

2015 UNOS Member Survey

What could UNOS do to make our organization more transparent?

Board/Committees

- Increased transparency on who makes up the board, the board selection process and why.
- Clarify how committee members are selected
- continue to include more OPO leadership on UNOS committees
- Explain how committee members are selected and why some committees have so many "at-large" members. What is the term of an "at-large" member?
- More information on how on boards, nominations. Feels like it is a good old boys club where you know people so you can serve.
- Having served on committees, I am baffled by how there are 2 year term limits for some committee members, while others have been in place for a decade. I have never received a clear explanation of this.
- increase diversity/rotation into its members
- Let us try to broaden the membership. It is not supposed to run as a boys club, where committees are packed with your buddies!
- The system for choosing Board members and committee chairs is not transparent and shows heavy favoritism and cronyism
- involve additional "boots on the ground" professionals such as transplant social workers, financial coordinators, dieticians...not just the docs and the nurse
- involve transplant coordinators more: to serve on boards, etc coordinators
- The board is still too dominated by transplant surgeons. I suggest you seek CEO's of transplant center hospitals to provide balance
- More opportunities to serve on UNOS committees, difficult to get on committees.
- I think that committee meetings (with certain exceptions) should be open to all OPTN members, so that the membership may know what is being proposed before it is brought up for a vote at the regional meetings.
- I think it is important to remind the members that they are the ones who staff the committees and drive the process. We need to be cognizant that if we want things to change we have to actively participate.
- Make OPTN Committee meetings Agendas and Materials available on public website.
- Allow committee members to access SharePoint using mobile devices.
- I also believe members on committees especially KPD committee lack experience doing KPD - how many actual exchanges have these policy writers actually conducted? It is incredibly frustrating to be dictated policy by policymakers who lack any practical clinical experience. To be more transparent - list all comments received for a policy so we can see how the

public is responding to a policy proposal and how the policy makers are responding to the comments. How do we know the policy makers are taking the comments into consideration?

- MPSC proceedings
- Provide the con arguments to voted items equally

Regions

- Get more input and disseminate more information about what is happening on the regional level.
- Have each transplant center send a representation from different organ specialties to attend UNOS meetings
- Have our regional rep more present and involved in our program. Understand how we function and needs we may have.
- Have the regional councillor be more accessible.
- I also think that the regional councilors should schedule and have quarterly conference calls with OPTN members to allow them to voice concerns with proposed changes to the bylaws or policies while they are in the initial stages of creation.

Education

- As a new coordinator, I am not aware of everything they have to offer.
- a history paper on UNOS and the function and future plans for UNOS.
- What if when one joins an OPO or other organization, there was an introductory packet to explain the availability and need for information gathering to the newbie. . .
- Presentations on how UNOS operates, i.e. what departments there are and how each interact with each other and OPO's as well
- There should be more introductory courses and learning opportunities.
- More clearly show who is the responsible party for issues/complaints. Who really governs OPOs....I was told by UNOS personnel it was CMS. How to transplant centers issue concerns with UNOS about a variety of concerns. For instance...rising SAC fees and transportation fees without any accountability by the OPOs.
- Include webinars about items in question #1
- Continue with the webinars.
- The recent webinar about PHS changes was very helpful to identify dates of changes
- I would love most webinar type education about new policies and how they will be put into place and evaluated.
- I could use more info on how to ED patients and family members
- I understand the need to maintain program confidentiality by the MPSC however we need to learn from other center's issues to improve safety for all of our patients. If it can happen at one transplant center, it can happen at any transplant center. There is no transparency if it doesn't hit the headlines of the news. The transplant community needs to do a better job.
- I'd like examples of what you want. Such as when you find a program doing something exactly as you want, share it.

- More conference offerings geared toward OPO staff instead of management level staff.
- Identify the MSW's who need to have an understanding with transplant and route info to them.
- More continuing education or make webinars available at more than one time
- Increase partnership with CMS providing educational webinars - functional crosswalks
- maybe a few short but to the point training sessions with regards to all the different but highly important aspects regarding patient data and source documents, and requirements within the world of UNOS.
- UNOS is currently doing an excellent job in terms of transparency. Perhaps more outreach to patient organizations including support groups. Webinars/live streaming are great for patients who don't have resources to attend town halls etc. in person so they can provide feedback
- make conferences available to all medical professionals including MOA's
- Organize TV discussions, invite members, lay people, clergy and take calls from the viewers. This type of open symposium will have a wide audience
Dimitri Novitzky, MD, PhD
- Offer Webinars different days of the week. Mostly, unable to attend due to work schedule.
- Providing information at various levels: technical terms and precise detail, as well as conceptual explanation of reason for change and specific changes

Compliance

- For policy updates, recommendations on how to be compliant.
- I find policies too vague in their description of how transplant centers can comply. When we have site visits, one auditor will want documentation done a certain way and another will want documentation done differently. Most centers want to comply exactly as requested by UNOS, but often times the vague wording of policies leaves too much interpretation of what is expected.
- You need to provide more concrete information on what you expect from an organization to be "compliant". We are often forced to rely on audit to get the auditors opinion on how the policies should be followed. Ever auditor will tell us something different or slightly alter the definitions provided by UNOS. We have requested over and over for things to be more clearly defined, but get nowhere. If you are requiring elements and will be auditing centers on those elements, then you MUST define those elements in writing so everyone does the same thing, from centers to users to auditors.
- Provide assistance and help with compliance rather than just be a punitive organization. Tighten up "areas that are open to interpretation" and be open to other interpretations.
- Be more transparent as to the impact policy will have on center audits and associated cost of compliance
- Outline exact requirements for an audit rather than leaving it up to the interpretation of the auditor

- Provide schedule of upcoming site surveys and desk reviews at least one year in advance
- Share more information related to process compliance - i.e. allocation issue reviews by DEQ/MPSC, MPSC investigations of member violations (sharing types of violations quicker), etc.
- When evaluating/auditing a transplant program, could there be less retribution for very minor errors, i.e. BP reading off by one, etc.

DonorNet/Technology

- Ask transplant centers feedback on DonorNet, very frustrating to have the procurement centers not update donor net in timely fashion as case progresses
- Describe how tasks are prioritized for policy, forms and IT-dependent changes
- Make all major policy change announcements on the UNET front page and require a read agreement prior to being able to log into database.
- I would also like it to be easier to get reports from UNOS and have a report I could download to help us validate our data entry (especially with lab values, dialysis dates, etc.)
- The donor testing for HCV, HIV etc. is easy to find. NAT testing is hard to locate at time in attachments. If the area for testing for HCV etc. were expanded for NAT and WN, EBV and others that would be very good.
- UNet cell version needs more info and web version as well. Could save time if info accessible on web page like current insulin. Current pressers. Also calcium and mg helpful with hearts.
- More data access. Hospital specific information on donors, eligible should be given. Why not be transparent? This should be fixed.
- Support Internet Explorer 11
- when major changes are being implemented, appropriate notification of the change esp when it's something that has to be programmed into our EMR's or impacts our data gathering

Policy

- The organization tries to appear transparent but in fact it is not at all. Huge policy reviews are initiated by very few people at the executive committee level who are conflicted in their loyalties and then disseminated with the words 'approved unanimously by the board' when in fact the board is simply rubber stamping these initiatives. Change is often made without good data and many of the changes will not affect the quality or fairness of the system except to add more regulation. There is a bias against smaller programs which is not surprising since most of the clinical people on the board are from large programs. The review process is heavy handed and arbitrary and punitive.
- I also believe members on committees especially KPD committee lack experience doing KPD - how many actual exchanges have these policy writers actually conducted? It is incredibly frustrating to be dictated policy by policymakers who lack any practical clinical experience. To be more transparent - list all comments received for a policy so we can see how the

public is responding to a policy proposal and how the policy makers are responding the comments. How do we know the policy makers are taking the comments into consideration?

- When the proposals are out for public comment and/or approved by the Board, it's just not as visible as it could be. Notify on Transplant Homepage every time they are released? Email notification? I know it in Transplant Pro, but by the time you enter it and get distracted by other articles, etc., it doesn't jump out. It is maybe the single most important thing programs have to deal with and I think it should be in our faces and notifications sent by multiple routes.
- Attempts to put out policies change
- Be more transparent as to the impact policy will have on center audits and associated cost of compliance
- Continue to work toward CLEAR policies and communication and coordination with other regulatory requirements
- Policies are too grey. Need to be defined better. A UNOs admin on call would be helpful in a dispute. I often fight for time or testing on donors without a time constraint
- Sometimes there are gray areas in policy and I wish it were more concrete, not open to interpretation.
- Describe how tasks are prioritized for policy, forms and IT-dependent changes
- Inform members of the policies and be inclusive of all members in your committees.
- Make it clear where the prerogatives that drive policy are from--HHS? DOT?
- More notification on policy changes to implement new or updated policy requirements prior requirement date. Having clearer communications on these changes will also help with this. UNOS has greatly improved in this area, but there are too many notices going out, without clear, to the point information. I would also like it to be easier to get reports from UNOS and have a report I could download to help us validate our data entry (especially with lab values, dialysis dates, etc.)
- when major changes are being implemented, appropriate notification of the change especially when it's something that has to be programmed into our EMR's or impacts our data gathering
- I am unsure if there are certain Dates to expect UNOS policy changes to be released.
- I feel as though there are changes made to policies and it could just be me, I'm pretty new, but for example the changes to the LD policies effective 4/1 - had no idea they were there, found them accidentally... frustrating
- Give a shorter synopsis of changes in policy.
- Make "To-do or Check Lists" for any policy changes
- Very quick bullet points to help comply with policies
- Make the rules more readable, quantity is not quality
- Provide more clear communication about policy changes and when they are implemented. Policies do not indicate the dates that they are in effect. For example clearly state on each page of policy IN EFFECT 2/1/15

- Make all major policy change announcements on the UNET front page and require a read agreement prior to being able to log into database.
- streamline the decision and implementation process
- The liver redistricting thing seemingly was being discussed before many in the community were aware. Would suggest to not get that far along in any future endeavor(s) without involving more stakeholders and considering other options.

Communications/resources

- Publish information when centers are placed under member not in good standing
- Publish lessons learned documentation, if applicable.
- Transplant Pro has been one of the best things UNOS ever did to consolidate communications, but there are still other "side" communications that come out and we seem to still miss those from time to time. It would be awesome if you could streamline ALL your communications into the Transplant Pro e-newsletter mechanisms so we don't miss anything.
- Centralize communication, way too many notices come through with varying levels of clarity. Important issues are lost in the sheer volume of notices - all from different email addresses, names, etc. Chronicle communication in a newsfeed so you can go back and see what was sent when.
- I think UNOS does a fine job in this regard. I DON'T think providing more information in many forms is necessarily helpful. It can be overwhelming. Communication w/ TX professionals/Centers should be short, succinct and to the point - maybe quarterly - and not include any fluff.
- Please, please, please consolidate your communications (preferably into the Transplant Pro e-newsletter and website. It's still too difficult to know if I've missed something or gotten it in duplicate. Please streamline into a "one stop shop" for ALL UNOS communications.
- The format of the transplant pro newsletter could be improved in regards to referencing policy updates. Is there a way to make these updates more prominent in the newsletter?
- UNOS communication tools should be more succinct and easier to follow. It is currently difficult to find relevant information.
- I do not think there is 'too much information'. Email updates/links are the best because they are timely and easily communicated to the rest of the team.
- Make it easier to sign up for newsletters - e.g. put a link at the bottom each time you email one out, so that if somebody is just getting it forwarded they could sign up for themselves. Even the newsletter web page doesn't make it obvious how to subscribe.
- I believe the communication has greatly improved (although I think it was pretty good already).
- Allow member discussion with central office re. survey results.
- Continue to ask for input
- BETTER EXPLANATIONS

- Create a simple bullet point driven set of statements that describe the organization and how it works. Distribute as a pamphlet and by email. Max 5 pages. Explain why SRTR is so confused about survival. ISHLT survival should drive the system not the current system that discourages risk taking to the extent that less donors are used now than before. SRTR is not in the best interests of the patient, encourages a timid approach for the small program, and encourages gaming by the larger programs.
- Do directed emails to the constituency affected - e.g., surgeons or transplant physicians or lab directors or coordinators. Too much email is not a good thing and I don't need to know everything that affects everybody.
- I agree that there are a lot of places to obtain changes that have been made but I would love to have these changes in the form of a crosswalk or even interpretive guidelines. I like to have step by step instruction of the change and why so I can be sure I am fully implementing each change into my program
- I do not think there is 'too much information'. Email updates/links are the best because they are timely and easily communicated to the rest of the team.
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- Very quick bullet points to help comply with policies
- I feel as though there are changes made to policies and it could just be me, I'm pretty new, but for example the changes to the LD policies effective 4/1 - had no idea they were there, found them accidentally... frustrating
- Include a UNOS speaker at every NATCO, Transplant, AOPO meeting etc.
- Make "To-do or Check Lists" for any policy changes
- involve additional "boots on the ground" professionals such as transplant social workers, financial coordinators, dieticians...not just the docs and the nurse coordinators
- a history paper on UNOS and the function and future plans for UNOS.
- Providing information at various levels: technical terms and precise detail, as well as conceptual explanation of reason for change and specific changes
- What if when one joins an OPO or other organization, there was an introductory packet to explain the availability and need for information gathering to the newbie. . .
- One source with portal to the multitude of resources - there are currently too many links
- Would be helpful to be able to navigate the web site easier to find information regarding items of interest. Right now it is quite a search to find a specific item

- Provide more clear communication about policy changes and when they are implemented. Policies do not indicate the dates that they are in effect. For example clearly state on each page of policy IN EFFECT 2/1/15
- Share more information related to process compliance - i.e. allocation issue reviews by DEQ/MPSC, MPSC investigations of member violations (sharing types of violations quicker), etc.
- More info
- More info in real time
- More local publicity, not everyone has Facebook.
- Work through kidney orgs, publications to better communicate with the kidney community.

Positive

- Already transparent
- all good
- I am satisfied with UNOS and the current level of transparency.
- Not sure. I personally think that UNOS and the processes it goes through to make and vet policies is pretty transparent already.
- I don't feel you need to be more "transparent"
- i think it's doing a good job
- Keep doing what you do.
- I feel UNOS is working well with us
- I think UNOS is very transparent
- Nothing, you are extremely transparent
- seems adequate now
- very transparent currently

Uncategorized

- More recognition that there are OPO related issues that get subverted to the perceived needs of the transplant programs.
- When an OPO files an issues with a transplant program provided follow up with the outcome.
- Financial status yearly.
- give smaller transplant centers an equal voice/
- frequently debriefing transplantation-associated information and not be so silo'd between UNOS and SRTR.
- Participate in meetings at the local level.

What change have you noticed at UNOS in the last year?

Policy-related

- I have noticed that the policies have been more clear and organized
- Language in policies is simpler.
- Re-write of policies so that they are easier to understand.
- improved readability, both of Transplant Pro and the rewrite of policies / procedures
- Consolidation of policies.
- policy changes
- Strong focus on donor evaluation and follow up which is positive
- A lot of policy changes.
- policy changes
- policies changes and updates
- positive changes with some of the antiquated policies & systems
- Allocations and how they affected patients already on the list.
- New policies are great.
- changes in allocation
- HCC applications for Liver
- getting very prescriptive in regulations
- I would say the lack of change. UNOS policies continue to be vague and open to interpretation. At the UNOS Primer, the liaison's had difficult times providing answers to questions because the policies were so vague. Don't hold Transplant Centers and OPO's accountable for your failed and poorly written policies.
- Improving response times to policy needs
- Increased distribution of information regarding policy changes including the changes in allocation system.
- Increased frequency and volume of policy notices and changes.
- improved policy language
- New allocation policy
- Changes to kidney allocation scoring.
- Change in organ procurement as of December 2014
- KI organ allocation.
- Drastic changes in kidney allocation
- KDPI
- the new KDPI -- however, I am so tired of so many acronyms without clear listings of what they stand for, I get lost.
- the biggest change that has affected me has been the new kidney and lung allocation scoring systems that were put into action.
- All of the changes with the new KAS.
- kidney allocations!
- Kidney allocation
- Kidney allocation system
- new KAS
- New KAS

- KAS
- KAS changes to include 85% KDPI and higher offers.
- KAS
- KAS
- other than the kidney allocation - I don't know
- Obviously the new KAS- I think transplant center education on the details could have been much better considering we are the point people for educating the public.
- KAS!! This process was slow, and I believe it would have been much smoother had the information been presented further in advance of the implementation.
- The chaos created with the new Kidney/Panc policy. The staff active actually taking referrals appear very busy and verbalized that as well.
- New Allocation System
- new organ allocation system
- LAS
- none other than change in LAS scores
- keep pace with transplantation-associated policy
- Lots with the lung program(LAS), lots with kidney programs
- Many changes have occurred because of new allocation and requirements are becoming more current in line with changes in the field requirements.
- Many changes including organ allocation
- Many policy changes in addition to new allocation systems! It is very hard to keep pace with all the policy requirements.
- too much new policy and changes. Centers overloaded and unable to keep up
- More policy proposals, more meetings, more data changes - all of this is a burden on members and takes us away from patient care.
- points system for recipients.

Compliance-related

- Become more heavy handed in their interpretation of compliance. Require more paperwork and staff time.
- Increased regulatory oversight and changes to policy. We have seen increased scrutiny in our on-site and follow-up desk audit requests from UNOS. We've struggled with the feedback during the follow-up process after our on-site audite with MPSC as we have written our corrective action plan. Despite our follow-up questions to UNOS staff to clarify, we are now on the second round of submitting another corrective action plan. It's very frustrating to become compliant when we don't know what the parameters are that we are shooting for. It's like reading the syllabus for a college class and writing your paper, only to find out after you submit your final paper that the syllabus has changed. Please be clearer in your member expectations for compliance.
- more enforcement
- More involvement in the Auditing aspects
- Much more punitive approach
- Reorganization of Compliance/Membership departments.
- Stricter adherence to your own policies

DonorNet/UNet/Technology

- Reports available for prior transplants
- Better IT practices
- a very positive change in the IT projects and timelines.
- increased concentration on IT
- I love that I can reset my own UNET password--thank you!
- Form changes have been good.
- Forms are more concise
- Improvement in electronic services
- The speed of change rollout has increased significantly, especially on UNet enhancements
- IT systems seem a little better. Answers usually come in a meaningful time-frame
- significant changes in Tiedi
- IT is making some nice changes and responding to requests in a timely manner. Very nice work!
- Updates to forms
- TIEDI form required fields
- My TIEDI forms have been changed
- TIEDI
- reporting in TIEDI.
- Tiedi improvements
- The TIEDI forms have changed for all organs and the Security Administrator fields for adding and removing a user has added new fields.
- New Tiedi forms
- The changes is the Tiedi forms
- streamlined data collection, esp. malignancy forms
- changes to histo forms in Tiedi
- I now have to add a UNOS user's middle initial when adding or deleting
- Increase in IT/IS production
- increase in technical updates and computer processes
- more IT changes
- Also have noticed lots of changes from the IT side of the shop.
- The telephone system was updated, the UNOS forms were revamped and the Unet pages have some new capabilities (e.g. hitting enter "submits" for some pages)

Communications

- A lot of information before the changes took place
- better communication
- improved communication
- Improved communication
- even better communication
- Some efforts to increase communication
- communications improvement
- More avenues of communication
- UNOS appears more organized and communicative

- More communication.
- more electronic communication
- More clarity and timeliness in the mailings which are of particular interest to me.
- More timely, relevant and frequent communications.
- More communication, especially with the new kidney allocation policies.
- more updates, email,...etc
- More email notices regarding upcoming changes and the rationale behind them.
- More communication
- Much more communication shared. Good thing.
- Getting you ready for the new changes to take place
- Good changes towards increased awareness to kdpi etc
- There has been more electronic distribution of necessary updates & information.
- Switch from paper communication to all electronic; like the format of transplant pro improved readability, both of Transplant Pro and the rewrite of policies / procedures
- Improved communication Transplant PRO website
- More organized and deliberate in content.
- additional newsletters--have been helpful
- more useful notifications
- More streamlined communication with the tech email summary, transplant pro emails
- Love the Transplant Pro Website and updates
- Transplant Pro
- Transplant pro has improved.
- Consolidated notifications.
- frequent notification and updates via emails
- I find the newsletters more difficult to negotiate so rarely read anymore. Notices that refer me to other places to get the information being announced, I rarely f/up on.
- I used to receive monthly transplant pro newsletters, I no longer receive them and have to go to the website to view them. What changed?
- I think that UNOS has made a good effort to more clearly communicate the activities going on "behind the scenes" to move policy changes along. In addition they have made it easier to complete the paperwork required to change your primary physician which is greatly appreciated!
- increased communication and awareness of responsibilities as OPTN contractor
- Too many emails--can't you consolidate them into one newsletter on a monthly basis or shorten the ones that can't wait. I am suffering from email fatigue and I end up potentially important things.
- New branding
- New logo
- Logo (its great).
- Rebranding, new logo.
- New Logo
- Updated Logo
- New logo
- The new logo
- new logo, changed structure of the strategic plan, improved web sites and communications

- Much better turnaround on projects, much better communication, more consistency from staff
- More exposure via social media which is great!
- music to the hold line when waiting to talk with organ specialist is terrible. Would be a great opportunity to run through highlights and changes to UNOS on a quarterly basis.
- increased communication to membership
- That you have started charging for publications. We formerly used your materials for patient who were being evaluated for Transplant but are considering not using them.

Website

- easier access of web
- I noticed they made the UNOS store user friendly.
- The UNOS website and OPTN website has too much going on and I can rarely quickly zero-in on where to find what I'm looking for (i.e. making a Data Request; finding Center-specific stats). I find I click around looking and rarely find what I want so quit trying. Used to be better before we became so web-based.
- improved website
- Helpful updates to website.
- New websites are great.
- Updated website
- Website- trying to get more of the grassroots involved
- Website is different.

Education/Resources

- A greater effort to educate and inform all members so we can work together to improve the care delivered and the management of our scarce resources. thank you.
- The new UNOS is much more supportive to the membership through increased communication and educational offerings.
- Great improvement is education and webinars.
- Increase in Educational offerings.
- increased # of webinars on critical subjects
- Kidney allocation- appreciate all the webinars to prep for it.
- less webinars for CEPTC's
- Great webinars, but too many not coordinated with ASTS, CMS, NATCO, etc... You are all wasting so much money replicating each other and giving slightly different messages
- More activity making the issues of organ donation apparent to the community
- Lots of good education.
- Obviously the new KAS- I think transplant center education on the details could have been much better considering we are the point people for educating the public.
- TransNet.
- UNOS offered more town meetings, videos, and FAQ memos.

Customer Service

- Additional costs for patient information.
- Change in attitude, communication, a bit more user friendly

- Data request response time, even for a straightforward extraction, takes 5-6 weeks over former 2-3 weeks. Generally also requires intermediate "hey, where's my data" e-mail ~week 4.
- Executive staff more accessible.
- feel that it is easier to reach out for questions, concerns, etc.
- increased interaction with programs and members. more access to the senior leadership
- More attentive to questions
- More interaction from leadership
- More visibility from top leadership
- Lack of knowledge in help center
- The staff is very courteous like always

Structure/organizational changes/infrastructure

- Brian has done an amazing job leading UNOS.
- Better managed
- Change in meeting dates.
- Change in the timing of the committee and board meetings
- The move to align the dates of the Regional meetings to better meet the Board's meeting schedule will really make a difference.
- priorities clearly established
- Staff reorganization
- Trying to be more user friendly. Attempting to work with CMS and others like AST.
- Trying to make an effort to align with CMS CoPs

Uncategorized

- same heavy handed doctrinaire approach
- Bigger centers carry even more weight than before.
- Knee-jerk reactions to errors in the transplant community. There does not appear to be any reasonable look at errors and why they occur, rather a rush to place more restrictions on transplant centers who practice safely. When is UNOS going to start making a stand against some of these centers who do not have a good safety record? Instead it appears as if your answer is to increase regulation without thorough review AND transparency to the community.
- None, it continues to expand into a larger more restrictive organization, having years ago outgrown its original purpose. I believe it should be radically reduced in size and scope.
- Seems like there is a big push for large centers to grow at the cost of mid and small centers.
- Organization has become very data-centric (want your database kept up)....not necessarily patient-care centric. I believe many rules/regulations do not ensure the improvement of patient care/outcomes.
- Several new hires at the Donor Center.
- Some projects moving faster.
- Starting to hear some discussion acknowledging the re: struggles the current SRTR reporting system has inadvertently caused to transplant programs from insurance

perspective and the need to potentially modify the system such that it has a "protected" information side and a public information side.

- More emphasis on increasing donor organs
- More focus on "specialty"/"boutique" patients.
- Things are getting worse
- I probably should not put that in writing.
- Don't care for this trend...

We are always looking for ways to make your job as a transplant professional easier. Are there ways we can improve our existing services or are there new services we should consider?

Policy/Compliance

- Additional education regarding policies and compliance. More direction when new policies are written
- Although compliance monitoring is supposed to be for process improvement, the current process feels very punitive and adversarial.
- I struggle with operationalizing UNOS rules and don't find out if I did it well or not until a site survey. Would like to see a service where we could submit forms, policies...etc. and have UNOS weigh in as to how well they meet the expectations before the team shows up and I have to re-do everything in an Action Plan!
- Pre-visit primer to help before a site visit or desk audit
- Provide examples, guidance for policy compliance. Example- donor culture reporting to transplant centers, be more explicit in what you are looking for with regards to documentation.
- Keeping on top of TIEDI and other reporting is a nightmare. Anything that you could do to development notifications systems would help the transplant centers (before we become delinquent and get into audit troubles).
- Provide insight to which policy changes are going to be in the certification test questions.
- Provide assistance and help with compliance rather than just be a punitive organization.
- As a new administration, I haven't found a good place that clearly outlines the various regulations our programs are held to. It seems every week I am hearing about something I didn't know.
- More clear policies and release new ones only at certain time periods. It is very very hard to keep up with policies when they slowly are released throughout the year. You know they may be coming...but it is a constant fight and takes a lot of time to ensure you have and are implementing the changes.
- Slower implementation of policy changes!
- PLEASE identify individual and SPECIFIC changes to policies, early and clearly..... with multiple warnings
- Also, give enough lead time for organizations to operationalize policy changes before they become effective, especially ones that have a big system effect. It's difficult to get a policy notice and learn we have 2 weeks to change our forms, internal polic, and train staff, etc. Sometime changes require changes to IT system and programming internally can take some time.
- clear policy regarding allocation
- Continuing to clarify policy language.
- policies need to be clearer with greater thought to how they are to be implemented
- Continue to develop risk adjusted metrics.
- Consistent policies across all regions related to patient selection, exception approval,
- Consolidation of UNOS and CMS policies and audits
- Understand the complexity of transplant centers and its ability to transition to updated policy and new policy deployment

- Ensure enough lead time for changes that have to be implemented. Quarterly summaries of changes and UNOS expectations for compliance. More regular communication from Regional Adm. to share answers to questions they are receiving that can assist all of us.
- flash emails with policy changes
- Knowledge regarding policy changes. Seems like no one has a quick answer to questions or the availability of the key contact is very limited.
- exception policies should be drafted more clearly
- Help to make regulations that are not made due to one or two cases. Our policies are more to keep up with regs than to really take care of our patients. This includes safety.
- I have no problem with UNOS staff, who do a good job. I DO have a problem with the policies generated from the live donor committee: it is ridiculous to insist on heavy-handed enforcement of the unfunded mandate to collect data at 6 mo/1 yr/2 yr when everyone knows that when renal failure in a donor develops, it's at 10 or 20 years post-donation. The effort expended would be better spent advocating for a single-payer healthcare system
- I have suggestions on improving the questions for listing patients to more accurately reflect the organs that would be acceptable. ie, DCD organs should be able to be local, regional and national. This would decrease offers that are not going to be accepted. Would be happy to explain further. I have requested this several times before!
- Move along the Liver allocation process - we are desperate for better access to organs in Region 9!
- Perhaps hearing from our regional representative more with common language updates of things that are changing, particularly focused on the specialties.
- Send the policies in a black and white- easy to read- easy to follow mechanism
- The biggest change I have begged for is to please find a way to have a separate list for liver/kidneys. As a kidney coordinator I am tired of being offered kidneys alone when the pt needs a liver/kidney. We have a separate list for K/P, why not L/K? There has to be a way to do this.
- We need to get a designation for pediatric heart transplants that require extra vessels so that lungs cannot be placed instead of having to exhaust the list prior to us being able to have the vessels.
- Force IT to match the forms to actual written policy, not the other way around.
- have your IT dept keep up with policies

Communications Needs/Ideas for Resources

- Have a once or twice a year publication of new requirements, broken down by affected areas that have been implemented since the prior year. 2. Restrict public comment documents to no more than 5 pages each. They are redundant and most professionals do not have time to read and re-read the same thing just because it is a required format.
- Again, shorter synopsis of changes in policy for benefit of those not directly involved but wanting to know
- Clearly communicate policy changes out of ALL the information sent
- Tighten up your emails!

- Try to make communications less "wordy"- do not have lots of time to read through legalese
- Simply state the policy change and what needs to be completed through a toolkit. This was done effectively with the new KAS, but is often not done in other areas. It seems that notices of policy proposals, policy approvals, and policy implementations are intermingled which makes it difficult to understand the status at all times. Help us be compliant with regulations.
- Again, shorter synopsis of changes in policy for benefit of those not directly involved but wanting to know
- Clearly communicate policy changes out of ALL the information sent
- As a new administration, I haven't found a good place that clearly outlines the various regulations our programs are held to. It seems every week I am hearing about something I didn't know.
- Develop documentation templates that meet all the regulatory requirements
- I am wondering if it would be helpful to have onsite question and answer sessions with the UNOS regional representative
- You should email each individual with UNET access, all new policy changes and WHEN they will take place, then offer webinars or in-serves for use.
- When the Board makes decisions that affect certain types of organizations, I think that identifying those changes would be beneficial. For Example, TransplantPro will announce "Board" decisions on in the newsletter but maybe more specific language like "hey OPO CEOs, please read this section on page 56 of 570".
- Send only information relevant to specific centers only..... Identify others as "for informational purposes only"
- Sometimes, information relevant to my role as a lab director gets lost in communications with large amounts of information. It would be beneficial to have discipline specific notifications
- Streamline the distribution of information. I am notified on the same subject multiple times and using several different vehicles. Reduce this redundancy.
- establish friendly interactive internet services
- I liked the checklists (for medical evaluation, psychosocial eval and informed consent) that were recently removed from the UNOS website. It would be nice to have them remain--with periodic updates as policy changes.
- Online guidance documents are very helpful
- online information, surveys like this.
- Online Chat to provide the information about patient and donor to service patients better.
- Place allocation calculators, Kidney, Liver in one easy to find place, as well as calculated organs per donor calculator. Can you make these all a phone app? I am sure you have been asked about this a million times already.
- The website still makes it difficult to find what you are looking for when questions arise. A more interactive indexing (more detailed) to allow answers to critical questions. It often takes a visit to DonorNet, OPTN and/or UNOS website to narrow down options when searching for specific answers. More detail regarding field entry for forms would be helpful as well. Many are described generically and require a certain amount of guess work

- Resource on making an idea or thought to change a policy - what process once goes to committee.
- Perhaps a "UNOS/OPTN 101" video and/or pamphlet for new (and experienced) transplant professionals that might not understand policy development, board functions, committee functions, ad hoc committee needs, etc. i.e., a "methods to the madness" type of resource.
- It would be helpful to have a UNOS staff directory available to members for phone/email addresses/titles to reach the person needed more efficiently.
- I love the UNOS/CMS crosswalk and find it really helpful. If this tool is kept current with changes highlighted that would be terrific!
- Yes. Stop promulgating "best practices". These are opinion driven, not evidence based, and are disruptive not helpful.
- The collaborative was a great forum for networking and sharing best practices/resources. Starting this up again would be one of the best things for our community particularly in this highly regulated environment.
- flash emails with policy changes
- ensuring I'm receiving all emails.
- Information regarding billing, especially kidney recipients who have Medicare.
- More program, hospital and OPO specific data. Provide open access to files that are able to be released to the public.
- You should consider providing tables & reference documents as Excel or at least .docx, in some instances this would make it easier on our staff.

Education

- Additional education regarding policies and compliance. More direction when new policies are written
- Develop standardized recipient and living donor consents and educational materials that meet all of the regulatory requirements.
- Education more for Transplant pros like myself
- CME credit for reviewing policy updates and changes
- Additional CEPTC offerings.
- I attended TMF this year. It seems to me that this event has gotten tired and needs refreshing. Many of the presentations were exactly the same as TMF 2013. Some of the presentations were simply not so good - with graphics too small or light to be seen, diffuse unusable content, and in one instance inexcusable grammatical errors. The RAPID demonstration was simply a joke. Maybe UNOS needs to make strides to introduce new and compelling material - and to enforce some sort of standards so PowerPoint presentations can actually be read (such as darker/larger fonts, etc.).
- Can you perhaps address the cost of the TMF meetings...they seem to be very costly compared to other national conferences that I've attended
- have pertinent information regarding TRR and TRF forms
- I think there ought to be an online learning module for new transplant professionals and paraprofessionals. The multidisciplinary team is getting bigger and I dare say that not all members in all member orgs are as well versed as they'd like to be.
- Provide information for new transplant professionals.
- would welcome access to on line video that new transplant staff could watch during orientation that would provide an overview of UNOS

- I like educational webinars.
- More webinars
- thank you for the webinars. I wish that we could get CEU's. I think the one person who registers for them gets the CEU's
- Webinars often have very poor sound quality - likely due to the speakers presenting over the phone. I would be good to improve if possible.

DonorNet/UNet/Technology

- Technology updates to DonorNet are needed, especially when it comes to entering serologies. A donor match run should not be able to be generated pre-serology. Our center recently dealt with a HCV NAT + donor whose initial HCV was negative. The offers were made on this donor from the HCV - match run. When we called to question this, we were told it was a system problem and to always look for attachments.
- The HCC progression system glitch that doesn't allow an auto increase for narrative HCC patients and places them at 27 instead of 28 needs to be fixed.
- Stat 7 patients do not show up on the MELD/PELD exception report in UNET. This is the report we are working from to track upcoming exceptions that will expire. Is there any plan to include patients that are stat 7?
- Lung - listing up dates. Right heart cath data on since you have a date for CVP separate from the remainder of the measurements it would be nice to provide a separate date for the CI. Pt's may have a follow up ECHO to est. Pulmonary artery pressures but there is no CVP or CI that is obtained from this test an adjustment in the LAS and removing the CI results in a decline in the LAS because the data has not been retained
- For LAS data, there needs to be a separate date option for cardiac output/index. We have issues with patients that get updated ECHOs providing a new PA pressure but then lose points because they no longer have a cardiac index entered. I don't think entering updated PA pressures should penalize our patients because DonorNet is using a default value for the cardiac index.
- UPDATE THE SYSTEM WITH ALL HLA LOCI PERTINENT TO MAKING A DECISION ABOUT TRANSPLANT
- Again, having the ability to run reports to validate data entry and policy requirements.
- Make a wide-variety of ad-hoc reports available and ability to go back at least 5 years.
- It would be nice to run reports off the system ourselves. For instance, when I audit for newly listed patients, it would be nice to run a list for a period of time vs. clicking on each patient within the waitlist for KIDNEYS. And it would be GREAT to identify the Liver Status 1's without having to request that data from UNOS. As well as INCLUDING which version of 1A STATUS on the patient history status vs. just 1A (1AC, 1AE, etc.)
- It would be valuable to me if I could get a report on my center that includes all recent (2-4 years) MPSC actions, decisions, etc
- I work in quality and I would love to have e-mail notices when the annual and biannual reports are due instead of checking UNet to find due dates.

- Next time a computer change happens, as an example DDR, please version it so all old DDR's do not suddenly have missing information and fields that are now empty due to new updates
- Make due data more visible. Donor confirmation is hidden
- yes, on donor net PLEASE make the UNOS ID and match ID much larger, and in bold.
- Improve donor net.
- It would be nice to be able to sort all the columns within the waitlist and removal list vs. the few columns that you are able to sort now.
- Please update the Waitlist page
- Also, allow all pages to recognize "enter" or "return" as "submit" instead of only a select few.
- More specific definition of variables. E.g: does continuous mechanical ventilation mean truly that or only a certain number of hours/day, such as 20?
- On the PTR have the donor information follow you down or up when you scroll
- Please add a feature to UNet that allows organ offers to be sorted by blood type of the donor.
- Donor Net update
- I believe that the database in Tiedi and DonorNet could be made more dynamic which would allow transplant professionals to mine their own center's data without the need to download entire forms (especially if only one field is needed).
- we work in transchart and not all data crosses over back and forth
- Digital media support platform for donor net
- Continue browser support updates
- Make your website portal fully compatible with mac computers. This is beyond ridiculous.
- Make DonorNet accessible to the OPO by mobile device.
- from a clinical perspective, if the UNET site was accessible and editable (not view only) from browsers other than IE (especially mac OS Safari), that would benefit our team greatly (especially for working organ offers from home)
- allowing your mobile site to be a full website
- Continue software development that integrates members systems with OPTN systems.
- Keep up the education!!! I love now being able to use the Ipad for donor net, why can't the Iphone do the same- the view on the Iphone is so restricted its hard to review organ offers esp. if they have already been harvested. You can't see all the information/details or attachments.
- More automation between the OPO EMR and DonorNet. The OPO staff still have to enter too much donor information in to DonorNet. The EMR companies should not have to fight with the systems people at DonorNet to make the data transfers, etc. easier, more automated and smoother. The DonorNet system should be able to accept all data entry fields from the OPO EMR systems. There is still too much data entry duplication.
- just catch up with the changes already in the parking lot
- Communicate changes/modifications to wait time in a timely manner.
- When the TIEDI forms were updated, the online instruction were not. This would help.

Infrastructure/Staff-related

- Add to data analysis staff!
- UNOS staff need to connect with members.
- Anonymous suggestion box?
- I think UNOS has done a wonderful job however, it can be quite a hot bed of political interests. I find it extremely difficult to find an opening to serve on a committee and I think this is related to political pressures during nomination and election of service positions. I'm not sure how this is tackled but the issue has grown very large over the last two decades in particular
- I would like to serve on the Thoracic committee or the MPSC board/committee
- Sadly, UNOS appears to be tied too much to the Feds and their bureaucratic think-set.
- I don't think UNOS is the problem. There are too many regulations and too many conflicting expectations and not enough staff for our programs to maintain expectations clinically and administratively. It is a collective regulatory problem. UNOS is not responsible, but the transplant discipline suffers.
- Will always ask for DECREASED duplication between CMS and UNOS!
- It would be nice if staff did not seem annoyed or frustrated when we reach out for help placing/backing up kidneys and Pancs.
- Last year, my program contacted UNOS for assistance with a clinical problem. UNOS responded by sending a team. Unfortunately, the response was directed towards repairing regulatory issues rather than addressing the clinical problem that we and other programs were having. It seemed to us at the time, that the OPTN, having access to all appropriate data, could pool results from several programs having similar difficulties and come up with a solution to help all of us. We were informed by the visiting UNOS personnel that it would take several years to organize such an effort! Not much help. In summary, we would all appreciate a more rapidly responsive and helpful organization rather than one fixated on Government style regulations.
- Make our regional rep more present. A quick once a year visit is not really enough. Or maybe hold conference calls to address current changes and clarifications.
- National admin on call for dispute.
- My biggest concern is that MDs lead most of the key committees and many MDs often assume they understand hospital finances/pressures, etc. and don't fully understand those intricacies. With the bundling of payments and reduction of Medicaid funding...UNOS to be successful in the future is going to need to someone engage the hospital administrator community more. You have to realize that when UNOS raises it's fees, hospitals don't get to negotiate those amounts, when OPOs raise their fees, they don't get to negotiate those....but when hospitals go to their payers we have to negotiate what we receive for transplants. With rising expenses we can't control, insurers don't cut us a break on trying to negotiate lower rates.
- more transparency
- More transparency in data releases.
- UNOS could reach out to third-party payors and standardize language such that surveys and RFIs are not ambiguous and overly resource demanding.
- Resume offering free publications

- MPSC function is far too antagonistic and judgmental, with biases and lack of transparency, unrecognized member conflict of interest, and lack of expertise to provide fair peer review.
- Since I don't work in clinical, I am unaware of what else is done by UNOS other than keeping the list of transplant needs, and making policies about that -- since it's mostly clinical, not sure if you shouldn't or don't offer any family follow-up, or assistance.
- Develop a connection with transplant social workers and involve us.

Committees/Regional Meetings

- If you could encourage transplant centers to send ALL of their employees to regional meetings--not just the managers and the administrators and the clinical staff--that would be great. I basically carry 1100 waitlisted kidney patient's data on my back but am given very little opportunity by my employer for continuing ed (plus as a data coordinator we don't get credits). Actually considering exploring positions at UNOS and at OPOs and other transplant centers because of this...not sure how many others out there feel the same way but there may be more of us than just me!
- Regional meetings should rotate between cities with busy transplant programs. Regional 4 always has meetings in Dallas even though there are large programs in Houston and San Antonio.

OPO-related

- Clear definitions for imminent and Eligible donors.
- Audit procurement organizations to ensure they are updating donornet as case progresses
- Better screening of organ offers such as by CIT. For example not giving us a 28 hour old kidney offer when the local cut off is 24 hours.
- More OPO input
- When an OPO needs to re-run a list and some patients will not show up on the next run list, would like to see UNET have an ability of send a mass "rescind offer" with reason, to be sent to all Tx center who have a provisional "yes" on the first run list.
- OPO having to explain more why they wouldn't perform a test or rushed to the OR without family constraints. Coming from an aggressive center I find we want organs offered late down the list. Say we're interested and told the OR has already been set. It's a fight every time and causing organ wastage.

Comments related to survey language

- I am not a transplant professional I am an organ donation professional whose work leads to helping to save lives of patients who are transplant professionals
- Recognize the important role that DIETITIANS have in the care of the transplant patient. DIETITIAN is not listed as one of the "titles" to select from below.

Living Donation/KPD

- Improve and emphasize live donor exchange opportunities

Positive

- Thank you.

- From my end everything is great.
- I am a satisfied customer!
- not sure, I think your team is very helpful
- UNOS is a wonderful organization that protects and supports transplant programs.