (I am looking for...)

Makes the separation of duties & responsibilities easier to understand

More category tabs that help get to where you want more easily.

More easier and faster to complete

More easily able to navigate to what I seek

More streamlined, user friendly.

Links to OPTN Web site

More user friendly

More user friendly

more user friendly

Mostly to get current transplant demographic data

much simple to read

n/a

NA

NA

Navigation
neater
No comment to add.
No comments.
no different
No increases time of looking at information
No opinion
No problem finding what I am looking for
None
None, it takes extra steps to get to the policies
Not hard to find information that I am seeking.
Not much
not much
Not much.
not very useful when trying to find clinical information. Mostly public education now.
nothing
nothing
nothing
Nothing
Nothing particular stands out from my point of view
Nothing. The change is confusing and the transferred data does not appear to be current.
Old habits die hard - I usually get to where I need to go but not always in the easiest manner
policy and bylaw dropdown
policies, Statistics, PowerPoint Graphs and graphics
Quick finding statistics to share w/my patients.
Information for patients regarding paired donation program
Quick like drop down box.
Separation of OPTN Policies and UNOS Bylaws.
Sorry but liked the original website better. Feels as if leaving UNOS and going to government now.
Stats are right up front on the main page
Still go to the UNOS website (as had been my custom) but am often redirected to the OPTN site which is where the info I need to find the most is located.
Access
The "I am looking for" search box
The ability to create a work order.
The 'I am looking for' option at the top of the page helps me what what I need relatively quickly.
The link to the OPTN website for data reports. Although having to be redirected is not convenient.
The quick reference to data/statistics
There are a lot of categories to choose from
This was a terrible redesign.
too many clicks to take you from the main unos page to the policy and bylaw page.
Transplant Trends - the counter on the front page of how many are waiting, metrics, etc.
Txp volume stats
usefulness
user and patient friendly
User friendly
user friendly
user friendly to lay public
Very easy to navigate. Very little, it has taken a bit of adjustment and at times it has been difficult to locate a specific resource, mostly on the OPTN view
Very user friendly
Vey simple to use
Would prefer to find everything on one site.
**UNOS Website – Improvement Suggestions**

**Question:** What are your suggestions for improving the Website?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A diagram explaining steps to the process of MPSC review would be helpful. Add a directory of all approved Transplant Centers along with the Transplant Administrators contact information.</td>
</tr>
<tr>
<td>2</td>
<td>Again, I have not been to the web site, recently. Annotated jumps to specific OPTN bylaws or the evaluation plan. At times, areas are difficult to locate. Better access to the links for allocation policies and first person designation information for OPO staff who use them daily.</td>
</tr>
<tr>
<td>3</td>
<td>Clean up policies and bylaws. There is a lot of redundancy and it is difficult to find something that may be needed quickly.</td>
</tr>
<tr>
<td>4</td>
<td>Combine UNOS, OPTN and SRTR on one website</td>
</tr>
<tr>
<td>5</td>
<td>Confusing to know where to go for what.</td>
</tr>
<tr>
<td>6</td>
<td>Continue to highlight patient resources</td>
</tr>
<tr>
<td>7</td>
<td>Cross link the committee membership data</td>
</tr>
<tr>
<td>8</td>
<td>Delay in requesting data using the UNOS website vs. the OPTN website.</td>
</tr>
<tr>
<td>9</td>
<td>Easier security administration features to set up new users, etc. It is not very user friendly in my opinion.</td>
</tr>
<tr>
<td>10</td>
<td>Easy redirect to the OPTN web site Every year I complain about the user &quot;unfriendliness&quot; when trying to put a new person on the list to be able to use the website, usually persons associated with HLA and other labs. It is still awful!</td>
</tr>
<tr>
<td>11</td>
<td>Get a professional web designer.</td>
</tr>
<tr>
<td>12</td>
<td>Go back to a single, consolidated site.</td>
</tr>
<tr>
<td>13</td>
<td>Go back to the old site</td>
</tr>
<tr>
<td>14</td>
<td>Go back to the way it was</td>
</tr>
<tr>
<td>15</td>
<td>Hard to intuitively navigate</td>
</tr>
<tr>
<td>16</td>
<td>Have a more directed page for transplant centers</td>
</tr>
<tr>
<td>17</td>
<td>Haven't really thought about it. Would need more time to look it over.</td>
</tr>
<tr>
<td>18</td>
<td>Having the policies be searchable would be wonderful.</td>
</tr>
<tr>
<td>19</td>
<td>I did not use this site before the redesign.</td>
</tr>
<tr>
<td>20</td>
<td>I dont use it much use secure site</td>
</tr>
<tr>
<td>21</td>
<td>I don't use it often enough to have a specific suggestion.</td>
</tr>
<tr>
<td>22</td>
<td>I find it harder to find data and to make a data request with new design. I find it harder to navigate than prior. Patients have voiced similar problem and dont seem to reference it as much other than Transplant Living.</td>
</tr>
<tr>
<td>23</td>
<td>I find the data that I need quickly, and love the multiple options for searching.</td>
</tr>
<tr>
<td>24</td>
<td>I have none at this time.</td>
</tr>
<tr>
<td>25</td>
<td>I like it. I miss having the Member directory with contact info that used to be on UNOS.org. I have not seen where this data is located on the OPTN website.</td>
</tr>
<tr>
<td>26</td>
<td>I still struggle with by-laws/policies that are UNOS and those that are OPTN. I wish there...</td>
</tr>
</tbody>
</table>
were a policy tab that would be a jumping point to which site holds the topic you're looking for. (I understand there are links...but not always helpful, still have to hunt.)

I think it's fine the way it is.

I think that it is more difficult to find information now than it was previously. I personally do not like the drop down link as it does not include all areas that may be required.

I think the KPD Pilot program info is kind of hard to find. The brochure is easy to get to, I am referring to the guidelines and participating centers, etc.

I would like to be able to access items - especially data - from the main website without being redirected.

I'd have to think more about this.

If possible 24/7 support

Improve search engine

It has taken me some time to find the site information that used to be in one place; I am still not completely used to this change and often find myself looking on both sites before I find what I need.

It might be helpful to have a short tutorial on the side explaining where to find things such as by-laws and policies and why you will leave the UNOS site and are connected to teh OPTN site. An explanation of who maintains what. As a new director I found that very confusing. I really like the new drop down list.

It was a bit confusing at first

It's a useful website - no specific suggestions right now.

It's fine!

It's more difficult to find things on the new site. I'm getting used to it, but it still seems illogical.

It's not as easy to find items. There are more than 2 clicks to get to specific pieces. I would place the most often used items on the front screen to reduce the number of clicks.

It's not as user friendly as the earlier version.

keep up the good work

links on front page to SRTR data

Maintain the UNOS site when being routed to the OPTN, that way you could toggle back and forth

Make it clear the distinction between OPTN and UNOS by-laws on the website

Make it clearer when policy changes became/beome effective.

make it easier to access policies and events

make it easier to find and get information

Make it easier to find information in the policies and bylaws -- still a challenge.

make it easier to find policies and bylaws

Make it friendly for different browsers- My computer updates Microsoft and Firefox that make it impossible to use from home. I hate having to drive to work on the weekends just to do a UNOS function.

Make it Mac friendly!

make policies easier available

Make sure that once work orders are completed, to contact the person creating them and inform them it is done.

Make the OPTN policy page easier to get to directly . Can't remember the OPTN.HRSA,transplant.GOV address . Create a UNOS policy link that is easy to remember so you can go to the policy / bylaw section in the fewest possible clicks. Also, make the OPTN site look more related to the UNOS site with some similar graphics and colors. The OPTN looks like a government site. I understand the need to clearly differentiate the two unos purposes are different corporate and OPTN but the OPTN site looks totally independent from UNOS. It's confusing to the public and most clinical transplant staff who arent familiar with the administrative structure and history of UNOS.

Make the profressional education tools for transplant centers in 1 central location.... webinars,
newsletters, and UNET Tutorials could all be here. More advertising focused toward potential and actual recipients. A lot of them are unaware it exists as a resource...

more user friendly, not so many levels to drill into

n/a

NA

No

No opinion

no specific suggestions at this time

No suggestions.

The separation seems redundant as there are individual links on the UNOS website to specific sections of the OPTN website (data, policies, etc.).

None

none

none

None

None

None

None

None

None

None

None

None

None

None

None

None

None

None at this time

none at this time.

None at this time.

None at this time.

None for now

none, haven't really thought about it

None.

None. The website is very user friendly.

Not sure

Please let Financial Coordinators know which pts are double-listed and where.

Policies on the front Page. Don't send us to the OPTN page

policy and by laws are still difficult to locate

publish data reports provided to the membership through requests after waiting an appropriate period for the requestor to use the information for publication, etc. This is public information and everyone might like to review the information.

put calendar as a stand alone tab on the front page. The calendar is very helpful when you get to it.
Searching for policies/bylaws is still SO difficult. Difficult to the point that when I searched "subtyping" last week, it came up with NO results, but when I typed in "subtype" the information came up. Still couldn't really find what I was looking for. This is very frustrating!

Seems hard to find what I need. Not a big fan.

Sometimes, the search area does not bring you to the specific area of the website.

Speed...site is terribly slow at times.

SRTR is difficult.

Still difficult to find things via UNOS site.

The overall website is somewhat difficult to navigate and would benefit from a redesign. Users see unos as one entity and getting redirected when accessing policies and procedures / bylaws is irritating.

Would love to be able to use the site on a mobile browser for password reset and call notification updates.

You can never have too many patient stories. I really like the numbers on the front page that states home many waiting and how many transplants have occurred.
# E-Newsletter—Usefulness

**Question:** What do you find most useful about the e-newsletter?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A quick glance at the content and link to information I want to access</td>
</tr>
<tr>
<td>2</td>
<td>ability to review past items and when they were discussed</td>
</tr>
<tr>
<td>3</td>
<td>Access to updated information and notice of upcoming events</td>
</tr>
<tr>
<td>4</td>
<td>access and retrieval of info</td>
</tr>
<tr>
<td>5</td>
<td>accessibility</td>
</tr>
<tr>
<td>6</td>
<td>alert to changes impacting my use of UNET</td>
</tr>
<tr>
<td>7</td>
<td>all information is located in one place as trying to hunt down all the emails</td>
</tr>
<tr>
<td>8</td>
<td>All of the current information is in one place.</td>
</tr>
<tr>
<td>9</td>
<td>any changes to policies</td>
</tr>
<tr>
<td>10</td>
<td>articles available, webinars available for educational purposes</td>
</tr>
<tr>
<td>11</td>
<td>as an update between meetings. don't always read it or follow links</td>
</tr>
<tr>
<td>12</td>
<td>back track notices, policy changes. Information on interpretations and what's new</td>
</tr>
<tr>
<td>13</td>
<td>Best Practice Articles and activities of other OPOs</td>
</tr>
<tr>
<td>14</td>
<td>Best way to distribute important information!</td>
</tr>
<tr>
<td>15</td>
<td>Can read whenever I want to.</td>
</tr>
<tr>
<td>16</td>
<td>Cohesive and compact, rather than assorted emails over time.</td>
</tr>
<tr>
<td>17</td>
<td>comprehensiveness</td>
</tr>
<tr>
<td>18</td>
<td>Concise</td>
</tr>
<tr>
<td>19</td>
<td>concise</td>
</tr>
<tr>
<td>20</td>
<td>Convenience</td>
</tr>
<tr>
<td>21</td>
<td>convenient and accessible</td>
</tr>
<tr>
<td>22</td>
<td>convenient to use</td>
</tr>
<tr>
<td>23</td>
<td>Convenient way to keep up to date on issues</td>
</tr>
<tr>
<td></td>
<td>Convenient, although I tend to pass over it with so many other e-mails and then fail to</td>
</tr>
<tr>
<td></td>
<td>remember to go back and look at it and have missed some things.</td>
</tr>
<tr>
<td>24</td>
<td>Current information about policy</td>
</tr>
<tr>
<td>25</td>
<td>Current news</td>
</tr>
<tr>
<td>26</td>
<td>Current up to date information from across the nation. Great articles and pictures.</td>
</tr>
<tr>
<td>27</td>
<td>discussions</td>
</tr>
<tr>
<td>28</td>
<td>Ease of access</td>
</tr>
<tr>
<td>29</td>
<td>ease of use</td>
</tr>
<tr>
<td>30</td>
<td>Easier access, less email</td>
</tr>
<tr>
<td>31</td>
<td>easier to assess which articles are relevant to me and which I elect to read</td>
</tr>
<tr>
<td>32</td>
<td>easier to track upcoming policy changes. Frequent e-mails often get 'lost in the system'.</td>
</tr>
<tr>
<td>33</td>
<td>Easy access</td>
</tr>
<tr>
<td>34</td>
<td>easy access</td>
</tr>
<tr>
<td>35</td>
<td>easy access to policy changes and reminders</td>
</tr>
<tr>
<td>36</td>
<td>easy to access</td>
</tr>
<tr>
<td>37</td>
<td>easy to click on links</td>
</tr>
<tr>
<td>38</td>
<td>Easy to find and read</td>
</tr>
<tr>
<td>39</td>
<td>Easy to find information and links are helpful.</td>
</tr>
<tr>
<td>40</td>
<td>easy to find topics of interest to me</td>
</tr>
<tr>
<td>41</td>
<td>easy to maneuver and good information</td>
</tr>
<tr>
<td>42</td>
<td>Easy to read and access</td>
</tr>
</tbody>
</table>
Easy to scan summary - let's me focus on the subjects/topics that I need to worry about

Email delivery & archiving

Everything...it's good to keep in the loop

Excellent review of stuff I might have missed, because I don't get all the emails.

Feature Articles about Donors and Recipients

Fewer individual e-mails, everything in one place

Finding things in one area and not multiple emails throughout the month

general information

General information concise manner

good information in one place

Good informative information, quick and easy to review for things I need to know

good overview of topics

Good positive information.

good reminder / update of what's going on w/ UNOS

Good summary of current happenings

great communication tool

great single source of information, don’t have to cross reference other sites

Great way to remain current.

Has cut down on the number of e-mail notifications

Having pertinent information in one area

Helpful reminder to check in and useful to engage other staff with information that is pertinent to their departments.

Hyperlinks to proposals for public comment

I am glad a newsletter is sent out.

I do not care for internet reading. It hurts my eyes. I resent the additional cost to print and the format makes printing difficult.

I enjoy receiving this on-line.

I have it with me no matter where I am. Yet I don't have to carry any paper with me. :)

I like getting the update on what is happening at different facilities and what is happening in transplant as a whole.

I like having it at my fingertips.

I like it.

I like the links and updated info when there are policy updates, or things that are going to change such as things UNOS or CMS will review on an audit

I love that all the communication from UNOS is collated into the one email. I feel like I'm getting access to the most current information and can reference and read in detail those items of specific interest to me.

I never receive it

I rarely read the newsletter as I find it never useful at all.

I use it for new policy information and learning about policies out for public comment

Information in one e-mail

Informational

Informative
informative about the community
Informative.
insight
interesting articles
It consolidates the information so I can obtain the information more efficiently
It is a quick highlight of topics
It is a terrific summary
It is a wonderful tool to keep updated and easy to link up for more information.
It is the go-to place for changes that we need to know.
It lets me know what updates are coming to UNOS.
It reminds me of upcoming proposals and meetings
It serves as either an "at-a-glance" type document or a thorough review document of upcoming UNOS happenings; I always feel I am more up to date when it is released.
It's efficiency.
Keep me informed
keeps me up to date on new regulations
keeps me updated on the latest news from UNOS and the transplant world
keeps you abreast of what's going on
less activity in my inbox!
little snippets of info
Love the newsletter!! Helps keep the staff informed in a better format
makes me feel more confident that I have the most up-to-date policy information available.
monthly summary of important need-to-know updates
more up to the point information I may need
Most current & updated info.
n/a
na
NA
Nice having information combined into one, instead of multiple emails.
nice summary of content for that issue. no paper.
Nice to see what other regions are doing and the different articles
no specific comments at this time
None
not so much junk
Notices of policy changes
Notification of the changes in policy and board members.
One communication vehicle
One place to locate important information.
One stop shopping for information
Policy and procedure help
policy changes, webinar/educational training updates
policy updates
Policy Updates.
Practical info about UNOS resources
Provides current updates on a real-time basis.
Puts useful information in my hands.
Quick access to info
Quick and dirty (not really DIRTY) news.
Quick update on current events and policies up for review.

rarely read

Really appreciate getting information in this format and not receiving multiple emails.

Received monthly - concise summary of up to date information/links.

Reference articles

Reminders, policy changes, live meeting recordings.

Seeing what is in the publication and using it as a resource for what the hot topics are in the country.

Sharing of information on a national basis

SHORT, CONCISE AND AUTOMATICALLY COMES TO US

Sometimes I find useful information or interesting/inspiring articles.

Stories shared and data

summary of happenings

summary of pertinent issues and policy issues

Synopsis of what's happening

the links

The links are helpful

The news, the guide and all that is going on in the UNOs world.

The questions that are answered

The updates

This is one of the most positive changes UNOS has made. It is much easier to stay current.

Timely information

Timely information

up to date info

update on policy

Updates

updates on policy changes

updates on policy

updates on upcoming changes

Updates; current issues.

Very handy to be able to refer back to articles.

Wealth of information and the ease of use. In addition, the availability of getting archive information with ease.

Well summarized. I am not interested in most of the items, they are too clinical or about aspects of operations I am not involved in. I can scroll and decide quickly what interests me or not.

You access the articles you are most interested in with out having to read through everything
## E-Newsletter—Improvement Suggestions

**Question: What are your suggestions for improving the e-newsletter?**

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Archive with other education resources to 1 location</td>
</tr>
<tr>
<td>4</td>
<td>Because I am in Communications, I would love more content about media and UNOS. Differentiate more clearly the differences between minor and major policy changes. Add programming changes so that programs and vendors can make necessary changes in a timely way.</td>
</tr>
<tr>
<td>5</td>
<td>difficult to ascertain when critical information is being offered</td>
</tr>
<tr>
<td>6</td>
<td>Go back to email</td>
</tr>
<tr>
<td>7</td>
<td>good format and useful - no suggestions</td>
</tr>
<tr>
<td>8</td>
<td>I don't read it anymore as too much clicking and searching to find an article and way too many choices. I found it easier to get hard copy newsletter or full newsletter send via email so I can read at my leisure without hunting for articles that might or might not be useful/interesting.</td>
</tr>
<tr>
<td>9</td>
<td>I find it difficult to find the time to fully read it. I didn't like getting so many individual emails but this is too much information to arrive at one time. I need something that is somewhere in the middle.</td>
</tr>
<tr>
<td>10</td>
<td>I have not consistently received the monthly emails. None received in October or November.</td>
</tr>
<tr>
<td>11</td>
<td>I preferred indiv emails</td>
</tr>
<tr>
<td>12</td>
<td>I think this is a good process.</td>
</tr>
<tr>
<td>13</td>
<td>I would stick with important changes in policy that would affect most institutions.</td>
</tr>
<tr>
<td>14</td>
<td>improve ability to locate news according to each policy</td>
</tr>
<tr>
<td>15</td>
<td>In the month before the BoD is to vote on policy/bylaw changes, please include the list of which changes they will be approving at their meeting. This would give centers a heads up and allow us to start working on forms, informed consent or policy changes that need to be made or created since many times we have to rely on 3rd parties to provide printing/approval of forms or changes (i.e. all informed consents at our center must go through the hospital lawyers before they can be used) and many</td>
</tr>
<tr>
<td>16</td>
<td>Include a case study</td>
</tr>
<tr>
<td>17</td>
<td>It always goes to spam on my company settings so maybe notify in individual emails anout its upcoming mailing.</td>
</tr>
<tr>
<td>18</td>
<td>it would be nice to have bullet points in the email as a teaser to read more.... It's almost too brief, I stopped getting the Update for some reason, so I feel kind of disconnected.</td>
</tr>
<tr>
<td>19</td>
<td>It's great!</td>
</tr>
<tr>
<td>20</td>
<td>Keep content to that which can impact our work. Articles on donors and recipients are interesting and inspirational, but not necessarily impactful. Keep it coming. I also think you could move towards an electronic distribution of the UNOS update publication to save costs. I would read it as often if it came to me electronically and probably more timely.</td>
</tr>
<tr>
<td>21</td>
<td>Let main OPO contact know that everyone receives this because it is remailed here several times.</td>
</tr>
<tr>
<td>22</td>
<td>Links often don't work</td>
</tr>
<tr>
<td>23</td>
<td>make policy implementation clearer.</td>
</tr>
<tr>
<td>24</td>
<td>making it easier to find the documents the article is about</td>
</tr>
</tbody>
</table>
making it very clear what is new since last newsletter, important deadlines

Need to utilize this as the only venue when making changes to policy, etc.

No suggestions

None

None

None

None

None

None

None

None

None

None

None

None

None

None

None at this time

None at this time

None at this time

None at this time

None at this time

None at this time

None for now

None, it is an excellent resource!

None.

None. This website doesn't replace Update print publication however.

Nothing unless you can free up my time for me

Send a print copy to those who request one.

sometimes the items don't open useful information, I don't have an example right off hand

of this happening

The flow of the newsletter could be further developed.

How about a UNOS Portal where members can log on, contact each other, share best

practices, and receive these notifications more regularly?

unknown

would be nice to highlight policy updates so that they catch your eye first
## Public Comment—Usefulness

*Question: What do you find most useful about the public comment process*

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Ability to comment</td>
</tr>
<tr>
<td>3</td>
<td>ability to comment on line</td>
</tr>
<tr>
<td>4</td>
<td>Ability to express my view</td>
</tr>
<tr>
<td>5</td>
<td>Able to comment on proposed policy</td>
</tr>
<tr>
<td></td>
<td>allows individuals and transplant programs to provide input to potential changes that will</td>
</tr>
<tr>
<td></td>
<td>impact patient care and possible budget and staffing requirements within the department.</td>
</tr>
<tr>
<td>6</td>
<td>articulating ones thoughts</td>
</tr>
<tr>
<td>7</td>
<td>at least get to comment</td>
</tr>
<tr>
<td>8</td>
<td>At the regional level, it is good to evaluate and discuss about the proposals and make</td>
</tr>
<tr>
<td></td>
<td>comment based on our regional need and also at the level of national benefit</td>
</tr>
<tr>
<td>9</td>
<td>Can't remember-- it's been awhile back.</td>
</tr>
<tr>
<td>10</td>
<td>Completeness of info about the proposed policy</td>
</tr>
<tr>
<td>11</td>
<td>Convenient and quick.</td>
</tr>
<tr>
<td>12</td>
<td>Done before the e-Newsletter came out</td>
</tr>
<tr>
<td>13</td>
<td>Don't remember</td>
</tr>
<tr>
<td>14</td>
<td>Don't remember</td>
</tr>
<tr>
<td>15</td>
<td>ease</td>
</tr>
<tr>
<td>16</td>
<td>ease of putting comments in</td>
</tr>
<tr>
<td>17</td>
<td>Ease of submission.</td>
</tr>
<tr>
<td>18</td>
<td>ease of use</td>
</tr>
<tr>
<td>19</td>
<td>Ease of use.</td>
</tr>
<tr>
<td>20</td>
<td>Easy</td>
</tr>
<tr>
<td>21</td>
<td>Easy</td>
</tr>
<tr>
<td>22</td>
<td>easy</td>
</tr>
<tr>
<td>23</td>
<td>Easy</td>
</tr>
<tr>
<td>24</td>
<td>Easy</td>
</tr>
<tr>
<td>25</td>
<td>Easy</td>
</tr>
<tr>
<td>26</td>
<td>Easy</td>
</tr>
<tr>
<td>27</td>
<td>easy access</td>
</tr>
<tr>
<td>28</td>
<td>Easy electronic process</td>
</tr>
<tr>
<td>29</td>
<td>easy to do</td>
</tr>
<tr>
<td>30</td>
<td>easy to do</td>
</tr>
<tr>
<td>31</td>
<td>Easy to do.</td>
</tr>
<tr>
<td>32</td>
<td>Easy to submit</td>
</tr>
<tr>
<td>33</td>
<td>easy to submit</td>
</tr>
<tr>
<td>34</td>
<td>easy to submit</td>
</tr>
<tr>
<td>35</td>
<td>Easy to submit</td>
</tr>
<tr>
<td>36</td>
<td>Easy to understand</td>
</tr>
<tr>
<td>37</td>
<td>Easy to use</td>
</tr>
<tr>
<td>38</td>
<td>easy to use</td>
</tr>
<tr>
<td>39</td>
<td>Easy to use</td>
</tr>
<tr>
<td>40</td>
<td>Easy to use</td>
</tr>
<tr>
<td>41</td>
<td>Easy to use</td>
</tr>
</tbody>
</table>
Electronic submission.
Ensures that we give sufficient time and thought to potential changes to Policy.
Fairly easy
Feeling that I am part of the community responsible for policy development
Felt that I was able to give some input
Give you a chance to express your opinion
Giving voice to the concerns on potential and living organ donors.
Heard other sides of the issue in more detail.
I like being able to view others’ comments.
Intuitive and straightforward.
It could be done electronically
It is another voice about the issues at hand.
It is easy to complete electronically and the issues are broken out nicely for ease of finding each one.
It is very easy to do
It was easy to comment.
It was easy to use.
it was user friendly
It worked fine
just being able to give my input, and encourage others to do the same
knowing that it will be read
Knowing that my comment would be thoughtfully considered.
knowing the suggestions and having input
made us think about the implications
makes me feel valued
most people now prefers emails.
N/A
n/a
N/A
N/A
n/a
NA
NA
No follow up on the general comments made for a particular process/policy.
nothing
Notification.
Opportunity to opine.
overall works well
participation
Pretty easy to submit
really find it easy to use, appreciate the clear & concise summary as well as the ease at which to see the full section and what is changed in it.
simple
simplicity without losing depth
Summary of policies out for comment
That they are eagerly solicited and listened to
that's a difficult one. I am not sure that anything is heeded as policy is so tightly controlled by CMS.
The ability to articulate our concerns.
The ability to ask questions and give input before the policy became required. Allows us to plan ahead for required changes or at least notify management that they have to be aware of possible changes.

The ability to participate
The chance to make my organization's voice heard.

The ability to participate
The chance to make my organization's voice heard.
The ease of use

The fact that public comment was allowed and taken into consideration.
The feeling that I helped shape policy.
User friendly
User friendly.

Very easy to put in comments.
Very user friendly.

Was easy to do.

We discussed and submitted as a group.
We had a group discussion as part of the Committee I'm a member on.
we have submitted from our center; our administrator has collected our comments and submitted
Public Comment—Improvement Suggestions

**Question: How would you improve the public comment process?**

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>&quot;cliff notes&quot; reader on policy changes for civilians who are directly affected and thereby interested parties but do not have the knowledge to interpret industry documents.</td>
</tr>
<tr>
<td>2</td>
<td>Ability to suggest revisions to a particular policy/process. Feedback on other comments and the impact on specific policies by these comments.</td>
</tr>
<tr>
<td>3</td>
<td>After responding, I have no idea how others are doing so; I would love to see others' responses, blinded, of course, but perhaps a graph of sorts that shows common responses and the amount each was given...just a thought</td>
</tr>
<tr>
<td>4</td>
<td>Anything that can increase responses by recipients or candidates.</td>
</tr>
<tr>
<td>5</td>
<td>Continually reaching out so people understand how to do it</td>
</tr>
<tr>
<td>6</td>
<td>Do what the public wants</td>
</tr>
<tr>
<td>7</td>
<td>Don't understand the time line. Things seem to be out for comment forever.</td>
</tr>
<tr>
<td>8</td>
<td>encouragement that anyone can and should comment</td>
</tr>
<tr>
<td>9</td>
<td>feedback loop needed to those who actively submitted input</td>
</tr>
<tr>
<td>10</td>
<td>Feedback on the final recommendations to the board would be nice.</td>
</tr>
<tr>
<td>11</td>
<td>Followup on issues raised and potential resolutions.</td>
</tr>
<tr>
<td>12</td>
<td>Good the way it is</td>
</tr>
<tr>
<td>13</td>
<td>Greater awareness and info sharing with interested stakeholdersd</td>
</tr>
<tr>
<td>14</td>
<td>Grouping into organ-specific categories.</td>
</tr>
<tr>
<td>15</td>
<td>I am most interested in the evaluation of the policy. The evaluation piece is not often well developed when the policies are available for public comment. I have found that the evaluation of the policy can be duplicative and burdensome and not in line with the intent of the policy.</td>
</tr>
<tr>
<td>16</td>
<td>I do not recollect recieving a notice that my comment was noted.</td>
</tr>
<tr>
<td>17</td>
<td>I like it</td>
</tr>
<tr>
<td>18</td>
<td>I like the process the way it is.</td>
</tr>
<tr>
<td>19</td>
<td>I think it would be good to send direct email reminders as due date approaches; sometimes I lose track of it knowing I have a few months.</td>
</tr>
<tr>
<td>20</td>
<td>It is cumbersome to have to enter the demographic information each time when submitting comments on several proposals at the same time.</td>
</tr>
<tr>
<td>21</td>
<td>It would be helpful to know what other physicians comment.</td>
</tr>
<tr>
<td>22</td>
<td>Make a standard powerpoint that can be posted on the public policy web site and used by members to educate and discuss with staff prior to submitting comments.</td>
</tr>
<tr>
<td>23</td>
<td>make sure more people know about it</td>
</tr>
<tr>
<td>24</td>
<td>making it easier to access</td>
</tr>
<tr>
<td>25</td>
<td>maybe more electronic notices. I know not enought people do not comment which is not your fault, more should get involved</td>
</tr>
<tr>
<td>26</td>
<td>n/a</td>
</tr>
<tr>
<td>27</td>
<td>n/a</td>
</tr>
<tr>
<td>28</td>
<td>N/A</td>
</tr>
<tr>
<td>29</td>
<td>n/a</td>
</tr>
<tr>
<td>30</td>
<td>n/a</td>
</tr>
<tr>
<td>31</td>
<td>n/a</td>
</tr>
<tr>
<td>32</td>
<td>NA</td>
</tr>
<tr>
<td>33</td>
<td>NA</td>
</tr>
<tr>
<td>34</td>
<td>NA - except possibly for helping UNOS members understand who they are representing</td>
</tr>
</tbody>
</table>
when they do this
need more representation
Need to have some ongoing communication regarding outcome. Once the notification comes out for public comment, you don’t hear anything else about it until it is passed by the board. If it doesn’t go to the board, it just sort of disappears. It would be nice for some sort of update, such as: due to overwhelming public comment the proposal is going back to committee for further development.

NO real human feedback - seemed as if I was communicating with a machine.
none
None
none
None
none
None
None at this time.
None.
None.
None...I like the format
On occasion I have had difficulty accessing the proposed policies and couldn’t comment on something I really wanted to.
Open sharing of the comments
Our managers and CEO’s should be keeping us up-to-date on the need for public opinion.
PLAIN LANGUAGE SUMMARY!
post all responses on the web site
Provide a very short summary of the issue and the options.
publicize it even more? Perhaps contact more professional organizations that might be interested? You contact ones that are obviously transplant, I think, but there are others that have transplant-related interest groups.
Publicize these and allow members to access these from a SYSTEM MESSAGE.
Reporting data results
Seems we are inundated with messages, emails, e-publications from UNOS these days. In past, there was not so much information being sent to centers. I find it very hard to find the time to review it all so I actually don’t anymore. I read info haphazardly when I have time - which is not very often.
Send more than just the initial email. Send reminders that the proposal input period is coming to an end..
some transplant staff at our institution do not receive the email
Speed the process up. Taking two to three years to approve the change often reflects in changes to the changes before implementation.
Still cumbersome...but is much better.
The Patient Affairs Committee should be more active in explaining to the transplant candidates and representatives that Public Comment is the time to give input--Once its policy, it is too late to change--transplant support groups should use their group functions to submit comments on policies out for comment. The basic transplant candidate does not know or understand they have a voice in how the policies are developed.
The policy proposals need to have a date that the proposal opens and closes. The summary pages are great but there is no date anywhere to reference later.
To share the public comments
when their is only 30 days left in the comment period send a second e-mail time running out to comment
When you email the proposals, if there was a better way to distribute them online to staff members who need to review so they could review online easier. We print them & distribute,
would prefer an easier way to distribute online to our team.
Would be nice if they could be addressed and we were able to review the responses.
would be nice to have the option once you've completed making comments to "email" other individuals with the link, encouraging them to comment as well.

Policy Notice—Usefulness

Question: What is most useful about the policy notice?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>They summarize and include exact policy changes</td>
</tr>
<tr>
<td>2</td>
<td>Ability to keep abreast of what's going on</td>
</tr>
<tr>
<td>3</td>
<td>Advance notice of changes</td>
</tr>
<tr>
<td>4</td>
<td>Again, not written in concise English. Not at all understandable - Needs background of issue and needs to be concise.</td>
</tr>
<tr>
<td>5</td>
<td>Alerting me that a policy has been proposed.</td>
</tr>
<tr>
<td>6</td>
<td>Alerts me to go out and review the proposals</td>
</tr>
<tr>
<td>7</td>
<td>all</td>
</tr>
<tr>
<td>8</td>
<td>Allows me to prepare my center for upcoming policy changes</td>
</tr>
<tr>
<td>9</td>
<td>allows people to stay informed</td>
</tr>
<tr>
<td>10</td>
<td>Appreciate email notices from UNOS.</td>
</tr>
<tr>
<td>11</td>
<td>As above, need to streamline the process. I don't understand the steps a proposal needs to go through to be implemented. Seems like it goes on forever and is discussed way too many times.</td>
</tr>
<tr>
<td>12</td>
<td>aware that changes are being considered</td>
</tr>
<tr>
<td>13</td>
<td>Backgound as to reason for policy change</td>
</tr>
<tr>
<td>14</td>
<td>Becoming aware of changes.</td>
</tr>
<tr>
<td>15</td>
<td>bring your attention to the issues</td>
</tr>
<tr>
<td>16</td>
<td>clear - easy to understand language.</td>
</tr>
<tr>
<td>17</td>
<td>Clear instructions, links and phone numbers provided.</td>
</tr>
<tr>
<td>18</td>
<td>Clearly illustrates changes - easy to follow.</td>
</tr>
<tr>
<td>19</td>
<td>cms /unos requirements</td>
</tr>
<tr>
<td>20</td>
<td>Communicated through e-mail</td>
</tr>
<tr>
<td>21</td>
<td>Concise</td>
</tr>
<tr>
<td>22</td>
<td>Ease of access.......</td>
</tr>
<tr>
<td>23</td>
<td>Ease of finding them</td>
</tr>
<tr>
<td>24</td>
<td>easy to access</td>
</tr>
<tr>
<td>25</td>
<td>Easy to access and understand</td>
</tr>
<tr>
<td>26</td>
<td>Easy to find notices that directly impact the lab.</td>
</tr>
<tr>
<td>27</td>
<td>Easy to read and understand</td>
</tr>
<tr>
<td>28</td>
<td>easy to read/understand</td>
</tr>
<tr>
<td>29</td>
<td>easy to understand</td>
</tr>
<tr>
<td>30</td>
<td>Easy way to stay current. Changes are tracked</td>
</tr>
<tr>
<td>31</td>
<td>Email format is very efficient</td>
</tr>
</tbody>
</table>
E-mail is very convenient, however, I tend to pass over it with intentions to read later, then sometimes forget about it. Also, I personally sometimes get overwhelmed with the changes, the work involved with all of this, compliance etc. with UNOS and CMS. Both need to get on the same page with requirements and policy.

ensures that txp personnel are up to date with policy changes
everything
Finally...they're organized! It was so difficult before when important changes were made but we were only notified by the "typical" email. Bravo!
find out what crazy thing is trying to be implemented
focused update and need to know what to do information is critical
getting in multiple formats
getting them in email
gives relevant background
Gives you a chance to express an opinion
good summary of what needs implemented
How they affect allocation
I dont find them useful at all.
I get an automatic notice of new policy.
I like that the notices are sent out far enough in advance to let the staff know of changes
I like the format you now have where you have the link button on the left and you show the chart of who is affected. That way, I don't have to wade through all of them - only the pertinent ones.
I like the matrix of what I need to pay attention to, I made read them all but I especially read the ones that effect my teams.
I read them if it pertains to laboratory practice.
I skim them
Informational
informative
Informative; and, reminder to review, discuss in internal meetings, submit comments.
It gives me warning of changes in the data required for Tiedi that I work on.
It helps me understand my job, what are the expectations and how this effects patient care.
It helps our program to stay aware of important updates/changes required for our program
It helps with my committee work and makes me more knowledgeable about transplant initiatives.
It is a heads up in case I need to evaluate our own internal policies for the change control process; it keeps me up to date and in the loop on compliance issues and PI Opportunities for our staff.
It is in nice bold type and is easy to read with the help of the matrix.
It is useful to know that the policy has changed and how it may affect your practice.
It keeps me updated
just keeping up and knowing what is coming, though I would wish to read them more carefully
Just knowing they occurred
Keep up to date
keep up with current changes to make sure they coincide with our practice
Keeping up to date on potential changes to current practices
Keeping up-to-date on policies being suggested.
Keep abreast of changes pertaining to me and helps to ensure we are
remaining current
Keeps me updated
Keeps me updated and our center, lab and OPO
keeps me updated in my practice
Keeps me up-to-date and informed
keeps us compliant
Keeps us up to date
Keeps us up to date on policy that may affect our practice
Keeps us updated. Without these it is difficult to now the changes because so
few staff can attend the UNOS Regional meetings or Forum
Keeps you in "the know".
keeps you up to date and allows practice consistent with new policies
keeping up to date
Lets me know of policy changes
lets me now i need to look at our internal work flow when the policy takes
affect.
Link to area from the overview page
links to language and the chart ot show who is affected by the changes
maintaining compliance in an ever changing regulatory world
Memory jogger. Reminds me to review changes.
Na
new updates are defined
Nice synopsis without having to read the comprehensive version.
nice to know if we need practice changes
nice to see what is being changed
plain language
Ready access
receiving new/current information
Response Text
Short, important points about policy
summaries
Summary
summary info
that they exist!
The "nutshell" content
The "what I need to worry about" section.
The ability to provide input on decisions being made.
The advance notice
The direct communication of what I need to know
The links are convenient. You can look for ones that apply to your institution
quickly.
The more I see them the better.
Whatever form they come in.
The summary titled "What you need to do"

The way they are delivered. You don't have to go looking for them.

They are a necessity to remain in compliance.

They are informative regarding changes.

They tell you who should be aware of these actions so you can find the pertinent information.

Thoroughness

Timely; frequent.

track changes,

Updating centers on what is in progress

Very thorough

Very well organized and developed. Like the grid to easily identify which groups are impacted by each policy. The links attached to each policy change summary is very helpful.

Well it's better to know than get a surprise

Well organized and provides good background info

With busy schedule of most of the people involved in transplantation these reminders are great way of informing people

With email notification, very specific and I share the ones which apply to our laboratory and the organs we transplant

Yes
### Policy Notice—Improvement Suggestions

**Question:** What are your suggestions for improving the policy notice?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>a prominent summary of the practical impact of these notices. not so many technical details to get lost in.</td>
</tr>
<tr>
<td>3</td>
<td>Again very hard to access and too many of them.</td>
</tr>
<tr>
<td>4</td>
<td>again, keep very focused on what is new/required and what to do with it. there is so much to be aware and know, so overwhelming!!!</td>
</tr>
<tr>
<td>5</td>
<td>Always include which organ groups are affected</td>
</tr>
<tr>
<td>6</td>
<td>Appreciate email notices from UNOS.</td>
</tr>
<tr>
<td>7</td>
<td>Clear summary of changes</td>
</tr>
<tr>
<td>8</td>
<td>create a standardized summary powerpoint available on the OPTN site that could be used to educate and update staff</td>
</tr>
<tr>
<td>9</td>
<td>Difficult to copy and paste sections of the policy</td>
</tr>
<tr>
<td>10</td>
<td>Difficulty in navigating to the policy for discussion.</td>
</tr>
<tr>
<td>11</td>
<td>Easier format to take a quick glance.</td>
</tr>
<tr>
<td>12</td>
<td>Find a way to have in a very short executive summary</td>
</tr>
<tr>
<td>13</td>
<td>Gosh there is so much and we are busy trying to take care of the patients......</td>
</tr>
<tr>
<td>14</td>
<td>Have an office secretary write them in plain English and then have them edited by an English major to make them concise. DO NOT have a lawyer or bureaucrat touch them.</td>
</tr>
<tr>
<td>15</td>
<td>I have none at this time.</td>
</tr>
<tr>
<td>16</td>
<td>I know you have people writing these trying to make them easy to understand, however, the verbage is very lengthy and not all that specific to real practioners. Also, many obvious unintended consequences are not addressed in the write up which is why some get significant negative feedback. This could be avoided up front with better review from e</td>
</tr>
<tr>
<td>17</td>
<td>I still like the paper book!</td>
</tr>
<tr>
<td>18</td>
<td>I think the notice is fine...I am not sure at times UNOS 'gets it' as far as the sheer volume of policy changes and how hard it is to make corresponding internal practice and policy changes- and how to hardwire the new practice in a program. I think sometimes UNOS staffers wonder &quot;geez, why didnt this program do this - the policy changed two years ago&quot; but again, its so hard to keep up with all the regulations we face when UNOS is the one regulator who makes such frequent released changes.</td>
</tr>
<tr>
<td>19</td>
<td>I want a clear final copy of the policy without strikethroughs and additions.</td>
</tr>
<tr>
<td>20</td>
<td>I would like every policy that is changed to come to my e-mail as a user to know there is a change. Also the policies are hard to read with the strike out lines through everything.</td>
</tr>
<tr>
<td>21</td>
<td>Line by line comparison with previous/existing policy and citation of relevant Federal regulations.</td>
</tr>
<tr>
<td>22</td>
<td>Make it short and sweet</td>
</tr>
<tr>
<td>23</td>
<td>Make them less cumbersome to read. It's difficult to find time to read a notice that links you to 50 pages of policy edits.</td>
</tr>
<tr>
<td>24</td>
<td>making the policies easier to read</td>
</tr>
</tbody>
</table>
Maybe increase the frequency or change the format so it is easier to get through the information.

More concise explanation of the policy, and how it will affect the specific area involved (i.e. allocation, registration, regional sharing, etc.)

More precise language that explains how we can realistically implement the changes. Also, the format seems scattered. You have to follow a good bit of links and then aren't sure if you've viewed everything. Easy to miss things due to the volumes.

N/A
n/a
NA
NA

Need to be written in plain concise english. Who, what, when, where, how. Make it simple. They are written almost as if you are trying to hide something. example: Modifications to Clarify which Transplant Program has Responsibility for Elements of the Living Donation Process and to Reassign Reporting Responsibility for Living Donation from the Recipient Transplant Program to the Transplant Program Performing the Living Donor Nephrectomy or Hepatectomy

none
None
None
none
None
none
None
none
None
none
None
none
None
none
None
none
none
None
none
None
none
None
none
None
none
Nothing
nothing at this time
please remove all the strike-outs in the policy from past versions—it is so hard to read
Policy and bylaw info hard to find
put them in basic language - good work by UNOS for putting all of them into public language that is easier to read and understand. Eliminate initials
see above
Send by email or print and snail mail.
Shade alternating columns...it is hard to follow them vertically on a screen.
Simplying the language for the non-health care professionals who may wish to comment.

Smaller file - takes too long to load.

some are to lengthy

Stick with e-newsletter.  Highlight change in the newsletter.

The changes need to be more plain language.

The language is difficult to understand-especially when sections are struck out.

It is also sometimes difficult to determine whether the policy is in effect or pending.

The language is not always clear so maybe additional examples of what it could mean in a real event setting

The language used could be more easy-to-understand rather than referencing policy numbers.

The policy notices are almost never applicable to my concerns.

There needs to be less steps to get to the meat of the policy.

They are most helpful when there are implementation dates or estimated dates.

This may not apply to me.

various role specific updates...

very lengthly; difficult to immediately ascertain whether it relates to my position

when changes to policy affecting tx ctrs occurs and need to be implemented- would be useful to have it highlighted in the notice and decent lead time for implementation would be helpful

Wider distribution to non management
## System Notice—Usefulness

**Question:** What do you find useful about the system notices?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Again - I haphazardly read these notices. Often the same notice is there for months.</td>
</tr>
<tr>
<td>2</td>
<td>Again, allows me to stay up to date for compliance of our OPO.</td>
</tr>
<tr>
<td>3</td>
<td>Again, direct communication</td>
</tr>
<tr>
<td>4</td>
<td>Being current of the changes.</td>
</tr>
<tr>
<td>5</td>
<td>Brief and to the point.</td>
</tr>
<tr>
<td>6</td>
<td>Catch your attention</td>
</tr>
<tr>
<td>7</td>
<td>changes</td>
</tr>
<tr>
<td>8</td>
<td>Clear information, phone number provided</td>
</tr>
<tr>
<td>9</td>
<td>concise instructions/discussion.</td>
</tr>
<tr>
<td>10</td>
<td>Concise, with references to view if further info is needed</td>
</tr>
<tr>
<td>11</td>
<td>Convenient and automatic</td>
</tr>
<tr>
<td>12</td>
<td>current updates for implementation</td>
</tr>
<tr>
<td>13</td>
<td>Describing the audience so that I know if the information pertains to my job description.</td>
</tr>
<tr>
<td>14</td>
<td>Ease of access........</td>
</tr>
<tr>
<td>15</td>
<td>easy</td>
</tr>
<tr>
<td>16</td>
<td>easy access</td>
</tr>
<tr>
<td>17</td>
<td>Easy access</td>
</tr>
<tr>
<td>18</td>
<td>Easy to determine if it is relevant to me.</td>
</tr>
<tr>
<td>19</td>
<td>Easy to determine which appley to our lab practice</td>
</tr>
<tr>
<td>20</td>
<td>Easy to keep staff current because they can just be forwarded to staff.</td>
</tr>
<tr>
<td>21</td>
<td>easy to read/understand</td>
</tr>
<tr>
<td>22</td>
<td>easy to see what is pertinent and sharing this information</td>
</tr>
<tr>
<td>23</td>
<td>Effective Date of the change and what our center needs to do.</td>
</tr>
<tr>
<td>24</td>
<td>Email is a good tool to use for these notices.</td>
</tr>
<tr>
<td>25</td>
<td>emailed directly to me; concise and easy to assess if they relate to my position</td>
</tr>
<tr>
<td>26</td>
<td>getting them in email so I can read them anytime I have a few extra minutes</td>
</tr>
<tr>
<td>27</td>
<td>helps me stay informed.</td>
</tr>
<tr>
<td>28</td>
<td>I answered no because I was not able to open the “system notice” for review. I can prepare for changes in Tiedi by attending live meetings when provided. It is easy to sign up for these.</td>
</tr>
<tr>
<td>29</td>
<td>I do not access UNet, so this is my only notification</td>
</tr>
<tr>
<td>30</td>
<td>I find most useful when receiving notification about current update and changes.</td>
</tr>
<tr>
<td>31</td>
<td>I have the ability to view all the important notices on UNET or as they are delivered via email.</td>
</tr>
<tr>
<td>32</td>
<td>I like seeing what other programs are doing.</td>
</tr>
<tr>
<td>33</td>
<td>I like that they are available by both email and on the front page of UNET</td>
</tr>
<tr>
<td>34</td>
<td>I read them if it pertains to laboratory practice.</td>
</tr>
<tr>
<td>35</td>
<td>I send these notices to the individuals that are affected by these changes If they are useful to the OPO I will read them but if they are primarily affecting transplant centers I am more likely to skip over them unless it deals with the transplant specific programs we serve locally (currently only kidneys)</td>
</tr>
<tr>
<td>36</td>
<td>Inform you in advance so you are aware of what and when it is going to happen.</td>
</tr>
<tr>
<td>37</td>
<td>information</td>
</tr>
<tr>
<td>38</td>
<td>information</td>
</tr>
</tbody>
</table>
information
Informs me of up to date changes.
It brings things to my attention so that I make time to read them. Otherwise, I never seem to have time to independently go to the site.
It is helpful to receive the notice without having to go to the web site. I am not always on the site so its helpful to get something.
It provides you with the notice before it happens
Its automatic, it pops up for me, its simple and easy to read and makes me read it.
keep s me updated on other issues beside those involvin thoracic tx
Keep you updated
Keeping current with upcoming changes
keeping my practice up to date
Keeps all up to date
Keeps me informed of current information.
Keeps me up to date
Keeps me updated
Keeps up to date
keeps you updated with new information.
good when policy date of implementation is reached
Learn about changes
like being informed - need to read to stay current w/ practice / compliance
Makes you aware or reminds you of deadlines, changes or system updates.
May impact operations
N/A
n/a
N/A
NA
Need to stay updated.
Nice and clear
no comments
Not to be behind of the game.
nothing
Nothing in particular.
notification by e mail is great
Notification of time periods in which UNET service may be interuppted.
notified of high impact changes.
One more reminder ....
pertinent updates affecting listing and allocation issues
plain language!
Policy updates and UNOS " down time" affect my practice - good to be kept aware
READILY AVAILABLE
receiving updated information
relevance to clinical practice
reminder to check for current updates.
Repetition;
somewhat helpful.
Staying abreast of changes and compliance policies
that they come directly to my e-mail and I do not have to go anywhere to look for them.
The advanced reminders in stages.
The information is always clear and probably as concise as could be expected. The way they are delivered, there should be another choice besides yes or no for numbers 31 and 32 - I would say "sometimes" is more accurate. They are right there when I log in. They are the first thing you see so they are hard to miss. They are there to help me keep up with my job. They can help me, as our lab’s IT liaison, to make changes to accommodate UNOS changes. They have reminders. They keep me updated. They are timely. They are to the point. They are to the point. Too busy; learn policy changes at team mtgs. Usually do not take the time to read the notices posted (other than UNET downtime messages) because I am actively working on a case when it pops up. Well organized, succinct. When applicable, they keep us informed. Yes.
System Notice—Improvement Suggestions

Question: What are your suggestions for improving system notices?

1. (I do not log onto UNet, so this question is not relevant, but surveymonkey forces me to respond.)
2. Any system notice that is extremely important, should include a notification to that effect.
3. As an I.T. person, the system notices almost never apply to my needs & concerns.
4. Change heading to red font.
5. DonorNet outages to be labeled as urgent to differentiate from general announcements to announcements that affect operational allocation.
6. Find a way for them to stand out from the other email we receive.
7. Font is hard to read sometimes.
8. For some reason nothing grabs my attention to read them so I forget.
9. highlight the new notices in anything other than the gray blue they are current displayed in. gets lost and doesn't flag me to read them when i am logging in to do a different task.
10. I did have a few questions one time and called the help desk. The assistant did not know the details of the notice and could not answer my questions right away.
11. I do not log into UNet on a regular basis so I often do not see these. I prefer receiving them as email.
12. I don't think I'm getting all of them.
13. I have none at this time.
15. I suggest using a different color font. The current grey is a bit bland for important notices, and could easily be disregarded.
16. I think the notice could still be put into a shorter paragraph so that a user can skim quickly and determine whether this notice is for them.
17. If it is on a log in page on UNOS, I will probably just click to the next page to get to what I am doing, and ignore messages. Perhaps you should put in bold a few key words so we can see if it pertains to us.
18. Just a lot of them!
19. Larger font, less white space wasted.
20. Making the language more clear to understanding rather than spoken in legal language.
21. N/A
22. n/a
23. N/A
24. n/a
25. N/A
26. N/A
27. NA
28. NA
29. No need to email, I read them when I log on.
30. no suggestions at this time
31. none
32. None
33. None
34. none
35. none
36. none
37. none
38. none
39. None
none

None.

nothing

plain english,

Read the emails sometimes, Read them more when they are on the log on.

the answer to all of the above is sometimes, when relevant to my area of expertise

The font is hard to read

The intended audience is frequently misleading and not consistent with actual practice.

The notification is haphazard; the "target audience" is sometimes a subset of people who need to get the information. In the past 5 years, there have been at least 2 major disruptions that we have identified during donors because advance notification of programming changes was not received by the appropriate individuals.

The reason I checked no to 31 and 32: I do not receive these notices, as I am not with a transplant center, but rather am with one of the coordinating centers for the KPD Pilot Program. However, once the KPD program i automated, I hope to receive these notices!

There are too many notices, I wish they could be managed better and make all the changes once a month (if possible...understanding some cannot wait.)

They seem complicated to understand on the surface.

They seem fine as they are to me

they're great.

This may not apply to me.

use them more often!

VERY CONFUSING WITH THE NUMEROUS DATES .... GIVE ME THE ACTUAL DATE THE RULE OR POLICY APPLIES NOT THE DATE THE DECISION WAS MADE ETC...

Write in English. Avoid ALL abbreviations and jargon and make concise.
**UNOS Primer—Usefulness**

**Question:** What did you find most useful about the UNOS Primer?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.</td>
</tr>
<tr>
<td>2</td>
<td>All of the information was useful in one form or another.</td>
</tr>
<tr>
<td>3</td>
<td>All the presentations Number 36 doesn't make sense</td>
</tr>
<tr>
<td>4</td>
<td>best learning session that I have attended in my 24 years. extremely helpful and wonderful presentations</td>
</tr>
<tr>
<td>5</td>
<td>Better understanding of the different departments and ability to meet with staff</td>
</tr>
<tr>
<td>6</td>
<td>everything! very informative</td>
</tr>
<tr>
<td>7</td>
<td>Excellent</td>
</tr>
<tr>
<td>8</td>
<td>Excellent information. I have attended</td>
</tr>
<tr>
<td>9</td>
<td>Extremely helpful to fully understand the way UNOS and OPTN &quot;works&quot;.</td>
</tr>
<tr>
<td>10</td>
<td>Focused material and face to face meeting of UNOS staff</td>
</tr>
<tr>
<td>11</td>
<td>Found it very interesting.</td>
</tr>
<tr>
<td>12</td>
<td>Gave a terrific overview of the multiple departments and body of work that is UNOS.</td>
</tr>
<tr>
<td>13</td>
<td>Great information! It made it a lot easier to understand the organizational setup. Who's who. This conference had the most job related information for me than any other I’ve attended.</td>
</tr>
<tr>
<td>14</td>
<td>Great to meet people that I have spoken with on the phone.</td>
</tr>
<tr>
<td>15</td>
<td>Hands down - the best 2 days I've spent in my transplant career getting clarity about the role of UNOS in transplant.</td>
</tr>
<tr>
<td>16</td>
<td>Have never attended</td>
</tr>
<tr>
<td>17</td>
<td>Having the contact with the UNOS representatives- helps with understanding UNOS function and committee processes</td>
</tr>
<tr>
<td>18</td>
<td>I attended in 9/2010 - it was excellent</td>
</tr>
<tr>
<td>19</td>
<td>I have encouraged my administrators to attend</td>
</tr>
<tr>
<td>20</td>
<td>I have not attended due to budget restrictions.</td>
</tr>
<tr>
<td>21</td>
<td>I have sent a number of my staff who find the broad perspective of the meeting helpful; prior to attending most only interacted with UNOS in a narrow/limited way.</td>
</tr>
<tr>
<td>22</td>
<td>I love it. The Primer was awesome. Understanding UNOS's role as it relates to the government was helpful. I think it all connected the dots. As a director I never really understand the role of UNOS. This was a great experience and I would highly recommend attendance from all transplant staff.</td>
</tr>
<tr>
<td>23</td>
<td>I think it was very useful but was focused on the transplant center. One needs to be done focusing on the OPO side.</td>
</tr>
<tr>
<td>24</td>
<td>I went to the first one. It could have been broken down even further - some of the things were over my head and has taken me a while to get up to speed.</td>
</tr>
<tr>
<td>25</td>
<td>Information on structure of OPTN, history of UNOS, information about data reporting (Jennifer Milton’s Talk)</td>
</tr>
<tr>
<td>26</td>
<td>Intimate setting at the UNOS office in Richmond; opportunity to put face with a name; group and one-on-one time with staff, thumb-drive take-home of presentations.</td>
</tr>
<tr>
<td>27</td>
<td>It was an excellent event. Being new to transplant I learned about the Evaluation Plan and now I access several times a month.</td>
</tr>
<tr>
<td>28</td>
<td>It was great information</td>
</tr>
<tr>
<td>29</td>
<td>It was so helpful especially being new to transplant. I attended and it was GREAT!</td>
</tr>
</tbody>
</table>
It was useful to see the Transplant Center side of things being an OPO employee; I understand much more of their processes and how UNOS fits into the transplant side of donation and transplantation.

Learning about the policies, and being able to ask questions.

Meeting with all the UNOS representatives

More insight into the transplant world. Getting to put a face on the many folks I've corresponded with.

Networking - the content of the meeting was excellent.

Networking with other center staff and meeting UNOS staff.

OPO track was nice

Primer is useful. Would not attend having been on various OPTN/UNOS committees

Sent by CAO as a new employee and she enjoyed it

Sent staff to meeting. Found it helpful

Staff we have sent find them very helpful. Basic information and education about UNOS and data collecting/reporting.

The explanation of UNOS/OPTN regulatory oversight process

The UNET portion

this is critical for the younger staff

very helpful for committee members to understand the workings of UNOS and the role in creating policy

We sent a staff member who felt it was heavily oriented to transplant centers as opposed to OPO's

Where to find reports, accurate teidi reporting
**UNOS Primer—Improvement Suggestions**

**Question: What are your suggestions for improving the UNOS Primer?**

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Ask people to introduce themselves to the group. Develop a game where folks have to find their &quot;secret&quot; partner through asking a series of questions throughout the Primer, like a mystery game... this will force people to speak to one another. I still think Transplant professionals are a &quot;cliche&quot; group.</td>
</tr>
<tr>
<td>3</td>
<td>Concerning that a UNOS &quot;Primer&quot; would take 1.5 days. Most of us don't have the time.</td>
</tr>
<tr>
<td>4</td>
<td>Consider adding more best practices</td>
</tr>
<tr>
<td>5</td>
<td>Consider making it more relevant to OPO's. Consider making an abbreviated version available as a webinar so more staff could be exposed.</td>
</tr>
<tr>
<td>6</td>
<td>Have a UNOS for Administrators to attend- review TIEDI Reports and utilizing the Evaluation Plan</td>
</tr>
<tr>
<td>7</td>
<td>Have it more often than twice yearly</td>
</tr>
<tr>
<td>8</td>
<td>heard great things from my colleague who attended</td>
</tr>
<tr>
<td>9</td>
<td>Hold more frequently. Hold it at least once in each region - or targeted regions. How about start with Region 5? :-) I would send all the nurses I could spare. As an Administrator - it is the best way to get the message across to nurse coordinators the importance of policy compliance. My nurses are on a rotating schedule to attend until 100% have attended. That's how well I think of the UNOS Primer.</td>
</tr>
<tr>
<td>10</td>
<td>I had several suggestions for improvement which I passed on in a phone interview after the event.</td>
</tr>
<tr>
<td>11</td>
<td>I heard that it is awesome</td>
</tr>
<tr>
<td>12</td>
<td>I plan on attending in the future.</td>
</tr>
<tr>
<td>13</td>
<td>I wold make it a 21/2 day seminar and include the OPO side: I was looking forward to that and felt that OPOs and their interaction with UNOS was not dually represented.</td>
</tr>
<tr>
<td>14</td>
<td>I would love to see this offered as a webinar series to be able to expose more of my staff to this information. We have limited budget and cannot afford to send everyone to the seminar.</td>
</tr>
<tr>
<td>15</td>
<td>invite a speaker to also give an overview of the key differences in CMS regs and OPTN rules. Although UNOS cannot speak to this, administrators have finite travel budgets and a fuller perspective of this would be a better benefit to those attending.</td>
</tr>
<tr>
<td>16</td>
<td>Is this for OPO too? ...or just transplant.</td>
</tr>
<tr>
<td>17</td>
<td>Let people know about it - was unaware of this.</td>
</tr>
<tr>
<td>18</td>
<td>Make it a webinar to eliminate travel costs.</td>
</tr>
<tr>
<td>19</td>
<td>Make one specific for OPO's. I gained a lot of knowledge even though it was directed for Transplant Centers. However one for OPO's in mnd would be wonderful!</td>
</tr>
</tbody>
</table>
Make the content easier to obtain without traveling to Richmond. The primer content is extremely useful and should be more easily accessible to a larger group of clinical transplant professionals that may not be able to attend. Need help developing a system for ongoing staff training related to OPTN/UNOS regulations and compliance.

maybe a Primer 2.0 for those who have attended the first and want to continue learning.

More crossover topics for the OPO side and Transplant side to improve process and communication

More hands on group work and less lectures. I liked when we had to find the policy.

More information for OPOs. Maybe one Primer for OPOs and one for Tx centers

More OPO focus.

n/a

n/a

n/a

N/A

n/a

NA

NA

NA

NA

none

none

none

None

None

none, I enjoyed it very much, very informative

Notify all staff members of clinical transplant facilities, coordinators, and other interested parties of its availability and cost.

Offer more.

Once a quarter - so more staff can attend.

OPO specific primer

Out Data Coordinator attended and endorses the UNOS Primer 100%.

Provide this as a covered expense for UNOS committee members to attend.

Question was asked at last Regional meeting if these meetings could be held in each region to diminish travel time/ expenses for those wanting to attend...

Should have a UNOS Conference for Administrators

The interactive sessions were really good.

Unfortunately we could not register due to 'space'. It would be helpful if there was an indicator of # of seats available when you look at the registration information on the website.

what is it?

Would love to help with this
Online Training Topics—Organ Allocation

*Question: If you are interested in online training about allocation policy, which specific organ types are you interested in?*

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>All - you can never not receive any reinforcements</td>
</tr>
<tr>
<td>2</td>
<td>Kidney and Liver</td>
</tr>
<tr>
<td>3</td>
<td>Kidney and liver</td>
</tr>
<tr>
<td>4</td>
<td>kidney, liver, pancreas</td>
</tr>
<tr>
<td>5</td>
<td>kidney, liver, pancreas, heart</td>
</tr>
<tr>
<td>6</td>
<td>liver, kidney, pancreas, heart</td>
</tr>
</tbody>
</table>
Online Training—DonorNet

**Question:** If you checked DonorNet functionality, what specific features are you interested in?

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1. More user-driven queries and reports to obtain donor specific characteristics, etc. and the ability to download or copy the resulting data in spreadsheet format.</td>
</tr>
<tr>
<td></td>
<td>2. Ability to inquire on a donor based on the UNOS Donor ID specifically without having to enter the match run number.</td>
</tr>
<tr>
<td>2</td>
<td>3rd party functionality.</td>
</tr>
<tr>
<td>3</td>
<td>A good tool to train new staff for using donornet to assess donor information and a separate session for how to investigate allocation process in using Donornet time stamps.</td>
</tr>
<tr>
<td>4</td>
<td>ability to access match runs without match ID.</td>
</tr>
<tr>
<td>5</td>
<td>acceptance time and evaluation time.</td>
</tr>
<tr>
<td>6</td>
<td>accessing information</td>
</tr>
<tr>
<td>7</td>
<td>All</td>
</tr>
<tr>
<td>8</td>
<td>all</td>
</tr>
<tr>
<td>9</td>
<td>all</td>
</tr>
<tr>
<td>10</td>
<td>All</td>
</tr>
<tr>
<td>11</td>
<td>all</td>
</tr>
<tr>
<td>12</td>
<td>all</td>
</tr>
<tr>
<td>13</td>
<td>all</td>
</tr>
<tr>
<td>14</td>
<td>all aspects</td>
</tr>
<tr>
<td>15</td>
<td>All aspects</td>
</tr>
<tr>
<td>16</td>
<td>All- I would like a detailed training session-</td>
</tr>
<tr>
<td>17</td>
<td>All the above</td>
</tr>
<tr>
<td>18</td>
<td>All.</td>
</tr>
<tr>
<td>19</td>
<td>any</td>
</tr>
<tr>
<td>20</td>
<td>Any changes and updates to the system.</td>
</tr>
<tr>
<td>21</td>
<td>As a data specialist for whom DonorNet is a new application, I would be interested in all aspects.</td>
</tr>
<tr>
<td>22</td>
<td>Attachments, browser support</td>
</tr>
<tr>
<td>23</td>
<td>Automated crossmatching</td>
</tr>
<tr>
<td>24</td>
<td>basic info</td>
</tr>
<tr>
<td>25</td>
<td>being able to view images</td>
</tr>
<tr>
<td>26</td>
<td>Best practices for utilizing</td>
</tr>
<tr>
<td>27</td>
<td>cannot identify specific items at this time, but for functions that are not routinely accessed, or provide more &quot;advanced&quot; functionality would be helpful</td>
</tr>
<tr>
<td>28</td>
<td>Changes in data</td>
</tr>
<tr>
<td>29</td>
<td>changes to make it more user friendly and effective</td>
</tr>
<tr>
<td>30</td>
<td>closing match runs (current tutorial needs to be expanded upon)</td>
</tr>
<tr>
<td>31</td>
<td>codes for refusal explained further</td>
</tr>
<tr>
<td>32</td>
<td>compatability issues with Mac computers and mobile devices</td>
</tr>
<tr>
<td>33</td>
<td>continuous improvement</td>
</tr>
<tr>
<td>34</td>
<td>Donor chart attachments, specifically uploading of radiologic studies</td>
</tr>
</tbody>
</table>
35 donor heart preservation
36 electronic offers, what does the transplant center see when the OPO sends offers?
37 everything
38 everything
39 Everything.
40 extending offers
41 General info
42 general information to make sure I am utilizing everything efficiently
43 General information for use by Histocompatibility lab staff.
44 general refresher for staff who work within the DonorNet system. Need a way to verify staff competency within DonorNet system.
45 General use.
46 having the different OPO's filling in information the same across the board so that people accessing the information on smart devices can get the information necessary
47 heart
48 How does it function, when no ABO is put in?
49 How it interacts with our patient tracking software. (I did attend the uploads class last year.)
50 How the OPTN can make donor data accessible without having to send all that paperwork. Copies and copies, etc. that requires a lot of resources and manpower.
51 how to customize reports and really use the system better
52 How to look up testing results.
53 How to use it better
54 How to use it to my advantage by knowing what each application is useful for.
55 I do not know how it functions.
56 I think you should be able to view attachments on your hand-held device. Why does the system allow for continued allocation of organs that have >XX hrs CIT to the opposite coast? You can set lab parameters and distance parameters, why can't you set cold time upon arrival parameters? Also, why don't you have an electronic link to Sterling Courier that allows us to check flight arrangements w/o bothering the UNOS call center?
57 Improvements especially for increasing utilization
58 Improving allocation process for marginal organs
59 issues pertaining to donornet's incompatibility with current IE browsers and how users are working through this
60 just basically how to navigate / get info
61 Just overall view of what we can and cannot do.
62 just tips to see if there is anything that I could do more efficiently
63 kidney paired donation
64 Laboratory aspects; might be a good adjunct to our current training for new techs.
65 Liver
66 look-up and reports
67 making modifications
68 Match Run
organ offer

69  Mobile access
70  Mobile device access
71  mobile phone
72  N/A
73  n/a
74  NA
75  NA
76  offers
77  Organ Allocation
78  Organ allocation & placement - I would like to see more specific details posted on UNet such as anticipated donor OR time and whether or not donor blood samples were sent for crossmatch.
79  Organ Offers
80  overall--do not work with it on a frequent basis so do not keep up with newest updates and recently got a mobile device but unsure how to adjust settings to access complete DonorNet vs the mobile application that automatically comes up when logging on to site
81  Overview for data coordinators.
82  Pressor use area
83  PTR code(no sera or positive crossmatch) entry for labs that bypass the transplant programs.
84  report availability and program specific generation
85  Reporting, searching...etc.
86  Required fields
87  result uploads
88  Review of donor offers.
89  Staff do not understand the implications of fields in Donornet. Plus we were trained once, I am sure there are features that we do not even know about.
90  Staff training aids.
91  Standardizing language, abbreviations and having the info in chronological order. Accuracy of info needs to improve a bit. Like smoking history, often different answers in history, narrative note and answer to > than 20 PPY. Should just have PPY total and if stopped when.
92  Tiedi Reports and how to accurately complete it-
93  To have training specially to everything Donornet can do that I'm unaware of, i.e. reports
94  Training of new staff and potential certificates of training completion
95  Understanding how it works
96  updates occurring
97  uploading images
98  Ways to easily obtain information
99  working in the lab need to know who was transplanted and which donor.
100  XML uploads
Online Training—UNet

*Question: If you selected UNet\textsuperscript{SM} as an online training topic, which specific elements are you interested in?*

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>More user-driven queries and reports to obtain our recipient data and the ability to download or copy the resulting data in spreadsheet format. The current method of Exporting Tiedi data is cumbersome, especially since the reports do not come with headers.</td>
</tr>
<tr>
<td>2</td>
<td>The ability in WaitList to customize reports that pull data from all of our wait listed patients, not just those currently on the list.</td>
</tr>
<tr>
<td>3</td>
<td>NA</td>
</tr>
<tr>
<td>4</td>
<td>Tiedi forms, guidelines for collecting/entering data</td>
</tr>
</tbody>
</table>
**Additional Educational Topics**

*Question: Please indicate any other education topics you would find useful.*

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Any major changes in UNOS or CMS requirements.</td>
</tr>
<tr>
<td>2</td>
<td>Any new policies</td>
</tr>
<tr>
<td>3</td>
<td>anything on living donation</td>
</tr>
<tr>
<td>4</td>
<td>Anything to help us get through a UNOS living donor survey</td>
</tr>
<tr>
<td>5</td>
<td>Background for new employees on the UNOS and OPTN list and numerical designation etc.</td>
</tr>
<tr>
<td>6</td>
<td>basic info</td>
</tr>
<tr>
<td>7</td>
<td>Comparison of CMS &amp; UNOS regulations</td>
</tr>
<tr>
<td>8</td>
<td>Criteria for status one listing.</td>
</tr>
<tr>
<td>9</td>
<td>Culture reporting, I find coordinators don't understand enough about reporting cultures/why it is done</td>
</tr>
<tr>
<td>10</td>
<td>DDR compliance-the instructions are not helpful. Would like more information what UNOS would like. Would like language agreement between DonorNet &amp; DDR completion. Would like improved &quot;streaming&quot; between DonorNet and DDR reporting site.</td>
</tr>
<tr>
<td>11</td>
<td>Distribution of OPO data</td>
</tr>
<tr>
<td>12</td>
<td>Expand a bit on giving a good offer utilizing UNet - have transplant surgeons presenting to OPO folks on how to do this well.</td>
</tr>
<tr>
<td>13</td>
<td>Exporting Reports</td>
</tr>
<tr>
<td>14</td>
<td>Extra-Renal identification and use of marginal donors. How ischemic times effect live donors transplants outcomes, that are allocated via local, regional and national methods</td>
</tr>
<tr>
<td>15</td>
<td>Financial support regarding food, travel, lodging and meds expenses for Puerto Rico and Virgin Island patients</td>
</tr>
<tr>
<td>16</td>
<td>Guidelines for follow up and monitoring post transplant for recipients.</td>
</tr>
<tr>
<td>17</td>
<td>Guidelines of the new Living Donor UNOS audit and what are the most important things to be focusing on.</td>
</tr>
<tr>
<td>18</td>
<td>Heart/VAd</td>
</tr>
<tr>
<td>19</td>
<td>Hospital Development as related to allocation and donation</td>
</tr>
<tr>
<td>20</td>
<td>How members can use data to drive quality/process improvement initiatives</td>
</tr>
<tr>
<td>21</td>
<td>I think I may need some fairly basic education. My knowledge base regarding UNOS is very limited.</td>
</tr>
<tr>
<td>22</td>
<td>If webinars are used, please archive in a single location to be found later by staff if they cannot attend the live presentation.</td>
</tr>
<tr>
<td>23</td>
<td>Impact of Adverse Events on Transplant Centers</td>
</tr>
<tr>
<td>24</td>
<td>information on preparing for the CCTC exam</td>
</tr>
<tr>
<td>25</td>
<td>Is there a standard application of Karnofsky's scoring relative to kidney TX candidates--patients may still be working, dialysis centers now have nocturnal dialysis which allows patients to work/attend school</td>
</tr>
<tr>
<td>26</td>
<td>Management of donors</td>
</tr>
<tr>
<td>27</td>
<td>Maybe there should be regular webinars for new policy proposals in addition to the PDF proposals</td>
</tr>
<tr>
<td>28</td>
<td>MMFI cut off, what they really mean and how different labs interpret them.</td>
</tr>
<tr>
<td>29</td>
<td>More education on compliance and understanding the policy</td>
</tr>
</tbody>
</table>
More in-depth donor management best practices

organ allocation training

organ preservation / perfusion

Paired donation

Patient safety incidents - are we reporting them all? Can we do better? - education

Policy interpretation

PR/public education, media, donor family/recipient communication, volunteerism/activism

requirements for status qualifications heart

RFI preparation. Understanding policies & by-laws.

something about legislative topics, organ transportation and policies in the US that hinder or help the safe and efficient movement of organs or the organ center itself

Standardization would be very helpful. If you are a kidney program basic standard policies and protocols for everyone especially with the QAPI programs.

TIEDI Reports- and how to complete-

To review "problem" policies that seem to be most common among centers nationally.

transplant finance

Transplant management best practices

Financial management - HMO and Medicaid

Understanding SRTR data and how it ties to UNOS reporting

UNOS structure

Use of the online data tool

Webinar addressing the latest policy revisions/new policies along with best practice suggestions from centers

Yes. After attending the PRIMER it appeared that the amount of time required to participate on a committee was much more than I could ever volunteer for. As an OPC, I am already on call >70 hrs a week. We are a small OPO! It doesn't mean I don't want to participate, but time is precious. Are there less time-consuming/demanding things to participate in?
Volunteer Contact Info

**Question:** If you are interested in serving on a committee or work group or would like to teach or develop an educational session, please give us your name and contact information.

<table>
<thead>
<tr>
<th>Number</th>
<th>Response Text</th>
</tr>
</thead>
</table>
| 1      | David Hull, MD, FACS  
Also was on the OAC and also Vice Chair and Chair  
Now serving on the MPSC and Associate Counsellor of Region 1 |
| 2      | Brenda Thrasher  
704 355-8071  
brenda.thrasher@carolinashcare.org |
| 3      | Karen Hess, RN, MS, MBA, ACNP (702) 671-1029. Karen.hess@umcsn.com |
| 4      | Betty Hunter hunterbj@upmc.edu |
| 5      | susan hall  
shall@ctdn.org |
| 6      | Victoria Vollbrecht  
tvollbrecht@core.org  
800-366-6777 x271 |
| 7      | Giorgio M. Aru, MD  
University of Mississippi Med Center  
(601) 984 5176  
garu@umc.edu  
Programs and literature to educate patients from underdeveloped areas |
| 8      | Colleen McCarthy colleen.mccarthy@bcw.edu  414-937-6961 |
| 9      | Paul Kroner; email: pkroner@stanfordmed.org. Thanks! |
| 10     | Cheryl Edwards RN MSN CCRN  
203 232 8288  
Particular interest in disease transmission and ethics |
| 11     | lisa florence MD  
lisa.florence@swedish.org  
206-386-3660  
issues related to kidney transplantation |
| 12     | Jenny Lee  
jenlee@stanfordmed.org |
| 13     | I'm already on a subcommittee for KPD, but would be interested in other committees. Laurie Reece, 512-961-6199, laurie.reece@paireddonation.org |
| 14     | Sheryl Moore, BSN, RN  
Lifepoint  
843-763-7755 |
| 15     | Jennifer Muriett  
602-222-2498  
jennifer@dnaz.org |
<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Phone/SIEM</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>Nance Conney</td>
<td>520-694-7367</td>
<td><a href="mailto:nance.conney@uahealth.com">nance.conney@uahealth.com</a></td>
</tr>
<tr>
<td>17</td>
<td>Sharon Walls</td>
<td>509-474-4702</td>
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</tr>
<tr>
<td>18</td>
<td>n/a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Esther-Marie Carmichael</td>
<td>714-330-2982</td>
<td><a href="mailto:esther-marie.carmichael@med.usc.edu">esther-marie.carmichael@med.usc.edu</a></td>
</tr>
<tr>
<td>20</td>
<td>Kim Phillips</td>
<td>(843) 792-0280</td>
<td><a href="mailto:phillk@musc.edu">phillk@musc.edu</a></td>
</tr>
<tr>
<td>21</td>
<td>Judy Baker</td>
<td>214-82-8863</td>
<td><a href="mailto:judyba@baylorhealth.edu">judyba@baylorhealth.edu</a></td>
</tr>
<tr>
<td>22</td>
<td>Charles B. Huddleston, MD</td>
<td>314-268-4183</td>
<td><a href="mailto:chuddle7@slu.edu">chuddle7@slu.edu</a></td>
</tr>
<tr>
<td>23</td>
<td>I have offered to serve on the OPO committee, but the process for how members are selected is confusing. Dina Steinberger, UW OPO <a href="mailto:dsteinberger@uwhealth.org">dsteinberger@uwhealth.org</a>, 608.265.0374</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>James Pagan</td>
<td>phone: 801 641 9941</td>
<td>email: <a href="mailto:james.pagan@hsc.utah.edu">james.pagan@hsc.utah.edu</a></td>
</tr>
<tr>
<td>25</td>
<td>Deonna Moore, MSN, ACNP-BC</td>
<td>P: 615-322-0034</td>
<td><a href="mailto:deonna.moore@vanderbilt.edu">deonna.moore@vanderbilt.edu</a></td>
</tr>
<tr>
<td>26</td>
<td>Julie Traub</td>
<td><a href="mailto:julie.traub@umcsn.com">julie.traub@umcsn.com</a></td>
<td>(702)383-2224</td>
</tr>
<tr>
<td>27</td>
<td>Janet Mize-Jugert RN</td>
<td>210-7005-6702</td>
<td><a href="mailto:janet.jugert@christushealth.org">janet.jugert@christushealth.org</a></td>
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<td>28</td>
<td><a href="mailto:schaffer.randolph@scrippshealth.org">schaffer.randolph@scrippshealth.org</a></td>
<td></td>
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</tr>
<tr>
<td>29</td>
<td>silas norman</td>
<td></td>
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</tr>
<tr>
<td>30</td>
<td>already serving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>elizabeth hemedinger</td>
<td></td>
<td><a href="mailto:ehemedinger@immco.com">ehemedinger@immco.com</a></td>
</tr>
<tr>
<td>32</td>
<td>Linda Grinnell-Merrick, NP</td>
<td></td>
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</tr>
<tr>
<td>33</td>
<td>Patricia Adams</td>
<td></td>
<td><a href="mailto:padams@wfubmc.edu">padams@wfubmc.edu</a></td>
</tr>
<tr>
<td>34</td>
<td>Lisa Martin</td>
<td></td>
<td>e-mail <a href="mailto:lisa.martin8@va.gov">lisa.martin8@va.gov</a>, phone (804) 675-5403</td>
</tr>
<tr>
<td></td>
<td>Name</td>
<td>Title and Institution</td>
<td>Contact Information</td>
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<tr>
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</tr>
<tr>
<td>35</td>
<td>Anna Gonzalez</td>
<td>Director of Information Systems, Donor Resource Center, and Kidney and Pancreas Allocation</td>
<td><a href="mailto:agonzalez@giftofhope.org">agonzalez@giftofhope.org</a></td>
</tr>
<tr>
<td>36</td>
<td>Deirdre McAdams</td>
<td><a href="mailto:dmcadams@dcids.org">dmcadams@dcids.org</a></td>
<td>8652507573</td>
</tr>
<tr>
<td>37</td>
<td>Amy Evenson</td>
<td>110 Francis Street, 7th Floor</td>
<td><a href="mailto:aevenson@bidmc.harvard.edu">aevenson@bidmc.harvard.edu</a></td>
</tr>
<tr>
<td>38</td>
<td>Leslie Semones</td>
<td><a href="mailto:leslie.semones@gunet.georgetown.edu">leslie.semones@gunet.georgetown.edu</a></td>
<td>202-215-0185</td>
</tr>
<tr>
<td>39</td>
<td>shelina merali</td>
<td><a href="mailto:shelina.merali@piedmont.org">shelina.merali@piedmont.org</a></td>
<td>404-550-0275</td>
</tr>
<tr>
<td>40</td>
<td>Jeanette Ohm</td>
<td><a href="mailto:johm@giftoflifemichigan.org">johm@giftoflifemichigan.org</a></td>
<td></td>
</tr>
<tr>
<td>41</td>
<td>Cynthia Laws</td>
<td>407-644-7030 x 261</td>
<td><a href="mailto:Cynthia.Laws@translife.org">Cynthia.Laws@translife.org</a></td>
</tr>
<tr>
<td>42</td>
<td>Linda Munro</td>
<td>313-916-2271</td>
<td><a href="mailto:lmunro1@hfhs.org">lmunro1@hfhs.org</a></td>
</tr>
<tr>
<td>43</td>
<td>Kelly Ranum</td>
<td><a href="mailto:kranum@lopa.org">kranum@lopa.org</a></td>
<td></td>
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<tr>
<td>44</td>
<td>Tamara Nunes</td>
<td><a href="mailto:tnunes@ctdn.org">tnunes@ctdn.org</a></td>
<td></td>
</tr>
<tr>
<td>45</td>
<td>Henry Randall, MD</td>
<td>Associate Professor of Surgery &amp; Immunology</td>
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<td></td>
<td>Director, Abdominal Transplantation &amp; HPB Surgery</td>
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<td></td>
<td></td>
<td>Saint Luke's Hospital of Kansas City</td>
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<td>4320 Wornall Road</td>
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<td>MP I, Suite 240</td>
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<td></td>
<td></td>
<td>Kansas City, MO, 64111</td>
<td>816-932-4655</td>
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<tr>
<td></td>
<td></td>
<td><a href="mailto:hrandall@saint-lukes.org">hrandall@saint-lukes.org</a></td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>Giorgio M. Aru, MD</td>
<td>2500 North State st</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Jackson, MS 39216</td>
<td></td>
</tr>
<tr>
<td>47</td>
<td>Kandi Byrd</td>
<td>813.844.5521</td>
<td></td>
</tr>
<tr>
<td>48</td>
<td>Karen Krok</td>
<td>215-349-8222</td>
<td><a href="mailto:karen.krok@uphs.upenn.edu">karen.krok@uphs.upenn.edu</a></td>
</tr>
<tr>
<td>49</td>
<td>Lori Markham</td>
<td><a href="mailto:lmarkham@mwt.org">lmarkham@mwt.org</a></td>
<td></td>
</tr>
</tbody>
</table>
50 Frank Rathman
Donor Alliance
(303) 501-6272
frathman@donoralliance.org
Would be willing to help with whatever I can

51 Donna Smith
Mid-America Transplant Services
dsmith@mts-stl.org

52 Marlene Abe
marlene.abe@stjoe.org

53 Mary Nachreiner
mnachreiner@uwhealth.org
One project that comes to mind is establishing a brochure on how to write your donor family
(unless there's one I couldn't find online)

54 Ramon A. Cruz-Castro, MSW
787/763-0104
cruzr@dneph.com

55 Ray Gabel, BA
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56 Paul Gaglio pjgaglio@montefiore.org

57 Tammy Wright, 858-650-5016, tammy.wright@sharp.com

58 Becky Harris-Burns
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59 Pamela Thiessen
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60 Brett Loehmann
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61 William Hasskamp
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62 Fadelle Powell, BSN
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63 N/A

64 Laurie Rose, MPH
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65 Lisa Allen
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66 Karen Walker
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67 Gloria DeMattio (614)384-7345 gdemattio@lifelineofohio.org

68 Rose Chappell
margaret.chappell@baylorhealth.edu
214-820-7699
Maureen Miller
mmiller@harthosp.org
860-545-3938
I would be interested in anything to do with the KPD program or testing.

Ryan M Lehoullier
New England Organ Bank
617-558-6607
ryan_lehoullier@neob.org

Robert Cirocco PhD
610-402-8121
robert.cirocco@lvh.com

Linda Letourneau, RN, CCTC
774-442-5274
Kidney/Pancreas patient education
Work w/others to develop ed project.

michele_prod@rush.edu
I supervise an HLA lab that does not do deceased donor testing. However, if you think I could be of assistance with something, please contact me.

sharon.burford@emoryhealthcare.org

Laurie Z. leder, LCSW, CCTSW
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Isabel Neuringer
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Chapel Hill, NC 27157
919-260-2242

Randall Heyn-Lamb, RN
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Christine Lee, RN, BSN, CCTC
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Stacia Hays, ARNP, CCTC
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Nicholas R DiPaola
614-293-8554

Meelie DebRoy
meelie.debroy@utsouthwestern.edu

Tracy Giacoma
816-945-6012
tgiacoma@kumc.edu

John Abrams, 215 557 8095
I am currently on a UNOS committee and participate in a work group. I enjoy this very much and find it very interesting

I already serve on a committee.

I can't at this time I would love to participate however we are very understaffed and currently there is no time

Nancy P. Ford, LCSW
904.956.3205
ford.nancy@mayo.edu

I already serve on a committee.
Am already on the PAC committee.

I already serve on a UNOS Committee as a regional rep
Christina Block, RN. christina.block@mountsinai.org, 212-659-8097
Ben Keebler 214-755-5953 bkeebler@organ.org
Alexander Gilbert
alexander.gilbert@nyumc.org
212-263-2692
Am an active serving committee member already
Melissa Roberts, MSN, RN, CPTC
mroberts@surgerybsd.uchicago.edu
Professional or patient education; I am also a transplant recipient.
Alexander Kuo
Alkuo@ucsd.edu
619-543-2675
I am already a member of a committee and several work-groups
Melissa Blevins - Administrator - Mayo Clinic in Arizona - Blevins.Melissa@mayo.edu 480-342-2691
Sukru Emre, MD
203 785-2565
Sukru.emre@yale.edu
(I'm on the living donor committee but willing to serve in other ways too). Mary Amanda Dew,
412 624 3373 dewma@upmc.edu
Dorrie Dils
ddils@lifelineofohio.org
Schawnte’ Williams- Taylor
8066980651/8067985568
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Organ Procurement or Minority Affairs
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Melissa Korb RN, BSN, CPTC
Transplant Administrator/Transplant coordinator
The University of Toledo medical Center
3000 Arlington Ave DH Rm2314
Toledo, OH 43612
419-383-6795
Marilyn Downs
mpdowns@swmail.sw.org
I am already on several UNOS committees
<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Contact Information</th>
<th>Role/Project Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>122</td>
<td>Nicole Johnson, RN, MBA,</td>
<td><a href="mailto:NicoleM.Johnson@Baylorhealth.edu">NicoleM.Johnson@Baylorhealth.edu</a></td>
<td>Quality Regulatory Program Manager Annette C. &amp; Harold C. Simmons Transplant Institute 214-820-7718 phone 214-818-8105 fax</td>
</tr>
<tr>
<td>123</td>
<td>Marian Charlton, 212-746-1742, <a href="mailto:mbc2001@nyp.org">mbc2001@nyp.org</a></td>
<td></td>
<td>Living donor or paired exchange</td>
</tr>
<tr>
<td>124</td>
<td>Lan-Phuong Vu-Yu</td>
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<tr>
<td>125</td>
<td>Darla Phillips, RN, MSN, CCTC</td>
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<td>Currently on Ops and Safety Committee</td>
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<td>126</td>
<td>Paula Gull</td>
<td><a href="mailto:Paula.Gull@stjoe.org">Paula.Gull@stjoe.org</a> or 714.771.8033</td>
<td>Would be interested in health promotion post op for either recipient or donor</td>
</tr>
<tr>
<td>127</td>
<td>Cindy Zarate 734.922.1264 <a href="mailto:czarate@giftoflifemichigan.org">czarate@giftoflifemichigan.org</a></td>
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<tr>
<td>128</td>
<td>Mia Hunter, RN, BSN, DCS</td>
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<td>129</td>
<td>Scott Pritchard</td>
<td><a href="mailto:mhunter@lifegift.org">mhunter@lifegift.org</a></td>
<td>707-773-1355 Topic - transportation (air/ground)</td>
</tr>
<tr>
<td>130</td>
<td>Barbara York, OPC; The Center for Donation &amp; Transplant; <a href="mailto:byork@cdtny.org">byork@cdtny.org</a>, Best practices for uploading images to SoftMD. This DOES result in more organs transplanted.</td>
<td></td>
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<tr>
<td>131</td>
<td>Angie Korsun</td>
<td><a href="mailto:akorsun@tgh.org">akorsun@tgh.org</a></td>
<td>813-844-4907</td>
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<tr>
<td>132</td>
<td>Heather Purvin, Gift of Life Donor Program</td>
<td><a href="mailto:hpurvin@donors1.org">hpurvin@donors1.org</a></td>
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<tr>
<td>133</td>
<td>Lauren Quinn</td>
<td><a href="mailto:lquinn@cdtny.org">lquinn@cdtny.org</a></td>
<td>518-262-9543 I am open in terms of developing content. Have extensive writing experience.</td>
</tr>
<tr>
<td>134</td>
<td>Vicky Young, PhD</td>
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<td>(928) 350-3200 office Living donor issues especially psycho-social, spiritual, disenfranchisement, advocacy, and long-term research on donor wellness.</td>
</tr>
<tr>
<td>135</td>
<td>Jennifer Carapellucci, RN</td>
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<tr>
<td>136</td>
<td>Jennie P. Perryman, RN, PhD</td>
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<td>404.712.4993 Content - living donor follow-up; disease transmission, CMS and UNOS - roles of each, etc, etc, etc.</td>
</tr>
</tbody>
</table>
Colleen Marchand  
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educational projects pertaining to heart transplant

Carolyn Light, 415-735-1144, carolyn.light@ucsfmedctr.org

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Already on committee

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[NOTE: I am on the Living Donor Committee]

Jacqueline Harris, RN, BSN, CCTC  
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Susan Zylicz  
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Heather Yergen, MBS, BA, CTBS. Gift of Life Donor Program, Philadelphia, PA. email: hyergen@donors1.org
I'd be willing to help in any way possible; I'm an experienced presenter and trainer.

I would be glad to assist in an education packet focused on post transplant.
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Kathe LeBeau, kathelebeau@gmail.com, 518-785-5283 (already a PAC member until 2012; willing and interested in serving in other capacities going forward)

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Jennifer Johnson, 708-327-2883, jennjohn@lumc.edu
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<th></th>
<th>Name</th>
<th>Phone Number</th>
<th>Email Address</th>
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<tr>
<td>195</td>
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<td>202-877-6029</td>
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<td>197</td>
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<td>200</td>
<td>Patrick Giordano</td>
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<td>TXSA</td>
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<td>201</td>
<td>Dave Gee</td>
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<td>Director of Information Services</td>
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<td>Willing to participate / develop / deliver content</td>
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<td>Mary L Walter</td>
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<td>Margaret Davidson</td>
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<td>210</td>
<td>Kevin Darnell</td>
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<td>211</td>
<td>Joan Abrams</td>
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<td>Vicki Fioravanti, RN, CCTC</td>
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Jerita Payne
jerita.payne@vanderbilt.edu
Final Additional Suggestions

**Question: Do you have any final additional comments?**

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<th>Number</th>
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| 2      | 1. E-mail communication from UNOS to broad audiences is not always appropriate. For example, recently an e-mail requesting confirmation of UNET administrators was sent to dozens of people in my organization. Not only did those authorized to sign the document received the e-mail, but many others as well. This led to duplicated effort and lots of explaining. I would ask that e-mail groups be reviewed and specific audiences targeted.  
2. UNOS maintains a member directory of individuals at each center - but this directory is not accessible to centers. It is hard to keep it up to date when we are unsure what is in it.  
3 All UNOS contacts should have alternate options in their out of office emails. Some UNOS staff will have an out of office that simply states they are out of office without any other options for assistance.  
4 As a data professional, I am very interested in using the wealth of data that UNOS collects to improve the operational processes that my OPO uses. Unfortunately, the data is deeply inaccessible. The ad-hoc query tool is clumsy, limited, and labor intensive. Submitting a data request takes so long that the answers are almost always irrelevant by the time they are received. Besides which, they give me only one snapshot in time. I frequently refer to UNet as a "write-only memory". I want a way to get to data programatically, securely, and without human intervention.  
Whenever I call UNOS for technical support, I get the distinct impression that UNOS does not care about my difficulties. I would like to have access to a problem escalation procedure. I would also like to start right off at level 2 support - by the time I am calling, all the easy stuff has been tried.  
I find UNOS to be opaque and mysterious. I have not had the opportunity to attend the Primer, but what I really want is to have an ongoing relationship with well connected people there. Other vendors that I spend a lot of money with have set up a weekly conference call with our OPO staff. Given the importance of UNOS to our operation, I would like at least the same with you. Such a relationship would go very far toward alleviating my frustration with UNOS.  
5 Because I'm not with a transplant center, sometimes I don't get all the notices that indirectly affect our organization. For instance, Dr. Rees received notice that the KPD program was becoming integrated w/ UNet in Dec. This is really important to me, as the main contact for our coordinating center (APD) but I didn't get the notice.  
Overall, I think UNOS does a great job of maintaining all of the policies and infrastructure that make transplantation possible.  
6 CAN YOU DO BUSINESS WITHOUT THE PATIENT'S SS#? THAT IS THE NUMBER 1 HIPAA ISSUE W/IN OUR INSTITUTION ...NO SS # YET UNOS HAS THEM ALL OVER. YIKES!! |
|        |               |
For me the tutorials are not beneficial, i am very hands on type and appreciate a structured teaching environment. i do better with interaction.

Have an option of NA for Donor Family Member who is not working for an institution using the UNOS tools for organ and tissue transplantation.

have been heavily involved with UNOS since its creation and still is. My major complaint and concern today is that UNOS is not governed by a Zero Risk mind set that is harmful to the patients. this mindset is promulgated by CDC, FDA, CMS and other agencies who all believe it is their charge to protect the patients from us, the professionals. it is time for the professionals to begin to protect the patients from the bureaucrats, patients are losing their lives because of thoughtless policies forced upon us. the most recent donor transmission policies are case in point. all the professional organizations turned them down, refused to sign on but the policies are still pushed. It is time to relegate the non-transplanters to advisers and not desicion makers - this includes the "politicians" form CMS/HRSA

How about a national transplant recipient conference? Bring as many recipients together as possible and share common experiences and collective knowledge.

I am interested in finding out what Transplant centers tell recipient's about their donors and promoting a standardization of that process. This should be done collaboratively with the OPO's.

I find it very difficult to find policy info when I am looking for a specific topic. For instance, there is not a lot of info about combined kidney/liver. It would be easier if there was an index instead of having to scroll thru many policies. (The policy #'s don't help if you don't know which one that you are looking for. A guide in straightforward language that delineates things such as what is absolutely required for listing, etc would be great. I know that the info is there, but the system is not user friendly.

I find it very discouraging that UNOS does not provide anyone to interpret policy. If these are your policies that an OPO needs to follow there should be someone available to interpret the meanings of these polies rather than saying its the OPO's choice but then they can still get in trouble.

I find submission of content to UNOS update to be extremely difficult and the editor to be hard to access. Since it really is the only widely read industry magazine, people and organizations want to share their news through it. I'd this is not the right portal, intentions of the publication need to become more clear.

I had to click yes to complete the survey and some of these items to do pertain to me such as policy notice etc.

I just attended the DonorNet seminar in Charleston. This was very well done. Could we have a similar seminar about other XML uploads: e.g. DDR?

I think directors / managers should encourage involvement / education re: UNOS.

I would like improved mobile device options on Donornet. I would like to be able to change the person on call from my Iphone, open donornet attachments, see all test results. In reality, I would like to be able to see all screens.

I would like to know more about your review classes--when, where are the held--since new at administration would like to learn more-thanks

I would love to be on a UNOS Committee

I would love to suggest that password reset be available to all members via personal challenge questions or through a text message token number. This would cut down on calls to help desk and give users alternate recourse.

I'm from a Canadian OPO. Inclusion would be great. I can not answer many of the questions above as it does not pertain to us.
I'm very glad you did this survey. Thank you for the opportunity to provide user/customer feedback.

In order to interpret my responses, I am on a UNOS committee. This question was not asked earlier.

I've seen a lot of development over the years to improve the process for patients and transplant professionals. Thanks for the continued interest in making the donation and transplant process better for everyone.

Keep up the good work!

Keep up the good work! I love UNOS :)

Make the UNOS Regional meetings a webinar format so travel isn't required

n/a

NA

NO

no

No

no

No

No

No, keep up the good work!

No.

None

None at this time

None at this time.

none, and thank you for this opportunity to rate your services.

not at this time

Not at this time

Not at this time

Not at this time

at this time.

Only that I enjoy my work with the use of the UNET/UNOS system because its so user friendly and the help/support I get from the people at UNET is very efficient and most of all wonderfully excellent! I raise my hat to them all:))

Please fix the search function for policies/bylaws!

Programming for automatic declines in DonorNet for recipients over 1000 on the PTR

Regarding UNet—would just recommend consistency in data provided and uploading all important studies and reports (ECHO, CXR, CT scans, EKG, cath etc.).

Shorter surveys, even if they have to come more often.

Thank you, the website is overall a great resource for donor management and follow up and the help desk staff and organ center staff are great

Thanks for everything!

the reason for decreased survey response is because I received one almost exactly like this - from UNOS I thought - and almost deleted this e-mail. Just FYI.

The UNOS/OPTN Policies could be written better. I believe I read that someone on the UNOS staff is reviewing them and evaluating them for clarity. Sentence structure used throughout needs review and improvement.

There is a lot of complexity of the OPTN/UNOS, SRTR, and HRSA and also overlap and also specific requirements of each. These should be simplified and their differences easily referenced. Also review of how payors and patients use all this and if meets the goals of the various oversight organizations, Transplant Centers, Labs, OPO's etc.
UNOS is an incredible organization overall. Thank you for the work you do for the field of transplant.

UNOS leadership needs to listen to committee recommendations, and advocate for them, especially when HRSA capriciously moves to block them.

UNOS should be more representative of the transplant community, less of a quasi-government bureaucracy, more interested in helping patients with renal disease and "sharing organs" and less of a "big brother" intruder.

Update the Help Documents for each Form. There are places on the Help Forms that need to be more specific to help centers stay compliant.

Update your learning modules in the resource section of UNet--some are from 2005.

When a patient transfers to a non-participating center, it is necessary to put in a ticket to get them removed from our site. There is no drop down option to use. (In the past, we could use ZZZZ, but that is now for transfer to a foreign country). Thanks.

When opening match runs, have it automatically open with 100 potential transplant recipients rather than only 20. It wastes a lot of time to have to change it every time when you've already passed sequence #20 during placement.

When running reports in Waitlist...the ability of the app to 'edit' elements of the requested report without having to input all the data all over again.

Would appreciate follow up on this survey, and again followup on outcomes of public comments. Appreciate the request for input.

Yes--PLEASE restructure the application process for primary surgeon/physician. The paper application is cumbersome and a tremendous waste of resources. This could easily be made into an online process that would be much more efficient.

You are doing a great job and thank you for soliciting community ideas for improvement; Great Move!