THE ALLIANCE ADVANCEMENT LEARNING SERIES

TRANSPLANT FOCUS | THE ALLIANCE ADVANCEMENT LEARNING SERIES

Leveraging Innovation and Patient Engagement in Pediatric Transplantation

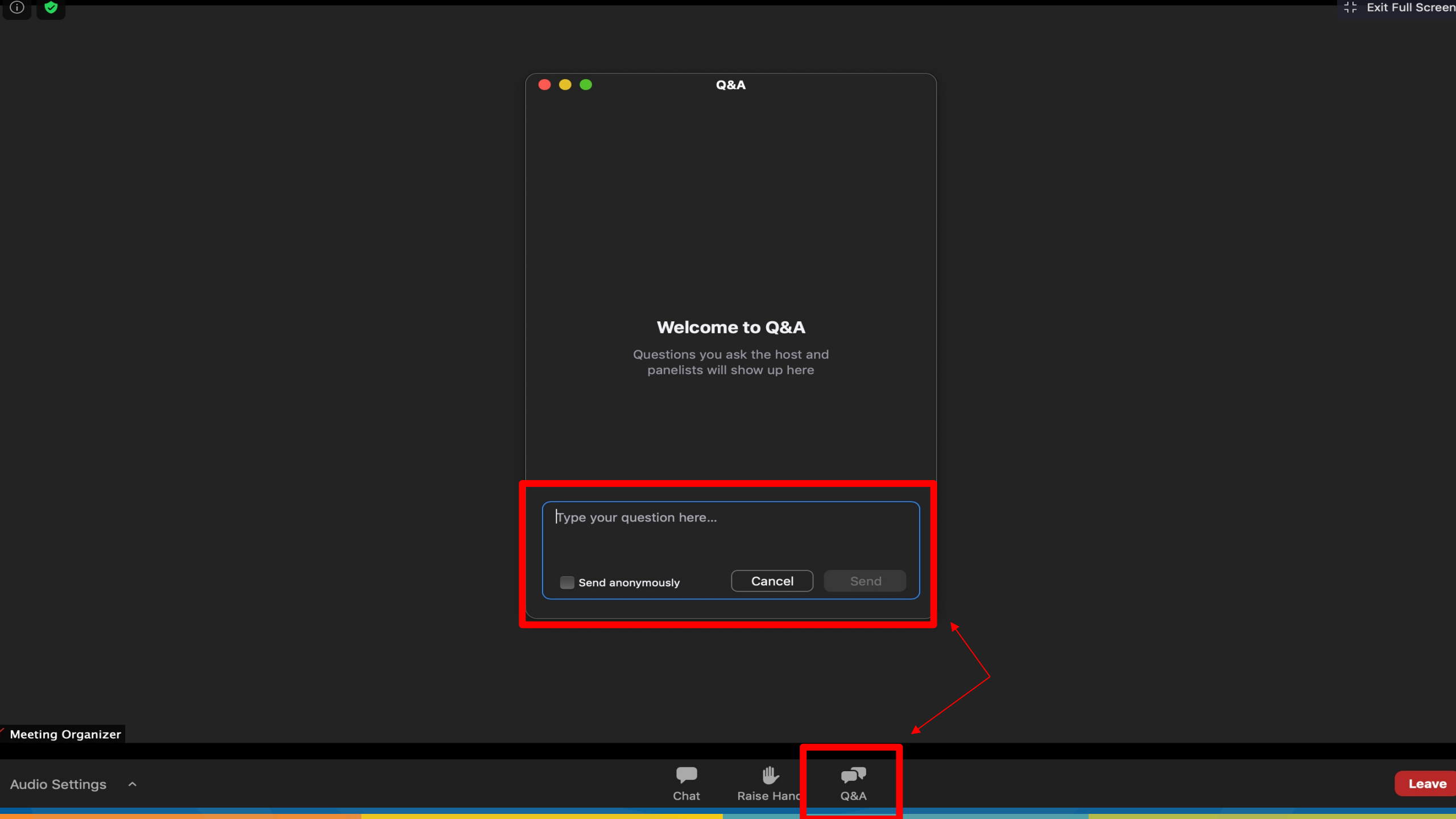
Speakers:

Adam Griesemer, MD | Douglas Mogul, MD, PhD | Emily Perito, MD

April 27, 2021

THE Alliance

Advancing Organ Donation & Tranplantation


Exit Full Screen
Q&A
Welcome to Q&A
Questions you ask the host and panelists will show up here
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Q&A
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DONATION FOCUS

THE ALLIANCE ADVANCEMENT LEARNING SERIES

Multi Organ Donation & Allocation

Tuesday, May 11, 2021
2:00pm – 3:00pm EDT
11:00am – 12:00pm PT

Available Continuing Education Credits:
1 CEPTC Credit, 1 Nursing Contact Hour

SPEAKERS:

Nicole Turgeon, MD, FACS
Transplant Director
The University of Texas at Austin Dell Medical School and Dell Seton Medical Center

TRANSPLANT FOCUS

THE ALLIANCE ADVANCEMENT LEARNING SERIES

The Living Donor: Making the Process Transparent, Efficient and Safe

Tuesday, May 25, 2021
3:00pm – 4:00pm EDT
12:00pm – 1:00pm PT

Available Continuing Education Credits:
1 CEPTC Credit, 1 Nursing Contact Hour

SPEAKERS:

Diana Manucci
Manager of Patient Relations, ILDA
UPMC Hamot

Amit Tevar, MD
Director, Kidney, Pancreas Transplant Surgery
University of Pittsburgh Medical Center, Thomas E. Starzl Transplantation Institute

THE ALLIANCE ADVANCEMENT LEARNING SERIES

Continuing Education Information

Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
- We highly encourage you to provide us with your feedback through completion of the online evaluation tool.
- Detailed instructions will be emailed to you within the next 24 hours.
- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.

THE Alliance

Advancing Organ Donation & Tranplantation

Meet Our Presenters

George Mazariegos
MD

MODERATOR

Professor of Surgery

UPMC
CHILDREN'S
HOSPITAL OF PITTSBURGH

Adam Griesemer
MD

Assistant Professor of Surgery

COLUMBIA UNIVERSITY

Douglas Mogul
MD, PhD

Associate Professor of Pediatrics

JOHNS HOPKINS
UNIVERSITY

Emily Perito
MD

Associate Professor, Dept. of Pediatrics

UCSF
University of California
San Francisco

THE Alliance | Leadership & Engaged Learning in Organ Donation & Transplantation

Minimally Invasive Pediatric Living Donor Liver Transplant

Adam Griesemer, MD

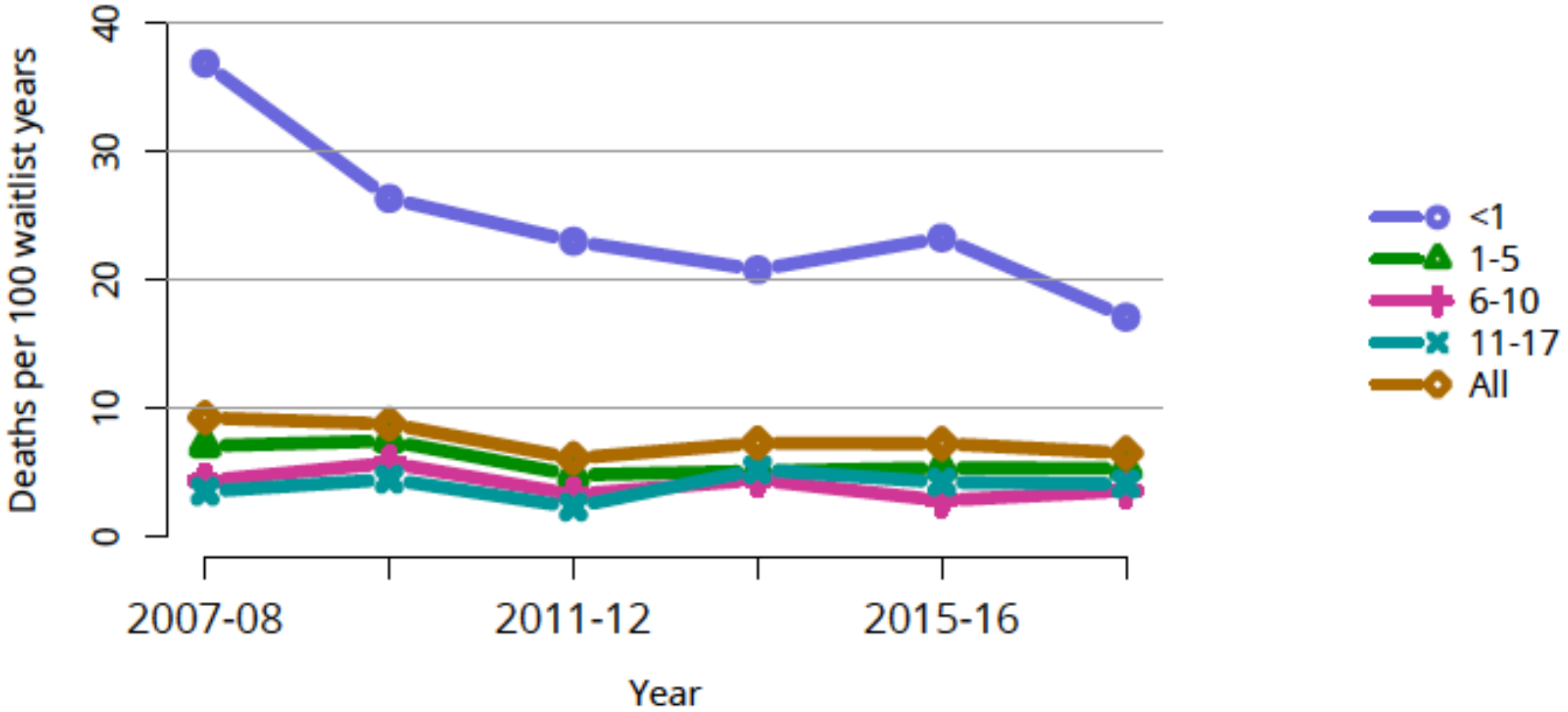
Assistant Professor of Surgery, Columbia University Irving Medical Center

Surgical Director, Pediatric and Living Donor Liver Transplantation

Columbia University Medical Center | Department of Surgery | Columbia Center for Translational Immunology

Disclosure: I have no financial conflicts of interest to disclose

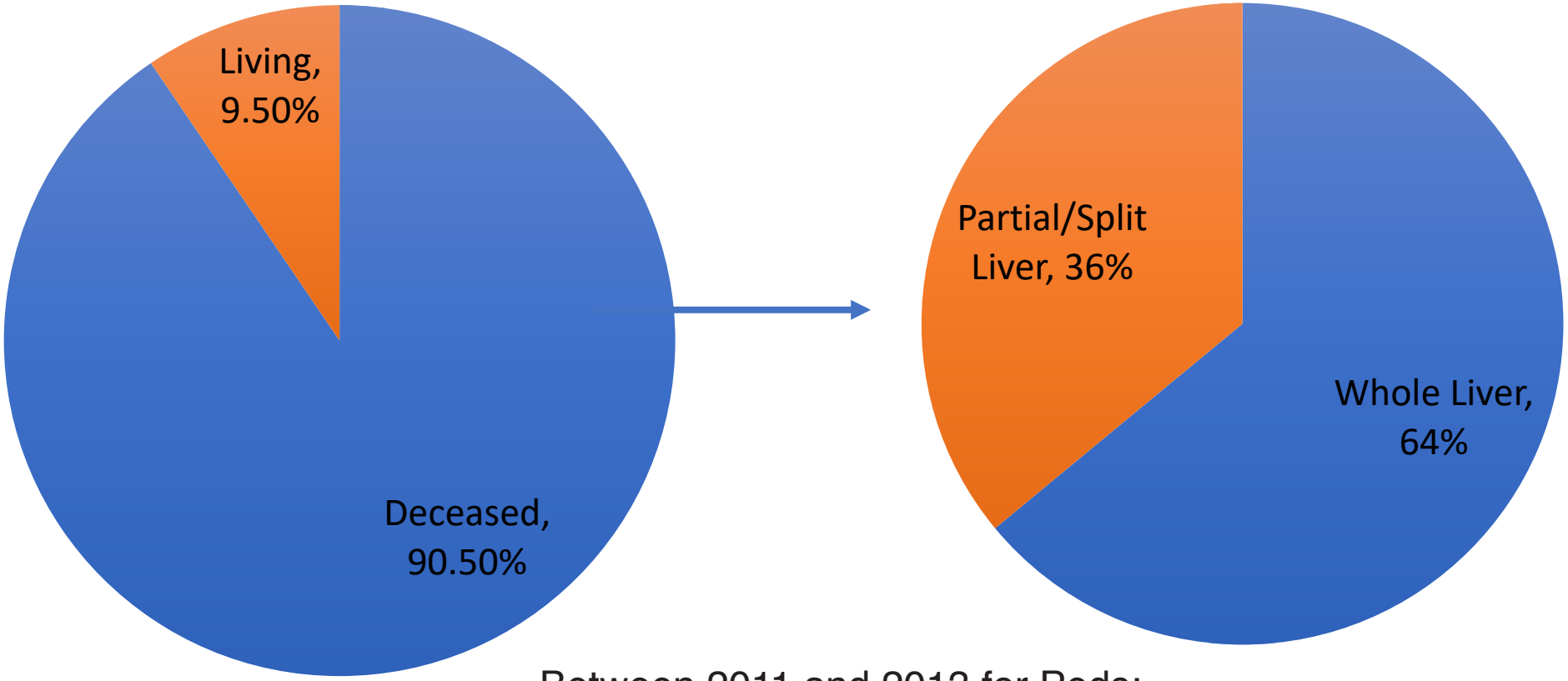
Need to Expand Donor Pool: Waitlist Mortality



Pretransplant mortality among waitlisted pediatric patients (by age)

Kwong et. al. *Am J Transplant* (2020). PMID:31898413

Utilization of Technical Variant Grafts



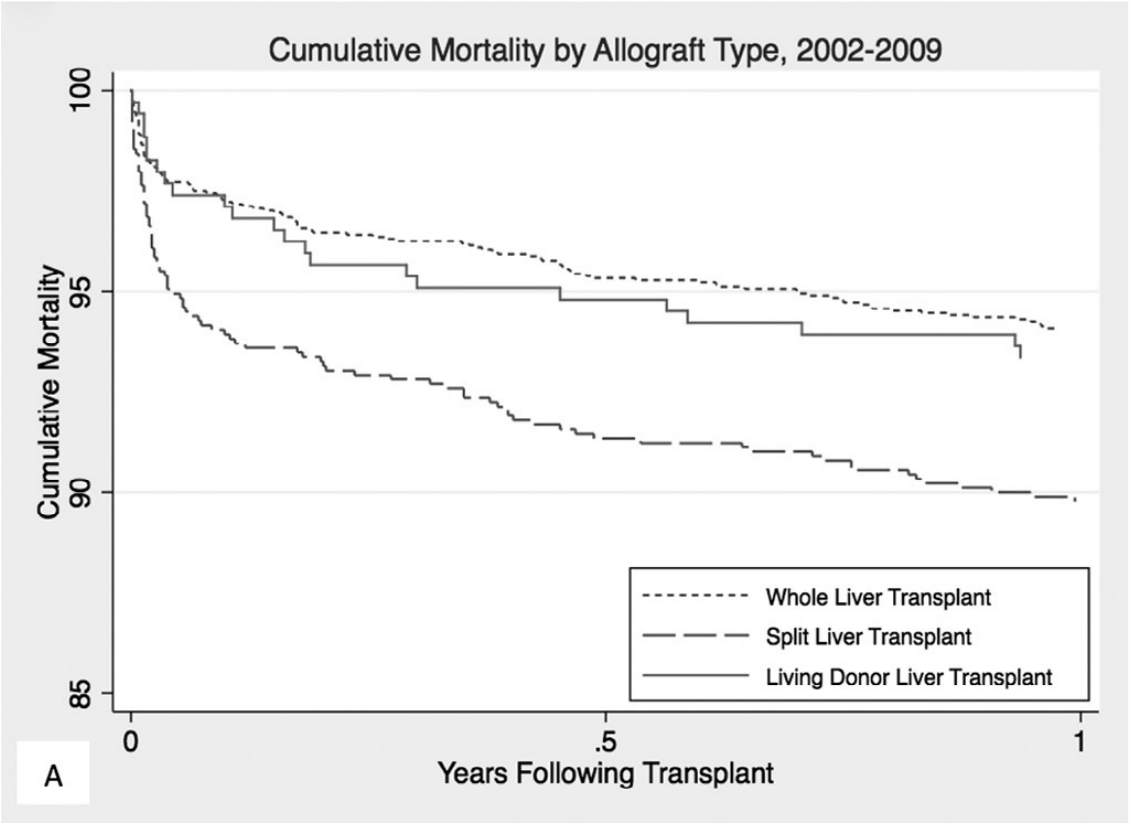
Between 2011 and 2013 for Peds:

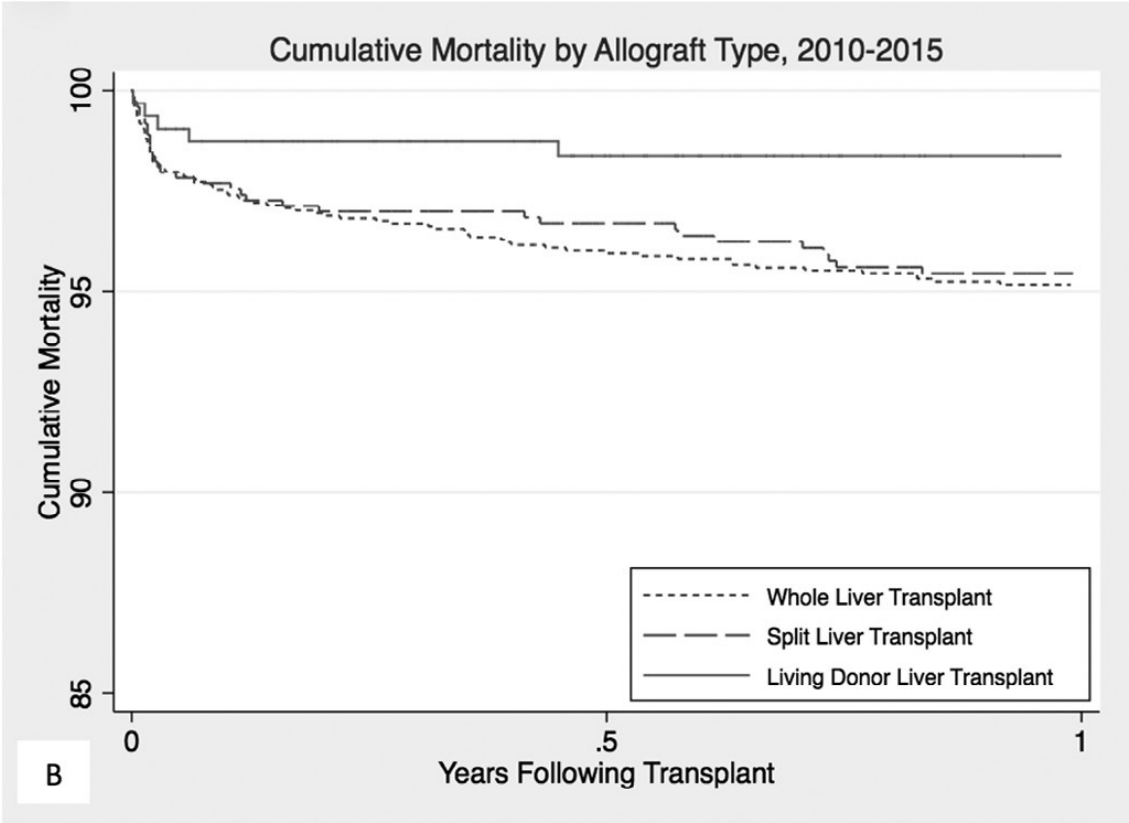
- 64% whole livers
- 26.5% partial/split grafts
- 9.5% living donor grafts

Hsu, E.K. & Mazariegos, G.V. Global lessons in graft type and pediatric liver allocation: A path toward improving outcomes and eliminating wait-list mortality. *Liver Transpl* 2017. PMID:27706890

SRTR Annual Report 2013

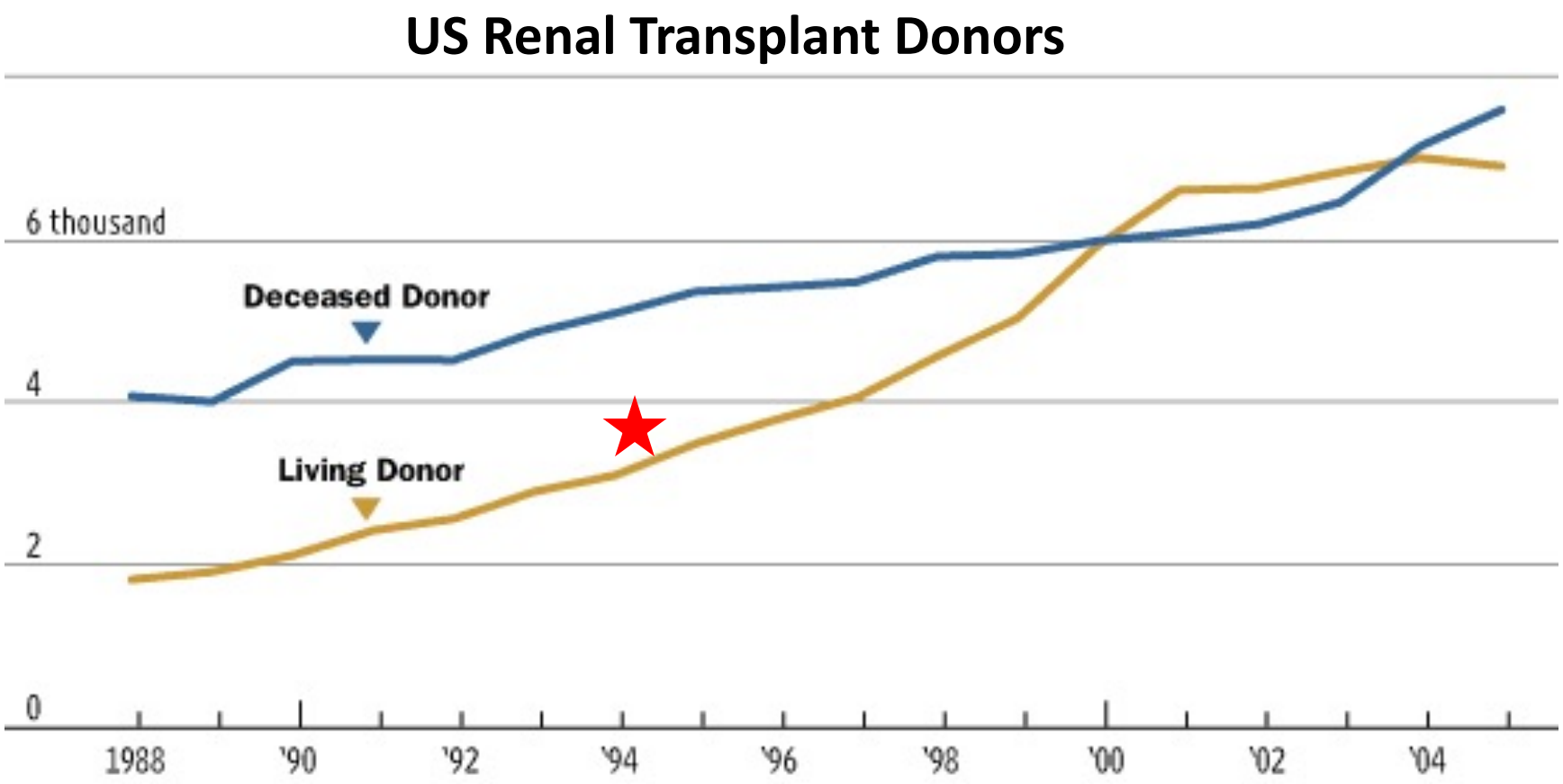
Outcomes of Technical Variant Grafts by Era





Mogul, D.B., et al. Fifteen-Year Trends in Pediatric Liver Transplants: Split, Whole Deceased, and Living Donor Grafts. *J Pediatr* 2018. PMID:29307689

Need for Innovation to Encourage More Living Donors: Laparoscopy



★ First case of laparoscopic donor nephrectomy

Ratner LE, Transplantation 1995; Segev DL, JAMA 2010

Innovative Surgical Management: Laparoscopic Donor Hepatectomy

Barriers to Laparoscopic LDLT

Patient:

- Perception of Surgical Risk
- Perioperative pain/recovery
- Time off from work
- Time off from being caretaker/parent
- Concern for recipient outcomes

Care Team

- Operative Time
- Learning Curve

Laparoscopic Donation Advantages
Fewer Complications

- 124 laparoscopic LLS donors from 5 centers compared to 300 laparoscopic nephrectomy donors[1]

	Liver Donors (n = 124)	Kidney Donors (n = 300)	*P*
Complications, n (%)	21 (16.9)	95 (31.7)	0.002
Minor complications	15 (12.1)	74 (24.7)	0.004
Major complications	6 (4.8)	21 (7.0)	0.407

- 72 open LLS vs 72 lap LLS[2]

Parameter	O-LLS (n = 72)	L-LLS (n = 72)	*P* Value
Complications			
Overall	21 (29.2)	3 (4.2)	<0.001
Minor	21 (29.2)	2 (2.8)	<0.001
Major	0 (0.0)	1 (1.4)	>0.99

1. Soubrane O, et al. Annals of Surgery 2015
2. Broering, DC. Liver Transplantation 2018

Comparison: Lap vs Open LLS

TABLE 2. Intraoperative Data and Donor Outcomes Between O-LLS and L-LLS Groups

Parameter	O-LLS (n = 72)	L-LLS (n = 72)	*P* Value
Conversion to open surgery	—	3 (4.2)	—
Blood loss, mL	200 (50-800)	100 (50-600)	<0.001
Operative time, minutes	244 (114-336)	293 (192-420)	<0.001
Transumbilical approach	71 (98.6)	69 (95.8)	0.24
Graft weight, g	238 (146-380)	218 (143-376)	0.82
First warm ischemia time, minutes	1 (1-6)	5 (1-11)	<0.001
Complications			
Overall	21 (29.2)	3 (4.2)	<0.001
Minor	21 (29.2)	2 (2.8)	<0.001
Major	0 (0.0)	1 (1.4)	>0.99

Broering, DC. Liver Transplantation 2018

Comparison of Lap and Open LLS

TABLE 1 Donors' baseline characteristics and outcomes

Parameters	Before PSM			After PSM		
	Studied group (laparo-scopic), n = 35	Control group (open), n = 68	*P* value	Studied group (laparoscopic), n = 35	Control group (open) n = 35	*P* value
Operation time, median (±SD), min	277.9 (±16.3)	274 (±15)	0.750	277.9 (±16.3)	270.3 (±14.9)	0.489
Blood loss, median (±SD), mL	96.8 (±16.5)	166.8 (±18.4)	**<0.001**	96.8 (±16.5)	155.8 (±17.8)	**<0.001**
Number of graft bile ducts, n (%)						
1	17 (48.6)	25 (36.8)	0.073	17 (48.6)	15 (42.9)	0.631
2	17 (48.6)	36 (52.9)	0.192	17 (48.6)	17 (48.6)	>0.99
3	1 (2.9)	6 (8.8)	0.580	1 (2.9)	2 (5.7)	0.555
4	0	1 (1.5)	0.141	0	1 (2.9)	0.314
Graft weight, median (±SD), g	261.6 (±21)	283.7 (±13.5)	0.068	261.6 (±21)	284.8 (±21)	0.116
Complications > grade II (Clavien-Dindo), n (%)						
IIIa	-	2 (2.9)	0.226	-	2 (5.7)	0.151
IIIb	1 (2.9)	-	0.164	1 (2.9)	-	0.314
IV	-	-	-	-	-	-
V	-	-	-	-	-	-
LOS, median (±SD), d	4 (±0.4)	7,2 (±0.5)	**<0.001**	4 (±0.4)	6.9 (±0.5)	**<0.001**

BMI, body mass index; LOS, Length of hospital stay; PSM, Propensity score matching.

Gautier S. Clinical Transplantation 2018

Laparoscopic Donation Advantages
Faster Recovery

- 11 open left lateral segmentectomy (LLS) vs 11 lap LLS[1]
  - Length of stay 9.8 vs 6.9 days
- 35 open LLS vs 35 lap LLS[2]
  - Length of stay 6.9 vs 4 days
- 72 open LLS vs 72 lap LLS[3]
  - Length of stay 4.6 vs 4.1
  - Less pain with lap vs open
- 20 open full left vs 22 lap full left hepatectomies[4]
  - Length of stay 5.95 vs 4.27
  - Return to work in 63 vs 33 days

1. Kim, K H. British Journal of Surgery, 2011
2. Gautier S. Clinical Transplantation 2018
3. Broering, DC. Liver Transplantation 2018
4. Samstein B, Griesemer A, et al. Liver Transplantation 2015

Equivalent Recipient Outcomes

Table 3 Data for paediatric recipients

	LLS ($n = 11$)	OLS ($n = 11$)	P*
Preoperative data			
Age (months)	11·1(8·1)	15·7(15·6)	0·391
Sex ratio (M : F)	5 : 6	4 : 7	0·665†
PELD score	12·7(6·3)	22·9(13·4)	0·035
Postoperative data			
Minimum prothrombin time (%)	36·6(4·8)	39·7(7·9)	0·278
Peak values			
Total bilirubin (μmol/l)	105·6(28·9)	180·6(226·7)	0·577
AST (units/l)	878·2(962·0)	589·9(558·0)	0·412
ALT (units/l)	866·9 (906·7)	716·3(813·7)	0·870
1 week postop.			
Total bilirubin (μmol/l)	44·3(13·6)	28·9(13·6)	0·223
AST (units/l)	57·4(27·0)	92·7(96·0)	0·742
ALT (units/l)	93·7(58·5)	200·9(20·5)	0·341
Prothrombin time (%)	58·3(11·1)	65·6(12·1)	0·217

Values are mean(s.d.) unless indicated otherwise. LLS, laparoscopic live donor left lateral sectionectomy; OLS, open live donor left lateral sectionectomy; PELD, paediatric end-stage liver disease; AST, aspartate aminotransferase; ALT, alanine aminotransferase. *Mann–Whitney U test, except †Fisher's exact test.

Kim, K H. British Journal of Surgery, 2011

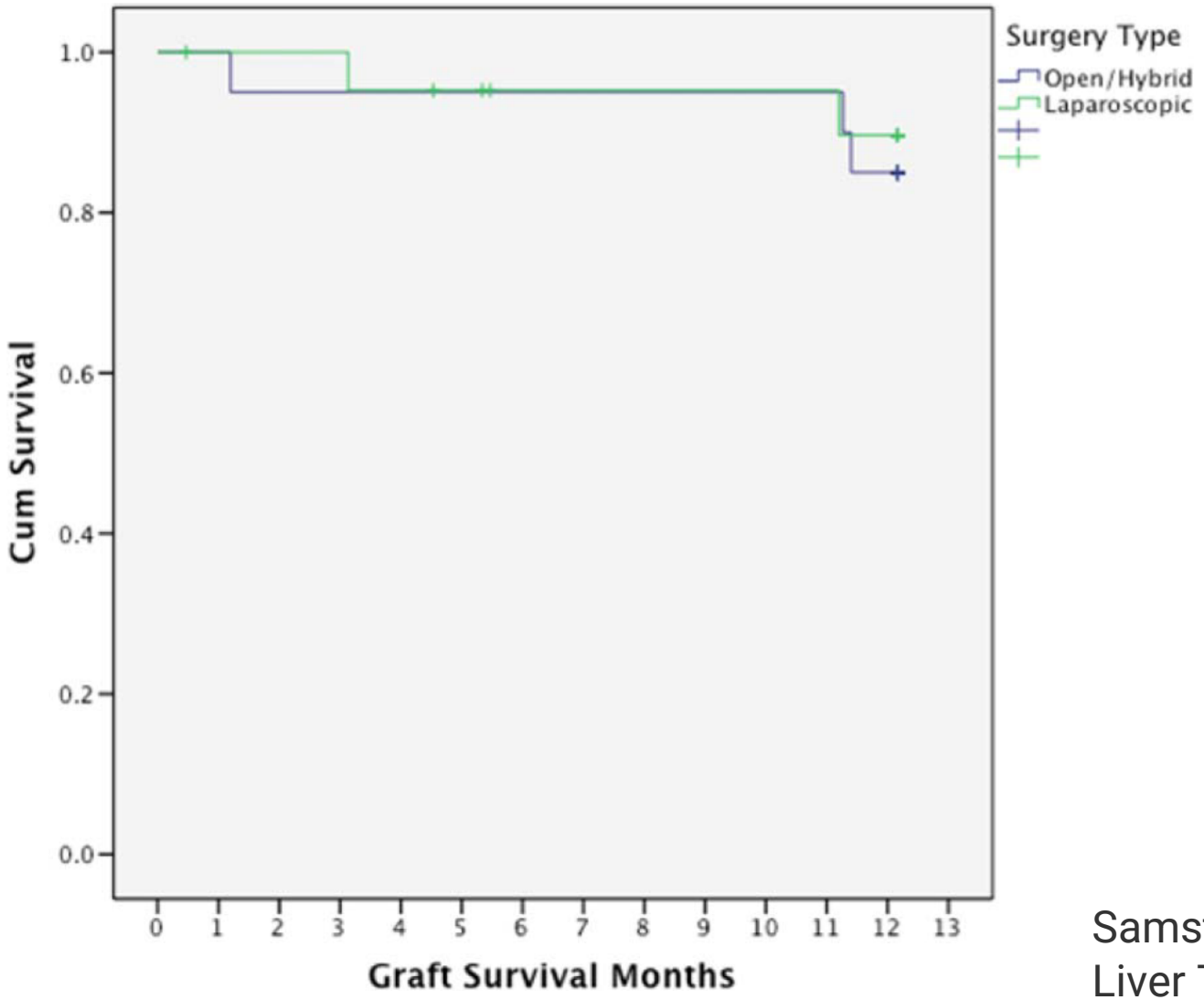
Equivalent Recipient Outcomes

TABLE 4. Recipient Outcomes With the Graft Procured With the Conventional and the Laparoscopic Approach

Parameter	O-LLS (n = 72)	L-LLS (n = 72)	*P* Value
Age	1.6 (0.2-17.2)	1.15 (0.2-12.4)	0.63
GRWR, %	2.6 (1.1-7.9)	2.5 (0.8-6)	0.36
Body weight at the time of transplant	9 (4.2-27.9)	7.8 (4.5-24.4)	0.82
Sex, male	35 (48.6)	35 (48.6)	>0.99
PVT	0	2 (2.8)	0.5
Hepatic artery thrombosis	0	1 (1.4)	>0.99
Bile leak	2 (2.8)	0	0.5
Bile strictures	5 (6.9)	6 (8.3)	>0.99
PNF	0	0	Not available
Retransplantation	1 (1.4)	1 (1.4)	>0.99
Retransplant due to chronic rejection	1 (1.4)	0	—
Retransplant due to chronic graft dysfunction	0	1 (1.4)	—
Intraoperative death	0	2 (2.8)	—
Overall mortality	5 (6.9)	7 (9.7)	0.76

Broering, DC. Liver Transplantation 2018

Equivalent Recipient Outcomes



Samstein B, Griesemer A, et al.
Liver Transplantation 2015

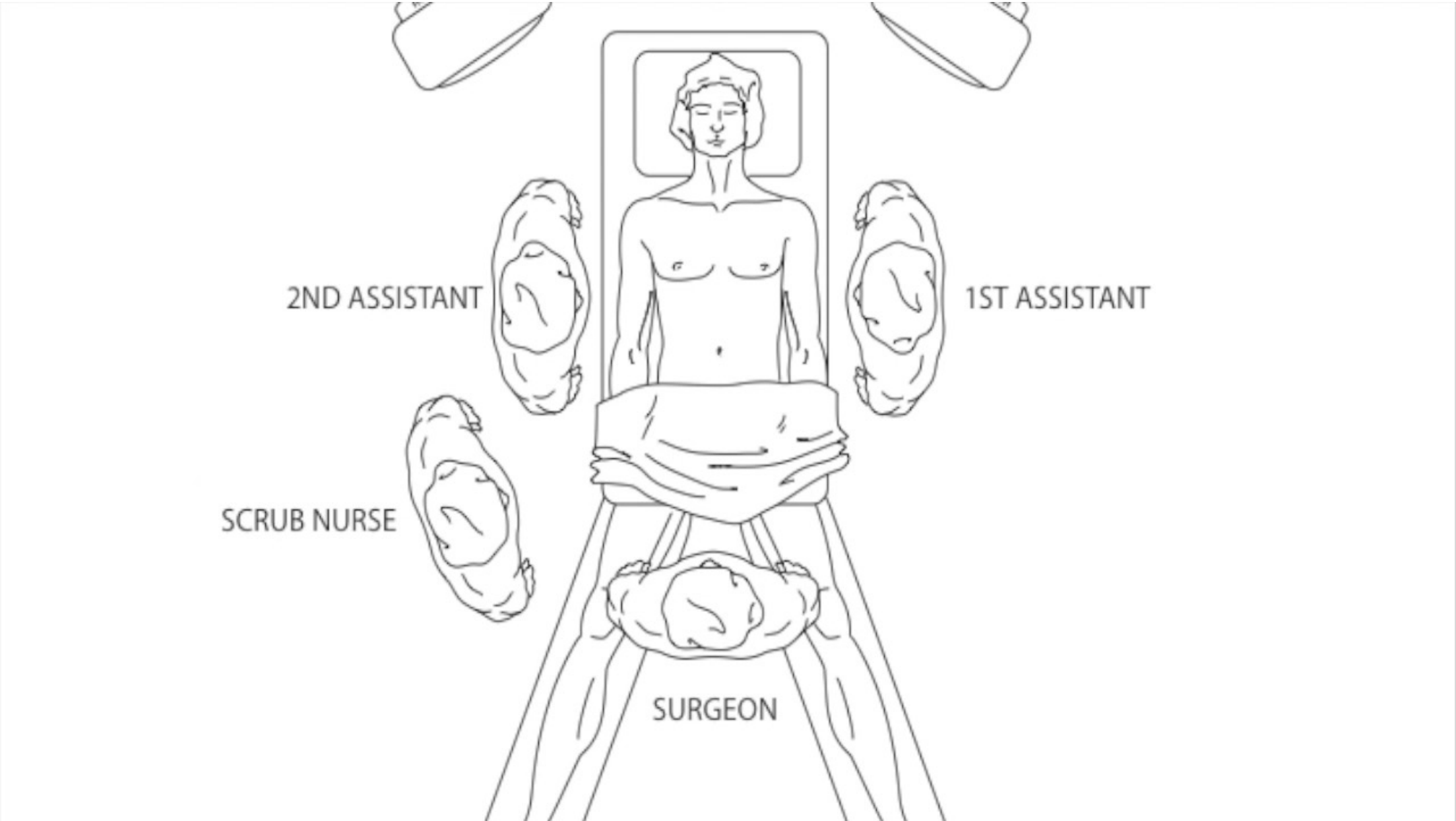
Learning Curve of LLS for Cancer

Table 2. Comparison of Early and Late Cases of Left Lateral Sectionectomy

Characteristic	Early group (n = 60)	Late group (n = 58)	p Value
Preoperative factor			
Age, y, median (range)	33.5 (19–71)	45.5 (25–80)	<0.0001
Sex, male/female, n	33/27	35/23	0.5569
BMI, kg/m^2, median (range)	23.1 (16.1–30.7)	24.3 (16.3–45)	0.0392
American Society of Anesthesiologists score, n			0.0025
1 or 2	56	42	
3 or 4	1	10	
Unknown	3	6	
Indication for the treatment, n (%)			<0.0001
Benign-borderline tumor/living donor	53 (88.3)	31 (53.4)	
Malignant tumor	7 (11.7)	27 (46.6)	
Operative factor			
Operative time, min, median (range)	255 (120–480)	240 (120–480)	0.2341
Blood loss, mL, median (range)	30 (20–300)	50 (20–500)	0.8980
Transfusion required, yes/no, n	0/60	0/58	NA
Pedicle clamping, yes/no, n	4/56	9/49	0.1248
Postoperative factor			
Overall postoperative complications, n (%)	9 (15)	10 (17.6)	0.7092
Clavien-Dindo grade III or higher, n (%)	3 (5)	1 (1.7)	0.3256
Mortality within 30 d, n (%)	0 (0)	0 (0)	NA
Postoperative hospital stay, d, median (range)	6 (3–12)	5 (2–29)	0.7762

NA, not applicable.

Technique - Positioning



Conclusions

- Lap left lateral/left hepatectomy for LDLT is associated with:
  - Fewer complications compared to laparoscopic donor nephrectomy and open left lateral hepatectomy
  - Less blood loss
  - Less pain
  - Lower length of stay
  - Faster return to work
  - Equivalent recipient outcomes
- Thank you!

A learning health system for pediatric transplantation:

Emily R. Perito, MD
Department of Pediatrics
Department of Epidemiology and Biostatistics
University of California, San Francisco

What do learning health systems do?

- Integrate research, improvement, management, and patient care such that every patient receives “the right care at the right time….every time.”
- Enable “continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience.”
- Bring together all stakeholders—including providers, patients, families, administrators, policymakers, and others—to identify challenges and potential solutions.
- Utilize quality improvement cycles to reduce variability and improve outcomes.

STARZL NETWORK
for Excellence in Pediatric Transplantation

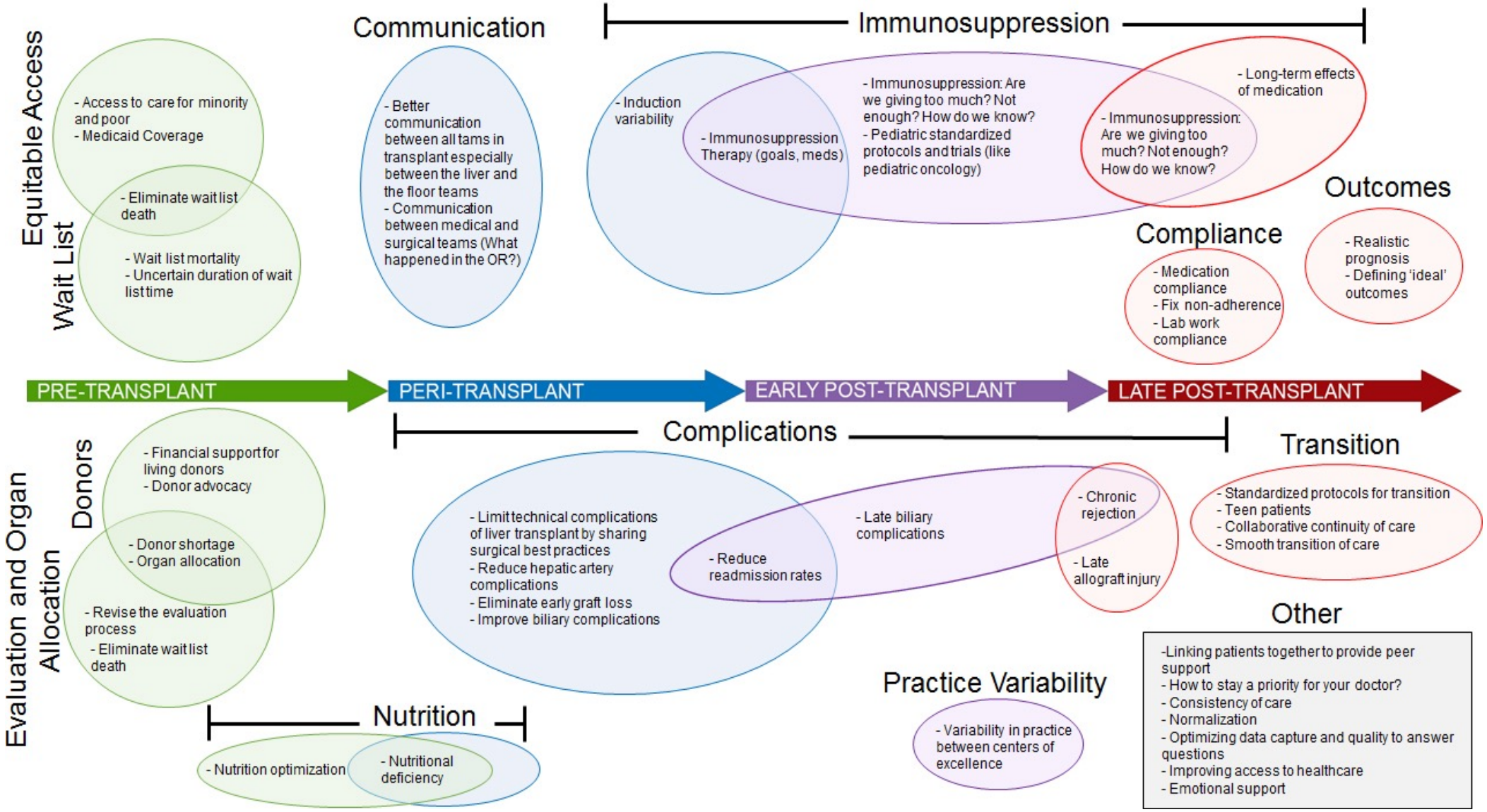
Starzl Network pediatric transplant centers

Network Members

1. Seattle Children's
2. UCSF Benioff Children's Hospitals
3. Ann & Robert H. Lurie Children's Hospital of Chicago
4. SickKids
5. Columbia University Medical Center
6. Mount Sinai
7. UPMC Children's
8. University of Virginia
9. Children's Healthcare of Atlanta
10. AdventHealth

Starzl Network Inaugural Meeting 2018

Pain Point #1: What problem would you like to solve or question would you like to answer in transplant?



Starzl Network current priority projects

- Quality of life (PeLTQL)
- Optimizing immunosuppression
- Transition from pediatric to adult care
- Anti-coagulation and peri-operative pediatric transplant practices

STARZL NETWORK
for Excellence in Pediatric Transplantation

Starzl Network strategic goals:

1. Facilitate transparency of practice variation and connection of practices to patient outcomes.
   - Sharing and comparing protocols for immunosuppression, transition of care amongst centers
   - Benchmarking reports to follow patients and center outcomes over time
2. Harness existing datasets to reduce the burden of tracking outcomes.
   - Building a Starzl registry based on the UNOS/OPTN dataset, with UNOS Solutions
3. Incorporate patient-reported outcomes (PROs) into outcome metrics.
   - PeLTQL: Pediatric transplant-specific quality of life measure, with e-reporting
4. Accelerate the implementation of knowledge into clinical practice.
   - PARTNER: preparing the Starzl Network for patient-centered outcomes research

STARZL NETWORK
for Excellence in Pediatric Transplantation

PARTNER

PAtient-centered Research in TransplaNt-Engaging families+Recipients

Elizabeth Eisenberg, PFV
Melissa McQueen, Transplant Families
Emily Perito, UCSF
James Squires, Children's Hospital Pittsburgh
George Mazariegos, Children's Hospital Pittsburgh
CJ Confair, Starzl Network/Children's Hospital Pittsburgh

STARZL NETWORK
for Excellence in Pediatric Transplantation

Transplant Families

Transplant Families

- Established in 2017
- Led by parents to aid the entire pediatric transplant community
- 2,500 members from across more than 40 transplant centers
- Aim = to inspire, educate, and support transplant families
- Melissa McQueen – President, mom of heart transplant recipient, co-lead on PARTNER
- Learn more: transplantfamilies.org

PARTNER = PCORI Capacity Building Engagement Award

- What is **PCORI**?
  - Funds research that provides patients, their caregivers, and clinicians with the evidence-based information needed to make better-informed healthcare decisions.
  - Believes that every step of research should be a collaboration between providers, patient partners, and other stakeholders.
- What is a **Capacity Building Engagement Award**?
  - Focus on building the knowledge and abilities of the community (patient partners + providers + others) to be meaningful partners throughout the research process.
  - Supports organizations with strong ties to patients, caregivers, clinicians, and/or other stakeholders – to equip them to engage as partners in patient-centered outcomes research.

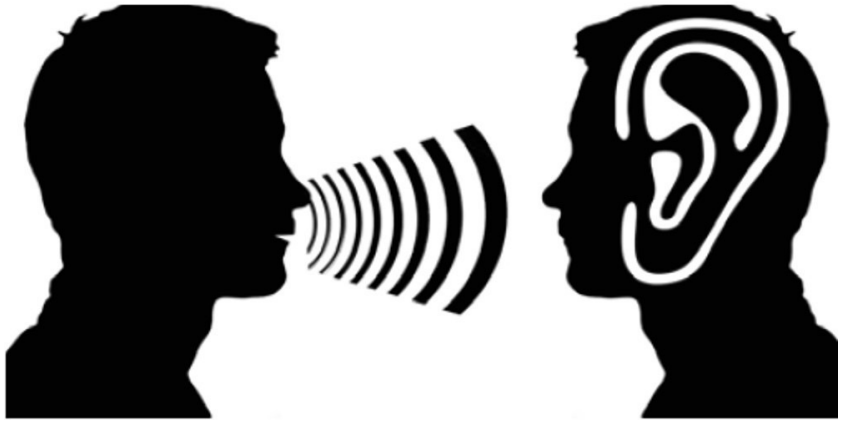
STARZL NETWORK
for Excellence in Pediatric Transplantation

Transplant Families

What is patient-centered outcomes research?

PCOR helps patients and families communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options. This research answers patient-centered questions:

1. "Given my child's personal characteristics, conditions, and preferences, what should I expect will happen to them?"
2. "What are our options, and what are the potential benefits and harms of those options?"
3. "What can I do to improve the outcomes that are most important to my child and our family?"
4. "How can clinicians and the care-delivery systems they work in help us make the best decisions about my child's health and healthcare?"



STARZL NETWORK
for Excellence in Pediatric Transplantation

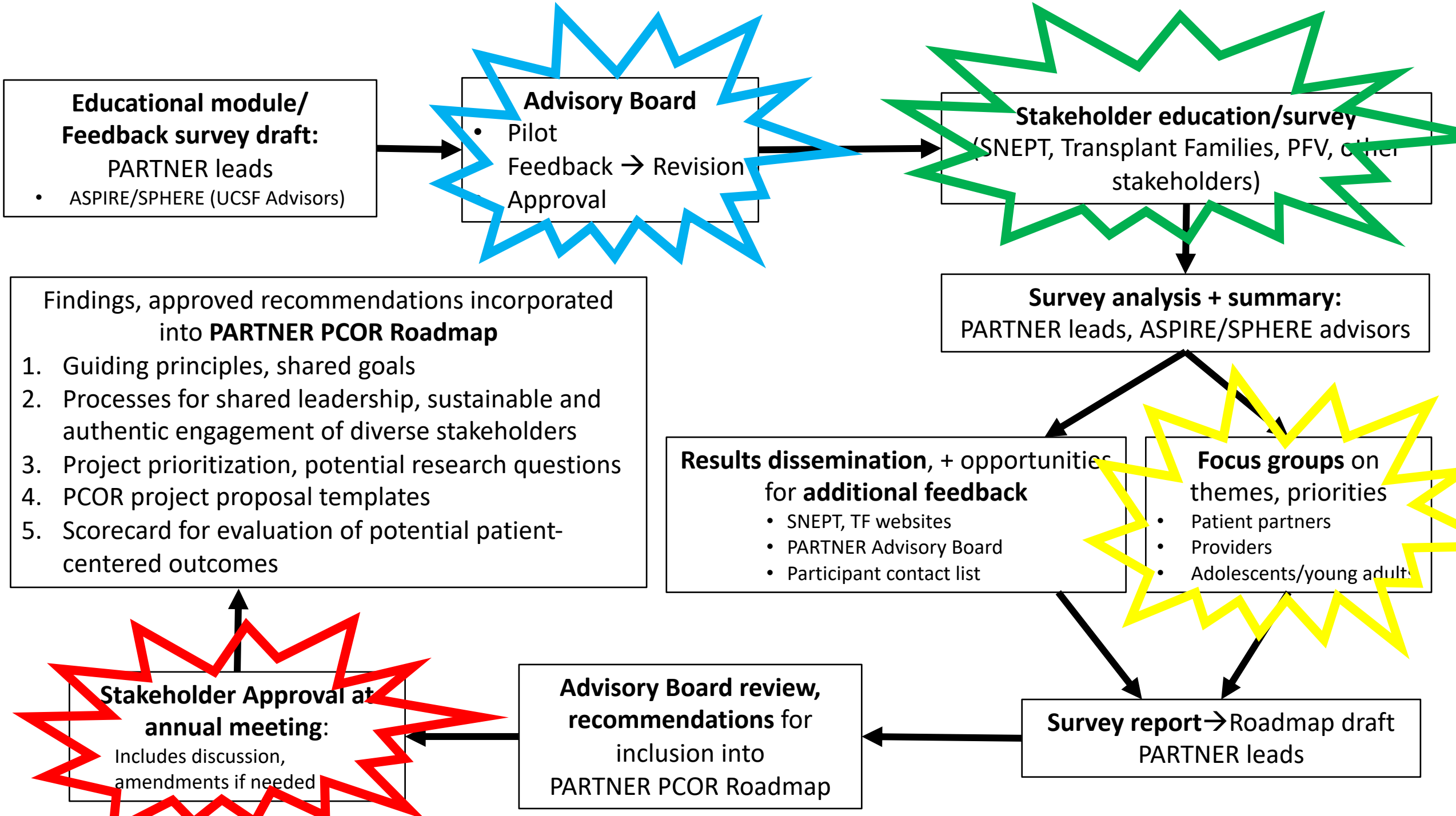
Transplant Families

Goals of PARTNER

- Help all members of our Starzl Network (and pediatric transplant) community learn about patient-centered outcomes research
  - 6 app/web-based learning modules—patient partner + provider versions
- Get feedback from ALL stakeholders about how the Starzl Network and Transplant Families should do patient-centered outcomes research
  - 6 app/web-based feedback surveys, delivered through RealTimeClinic
- So that TOGETHER we can improve the lives of all pediatric transplant recipients—including those that you know and love!
  - PARTNER Patient-Centered Outcomes Research Roadmap
    - What questions do we need PCOR answers to? How can we include all stakeholders in the PCOR process? What should PCOR projects within the Starzl Network look like?

STARZL NETWORK
for Excellence in Pediatric Transplantation

Transplant Families


Educational module/
Feedback survey draft:
PARTNER leads
ASPIRE/SPHERE (UCSF Advisors)
Advisory Board
Pilot
Feedback → Revision
Approval
Stakeholder education/survey
(SNEPT, Transplant Families, PFV, other stakeholders)
Survey analysis + summary:
PARTNER leads, ASPIRE/SPHERE advisors
Results dissemination, + opportunities for additional feedback
SNEPT, TF websites
PARTNER Advisory Board
Participant contact list
Focus groups on themes, priorities
Patient partners
Providers
Adolescents/young adults
Survey report→Roadmap draft
PARTNER leads
Advisory Board review, recommendations for inclusion into PARTNER PCOR Roadmap
Stakeholder Approval at annual meeting:
Includes discussion, amendments if needed
Findings, approved recommendations incorporated into PARTNER PCOR Roadmap
1. Guiding principles, shared goals
2. Processes for shared leadership, sustainable and authentic engagement of diverse stakeholders
3. Project prioritization, potential research questions
4. PCOR project proposal templates
5. Scorecard for evaluation of potential patient-centered outcomes

Thank you!

- Learn more at: https://starzlnetwork.org/
- Questions or suggestions? Email us at partner@starzlnetwork.org
- transplantfamilies.org

STARZL NETWORK
for Excellence in Pediatric Transplantation

Transplant Families

JOHNS HOPKINS
SCHOOL of MEDICINE

Patient education tools:

What is available and how can we use technology to better engage patients?

Douglas Mogul, MD PhD
Associate Professor of Pediatrics
Johns Hopkins University

April 27, 2021

Objectives

- To review existing public patient education tools for pediatric liver transplantation
- To review best practices in patient education
- To explore how novel (i.e., digital) technologies can enhance patient education and engagement

Objectives

- To review existing public patient education tools for pediatric liver transplantation
- To review best practices in patient education
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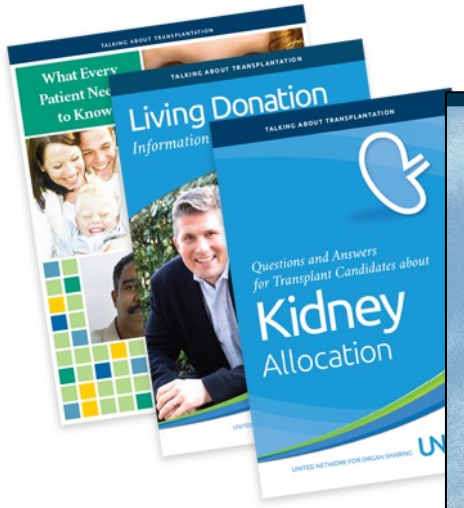
What's out there?

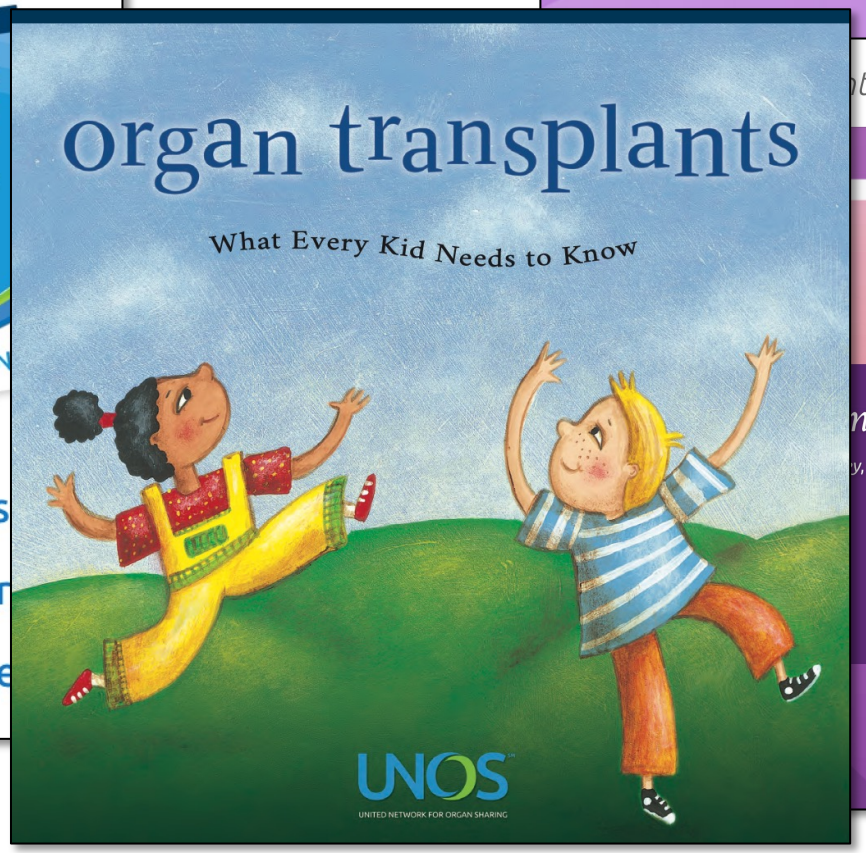
Patient Materials

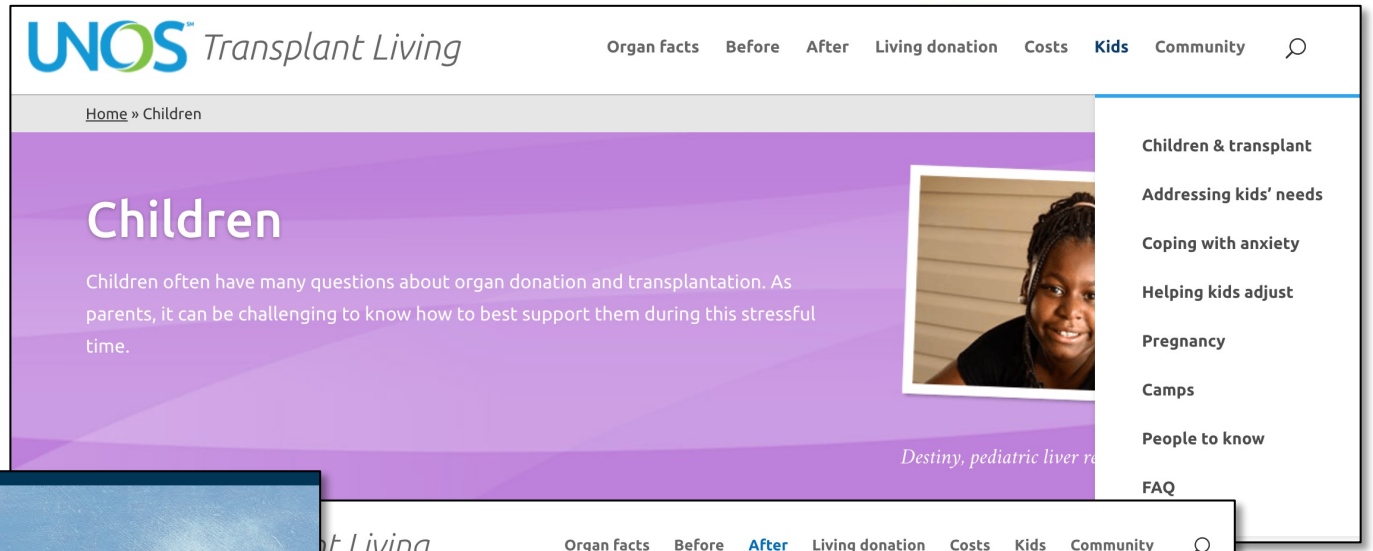


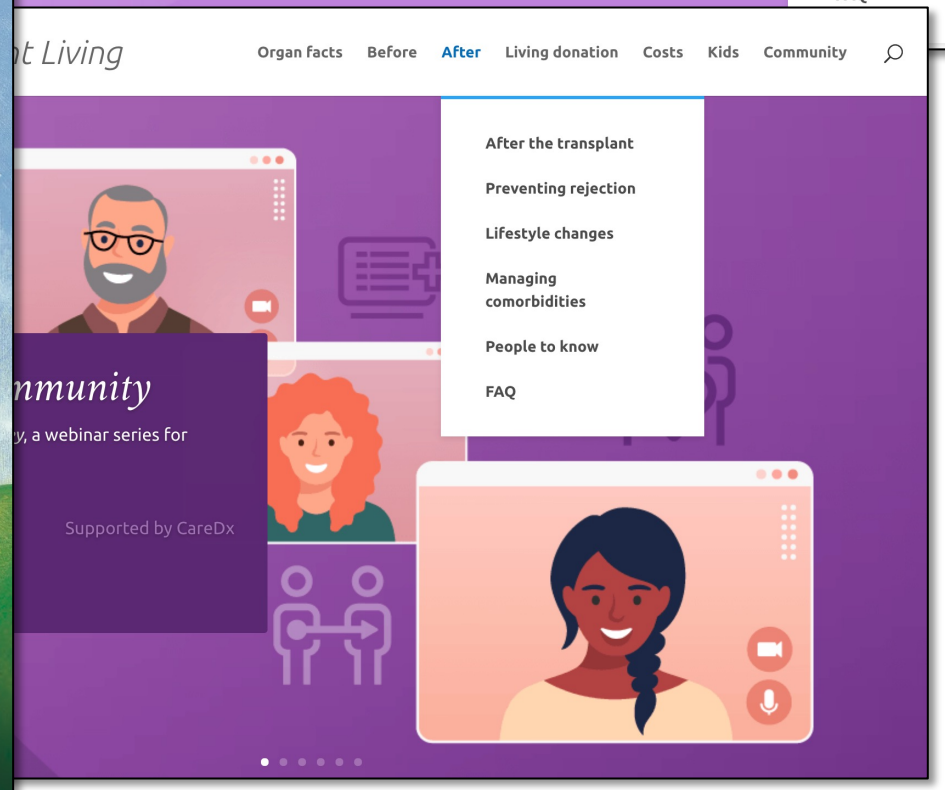
UNOS Facts & Figures

Living donation brochur

Other patient brochure







What's out there?

AST Power2Save
ONE TRANSPLANT FOR LIFE

WHAT IS POWER2SAVE? | TRANSPLANT LEARNING | GET INVOLVED | COMMUNITY CORNER | DONATE

COVID-19 RESOURCES +

PRE-TRANSPLANT +

POST-TRANSPLANT −

- Being a Parent After Receiving a New Transplant
- Organ Rejection
- Living with a Transplant
- Strategies for Safer Living After Transplant
- Medicines to Keep Your New Organ Healthy
- Guide to Safe Travel After Transplant

PEDIATRIC TRANSPLANTATION +

What’s out there?

TeensHealth from Nemours

for Parents | for Kids | for Teens | For Educators

You searched for: **liver**

(viewing results 1 to 10) next ▸

When Your Child Needs a Liver Transplant for Parents
If your child needs a liver transplant, you're probably feeling lots of emotions. Fortunately, most kids who have liver transplants go on to live normal, healthy lives.

Liver Tumors for Parents
Tumors happen when cells form a mass or growth. Liver tumors can be benign (not cancerous) or malignant (cancerous).

Undifferentiated Embryonal Sarcoma of the Liver (UESL) for Parents
Undifferentiated embryonal sarcoma of the liver (UESL) is a rare kind of liver cancer that happens mostly in children.

Rhabdoid Tumor of the Liver for Parents
A rhabdoid tumor of the liver is a cancer that often spreads quickly to other parts of the body. Most of these very rare tumors happen in babies and toddlers.

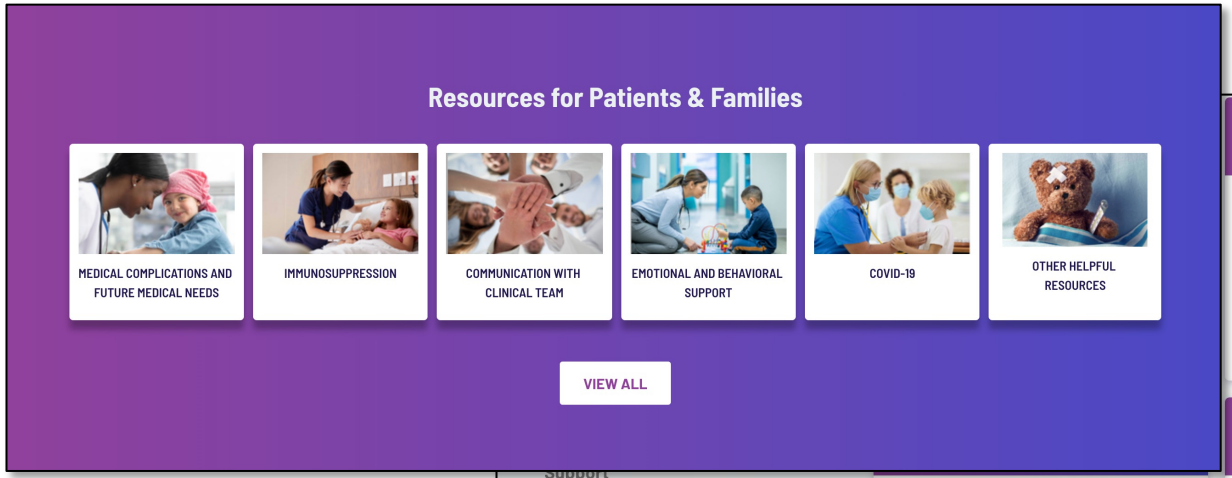
Blood Test: Liver Function Tests for Teens
If your liver isn't working properly, it can affect your overall health. Find out why doctors do liver function tests and what's involved for teens.

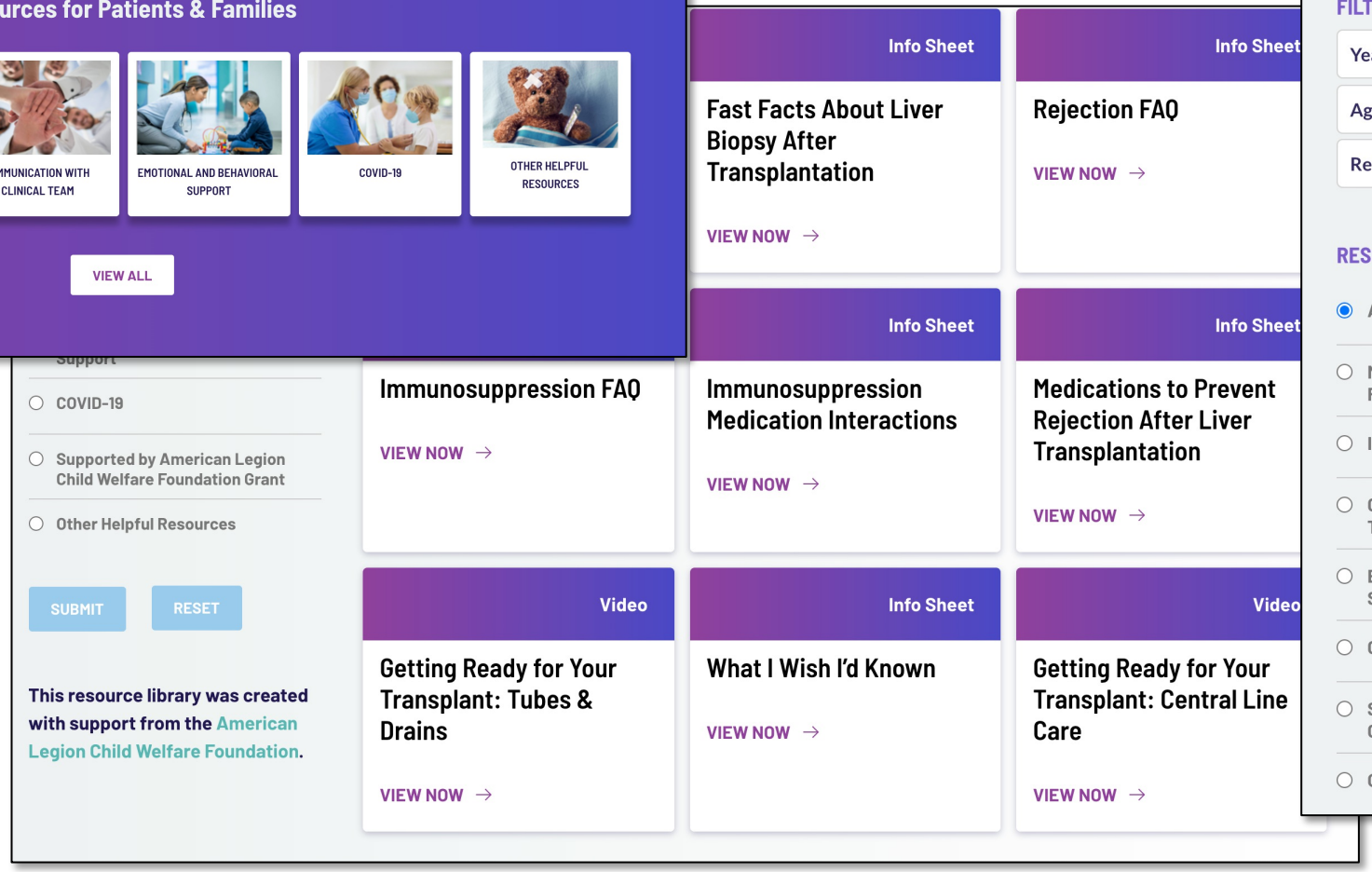
Your Liver for Kids
Your liver cleans your blood and plays an important part in digestion. Find out more in this article for kids.

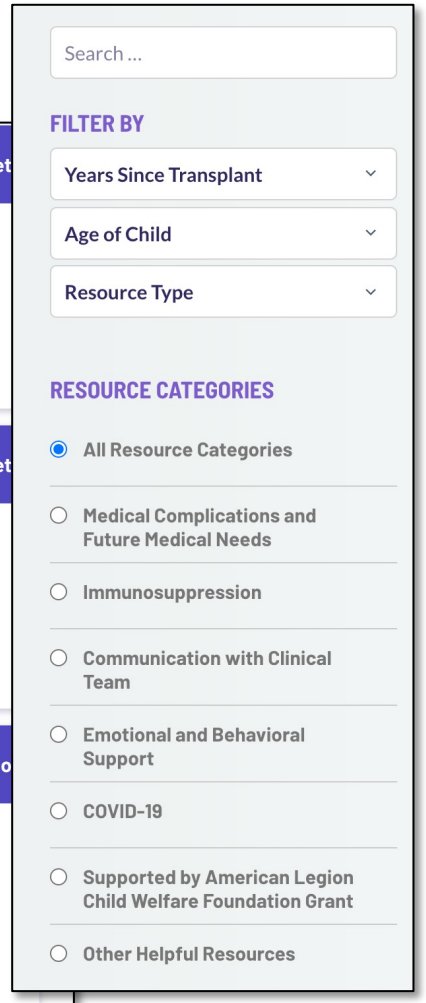
Blood Test: Hepatic (Liver) Function Panel for Parents
Liver function tests can help doctors see if the liver has been damaged. They also can help diagnose infections and monitor medications that can cause liver-related side effects.

Hepatocellular Carcinoma (HCC) for Parents
Hepatocellular carcinoma (HCC) is a type of liver cancer. It's treated by a health care team of specialists in many areas.

What's out there?







STARZL NETWORK
for Excellence in Pediatric Transplantation

18 info sheets
4 videos

Objectives

- To review existing public patient education tools for pediatric liver transplantation
- To review best practices in patient education
- To explore how novel (i.e., digital) technologies can enhance patient education and engagement

Best practices in patient education

- Use patient-preferred formats
- Assess patient health literacy
- Utilize patient teach-back
- Lean on health technology

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Traditional formats for patient education

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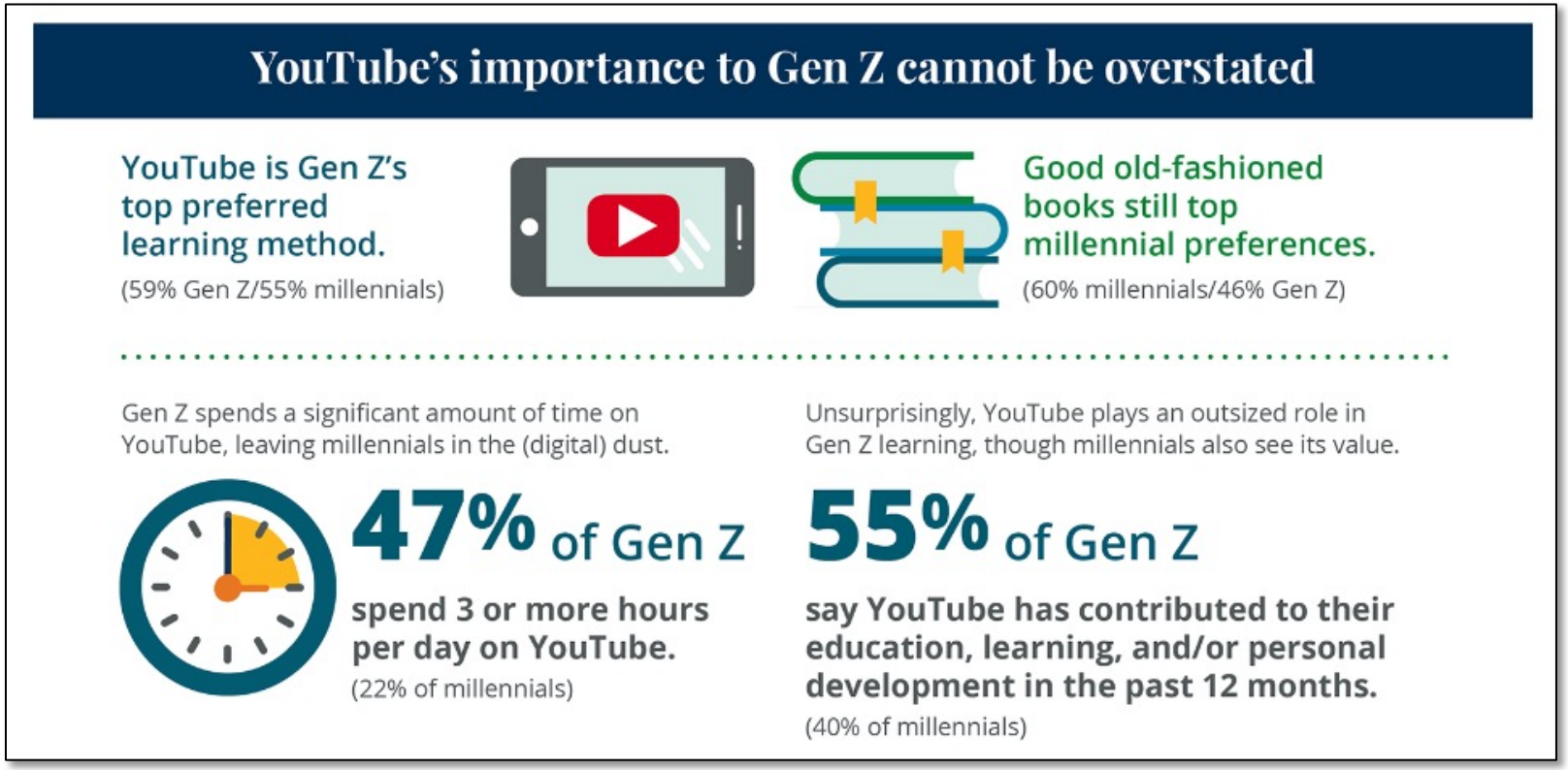
- Printed materials and brochures
- Web platforms
- Charts and infographics
- Slidedecks
- Videos (YouTube and elsewhere)
- Models and props
- Group classes
- Peer educators

People like videos because…

- Appeals to visual learners and is easier to grasp
- Relatable
- Can be paused, rewound
- Ready when you are
- Short and digestible

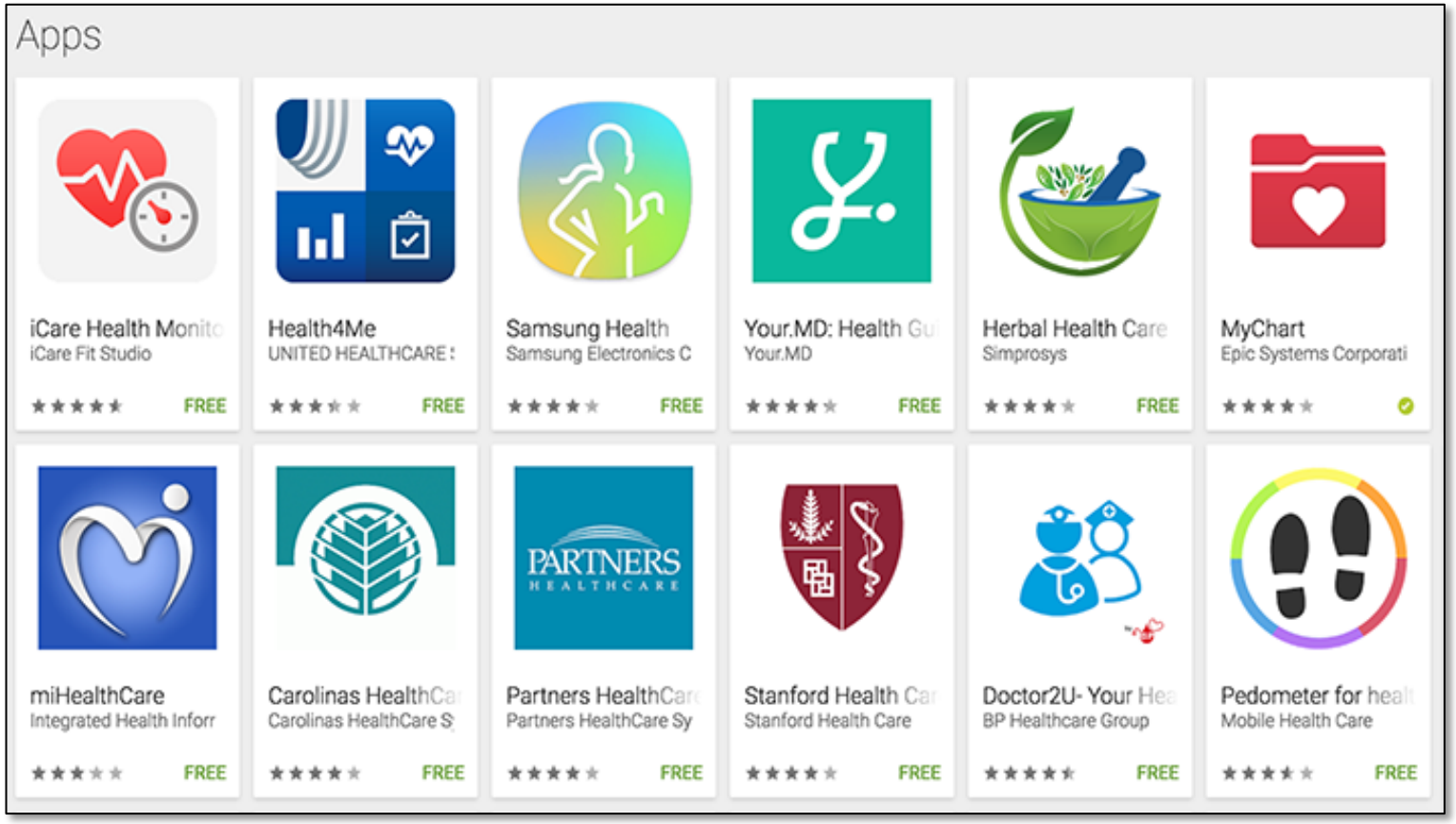
Source : What do Generation Z and millennials expect from technology in education?
Pearson | May 24, 2018 in Higher Education, PreK-12 Education

How do people learn today?



Source : What do Generation Z and millennials expect from technology in education?
Pearson | May 24, 2018 in Higher Education, PreK-12 Education

And people like apps

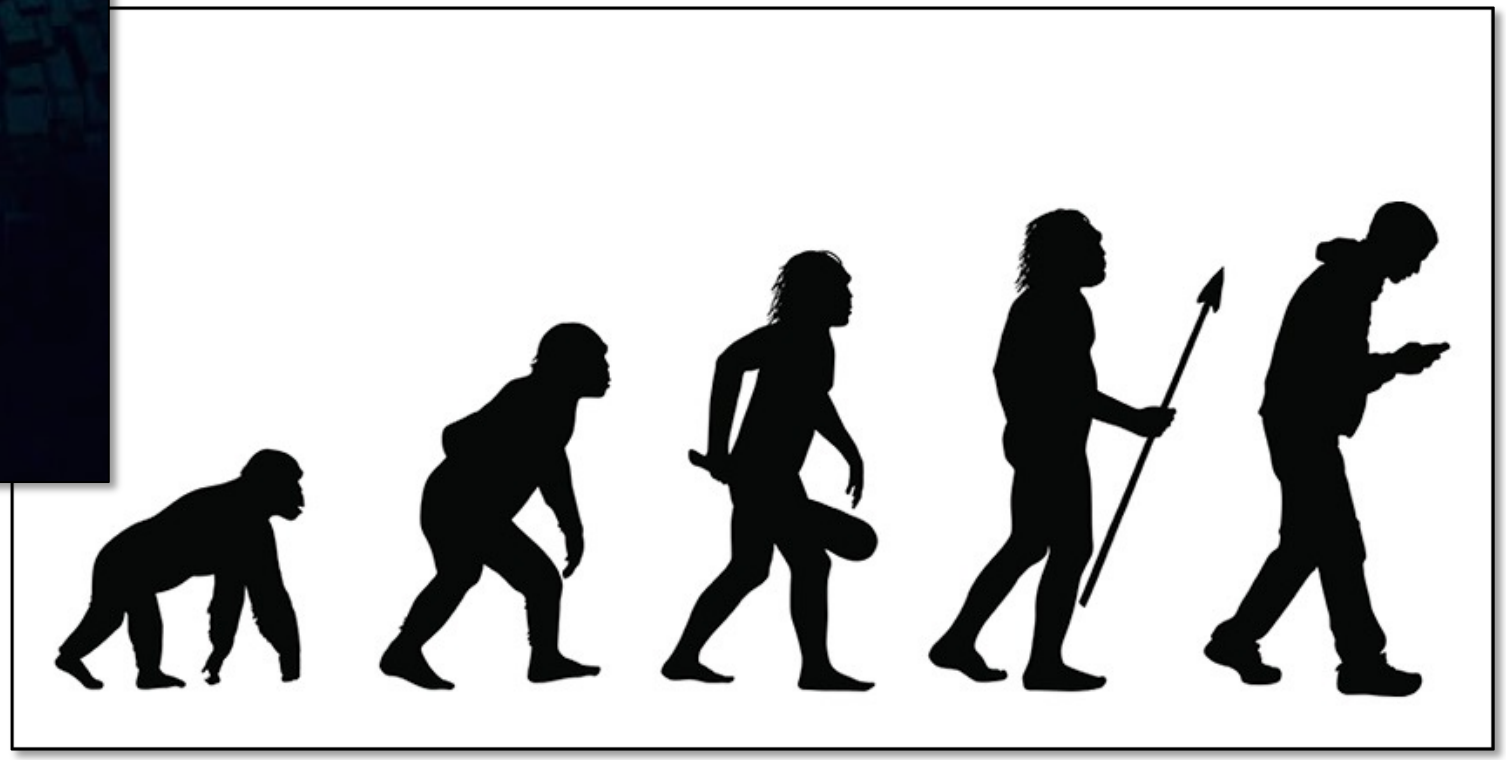


47% of Gen Z like to use interactive learning apps or games to learn

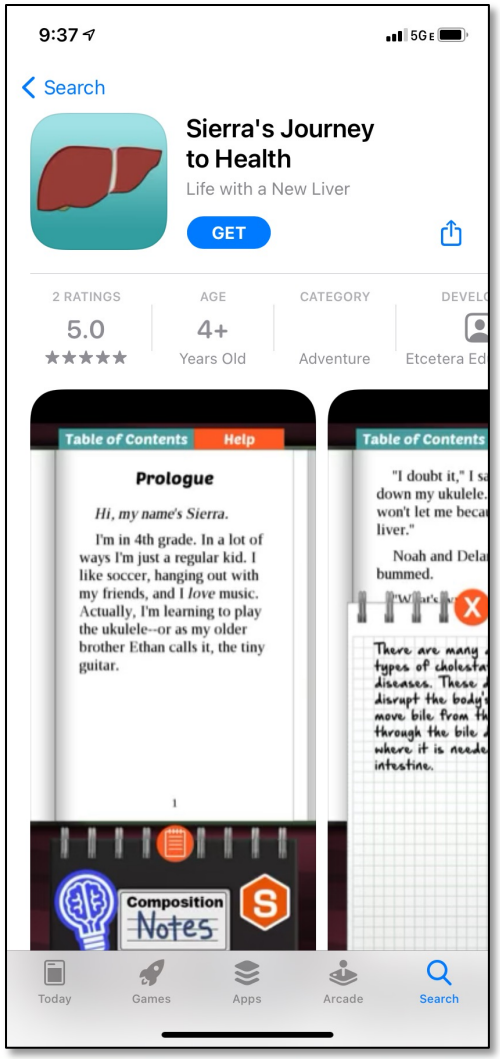
41% of Millennials

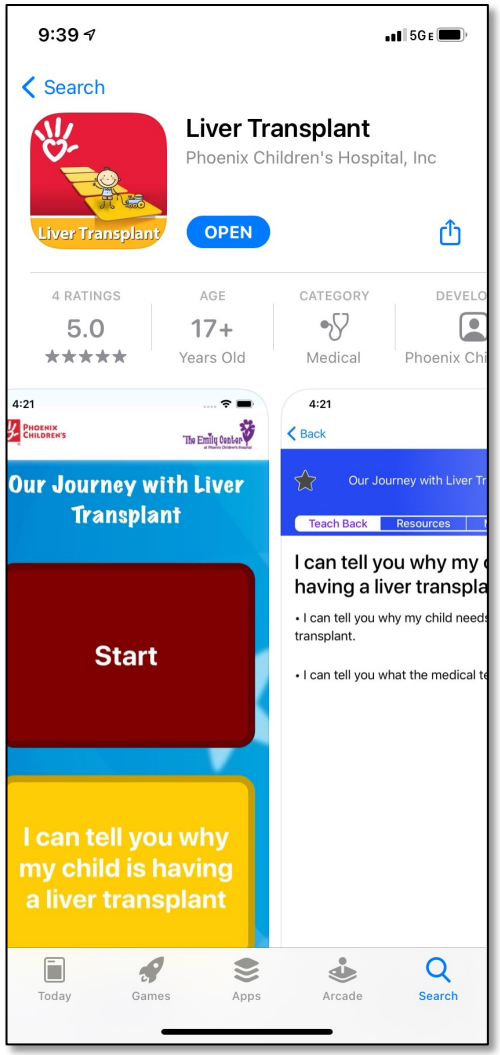
Source : What do Generation Z and millennials expect from technology in education?
Pearson | May 24, 2018 in Higher Education, PreK-12 Education

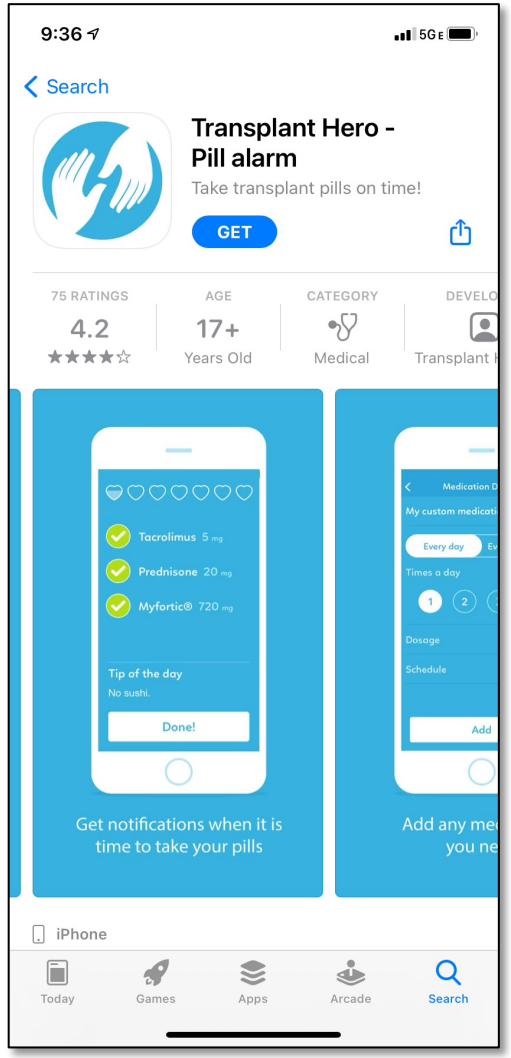
Where can we go?

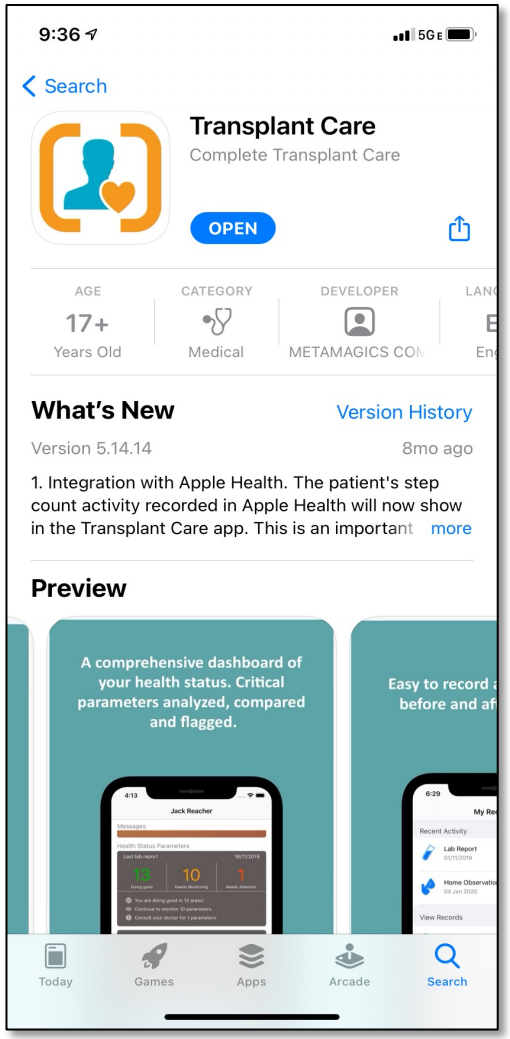


Transplant-specific apps









Can we go further?

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Best practices in patient education

- Use patient-preferred formats
- Assess patient health literacy
- Utilize patient teach back
- Lean on health technology

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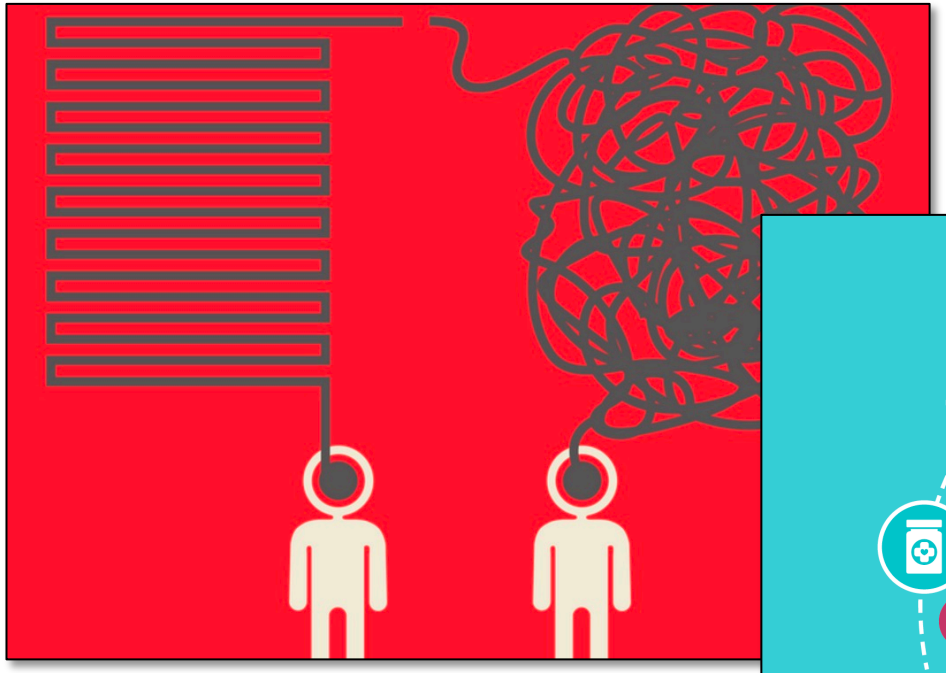
Patient health literacy

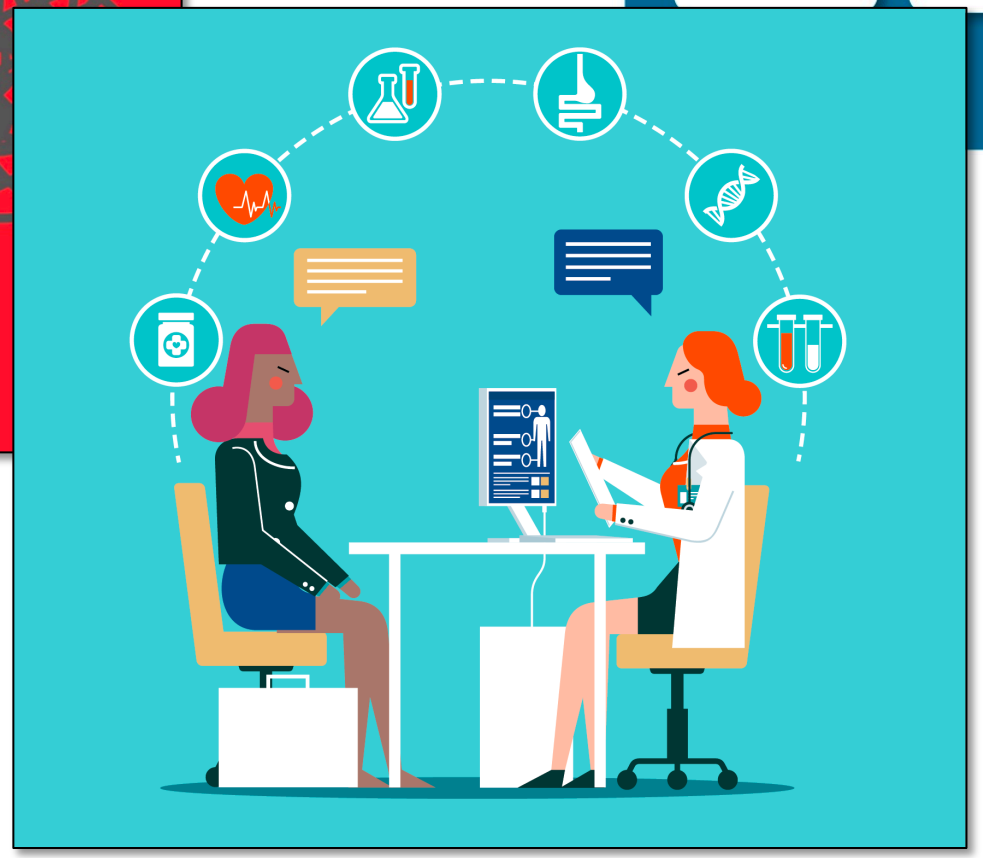
Agency for Healthcare Research and Quality (AHRQ) defines health literacy as:

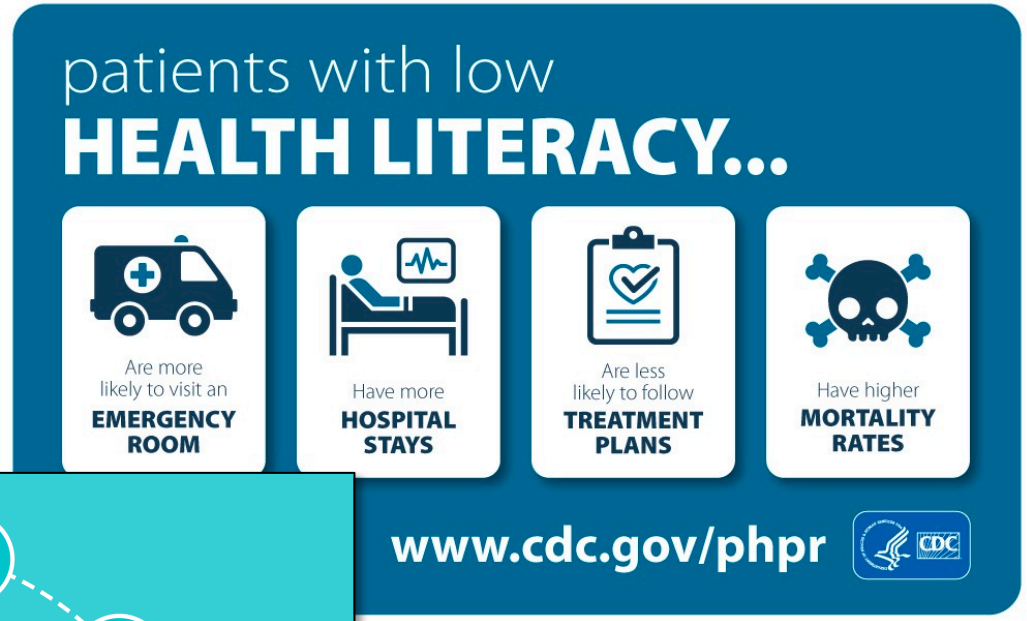
> *"The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."**

*(www.AHRQ.gov/health-literacy)

Patient health literacy







Assessing health literacy

Instruction for Administering *SAHL-E*

SHORT ASSESSMENT OF HEALTH LITERACY-ENGLISH
Interviewer's Instruction

The *Short Assessment of Health Literacy-English*, or *SAHL-E*, contains 18 t
assess an English-speaking adult's ability to read and understand common n
test could help health professionals estimate the adult's health literacy level.
the test could facilitated by using laminated 4"×5" flash cards, with each car
medical term printed in boldface on the top and the two association words—
distracter—at the bottom.

Directions to the Interviewer:

1 Before the test, the interviewer should say to the examinee:
"I'm going to show you cards with 3 words on them. First, I'd like y
word out loud. Next, I'll read the two words underneath and I'd lik
which of the two words is more similar to or has a closer association
If you don't know, please say 'I don't know'. Don't guess."

2. Show the examinee the first card.

3. The interviewer should say to the examinee:
"Now, please, read the top word out loud."

4. The interviewer should have a clipboard with a score sheet to record the examinee's answers. The clipboard should be held such that the examinee cannot see or be distracted by the scoring procedure.

5. The interviewer will then read the key and distracter (the two words at the bottom of the card) and then say:
"Which of the two words is most similar to the top word? If you don't know the answer, please say 'I don't know'."

6. The interviewer may repeat the instructions so that the examinee feels comfortable with the procedure.

7. Continue the test with the rest of the cards.

8. A correct answer for each test item is determined by both correct pronunciation and accurate association. Each correct answer gets one point. Once the test is completed, the interviewer should tally the total points to generate the *SAHL-E* score.

9. A score between 0 and 14 suggests the examinee has low health literacy.

Stem	Key or Distracter		
1. kidney	__urine	__fever	__don't know
2. occupation	__work	__education	__don't know
3. medication	__instrument	__treatm	
4. nutrition	__healthy	__soda	
5. miscarriage	__loss	__marria	
6. infection	__plant	__virus	

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Best practices in patient education

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Teach back

- Evidence-based health literacy intervention that has been shown to promote engagement, safety, adherence and quality
- More than repeating – they are asked to “teach” it
- Studies have shown that 50-80% of medical information is quickly forgotten, and that this is significantly reduced after “teach back” implementation

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Best practices in patient education

- Assess patient health literacy
- Utilize patient teach back
- Use patient-preferred formats
- Lean in to health technology

Objectives

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Innovations in patient education

Historically:

- One source - your healthcare team
- Limited by what could be taught in clinic/hospital, what could be spoken and what could be displayed on handouts

Moving towards **dynamic** content that is **patient-centered** and **patient-responsive**

Innovations in patient education

Engaging content

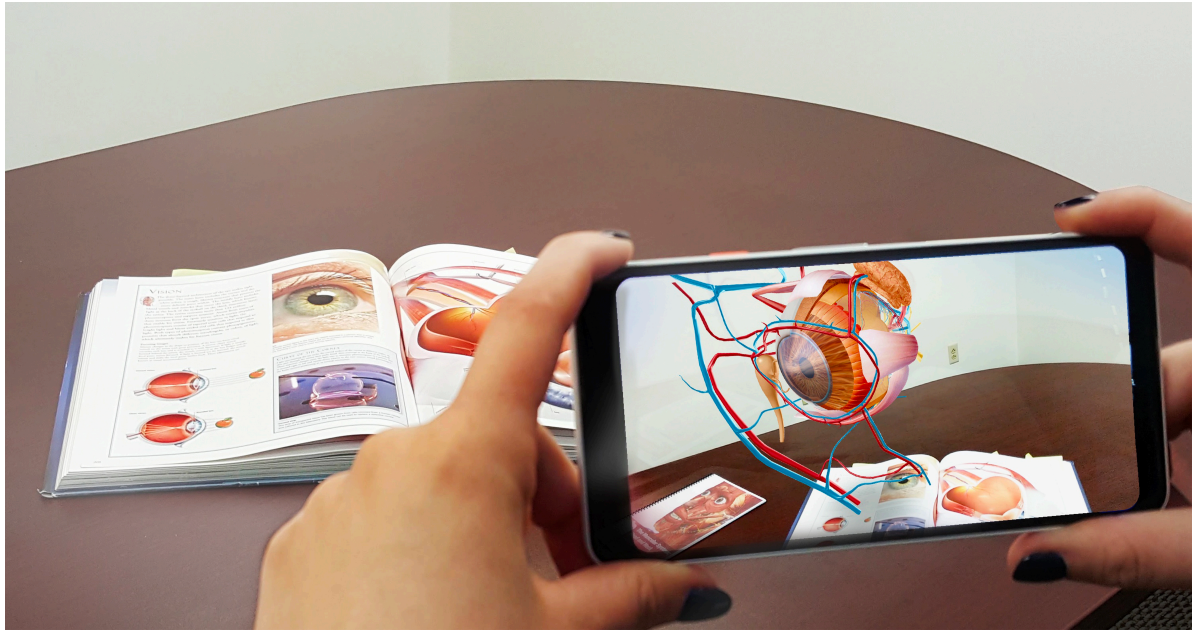
- Augmented reality and 3-D imaging, gamification
- Personalized

Additional touchpoints

- EMR
- Digital home

Engaging content

Multi-color and multi-material bio-model.
Technology: PolyJet



augmented reality

Engaging content

Clinical Report

Journal of INTERNATIONAL MEDICAL RESEARCH

The impact of using three-dimensional printed liver models for patient education

Journal of International Medical Research
2018, Vol. 46(4) 1570–1578

DOI: 10.1177/0300060518755267
journals.sagepub.com/home/imr
SAGE

Tianyou Yang, Tianbao Tan, Jiliang Yang, Jing Pan, Chao Hu, Jiahao Li and Yan Zou

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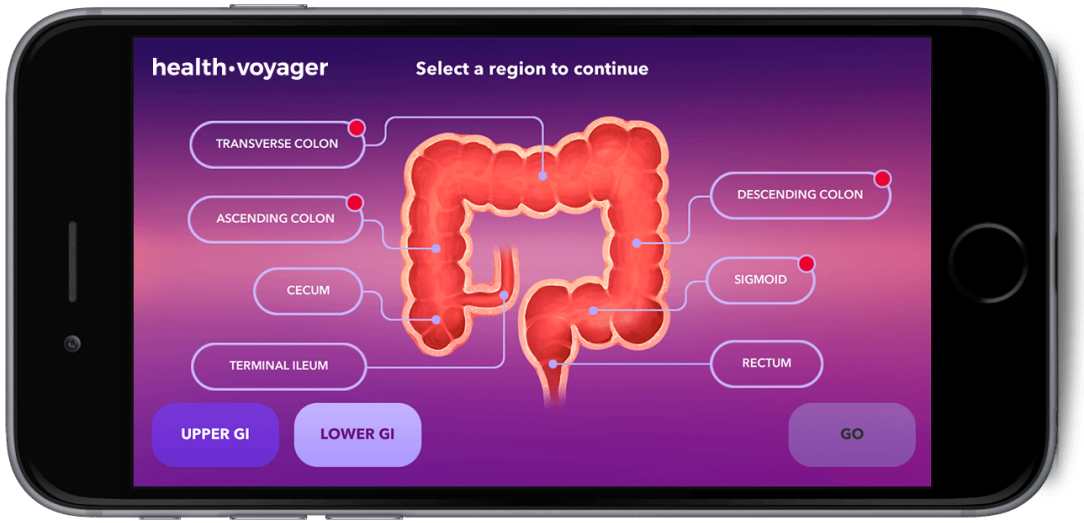
Engaging content



personalized

health•voyager

Gamification

- More than 80% of children report regular use of video games (Holtz et al., *Games for Health Journal*, 2018)
- Many “serious games” incorporate behavioral change theory
- Promote behavior change (e.g., adherence), skill or education
- Most common examples: diabetes, and asthma; static encephalopathy (for exercises)
- RCTs generally show favorable response

Additional touchpoints: EMR integration

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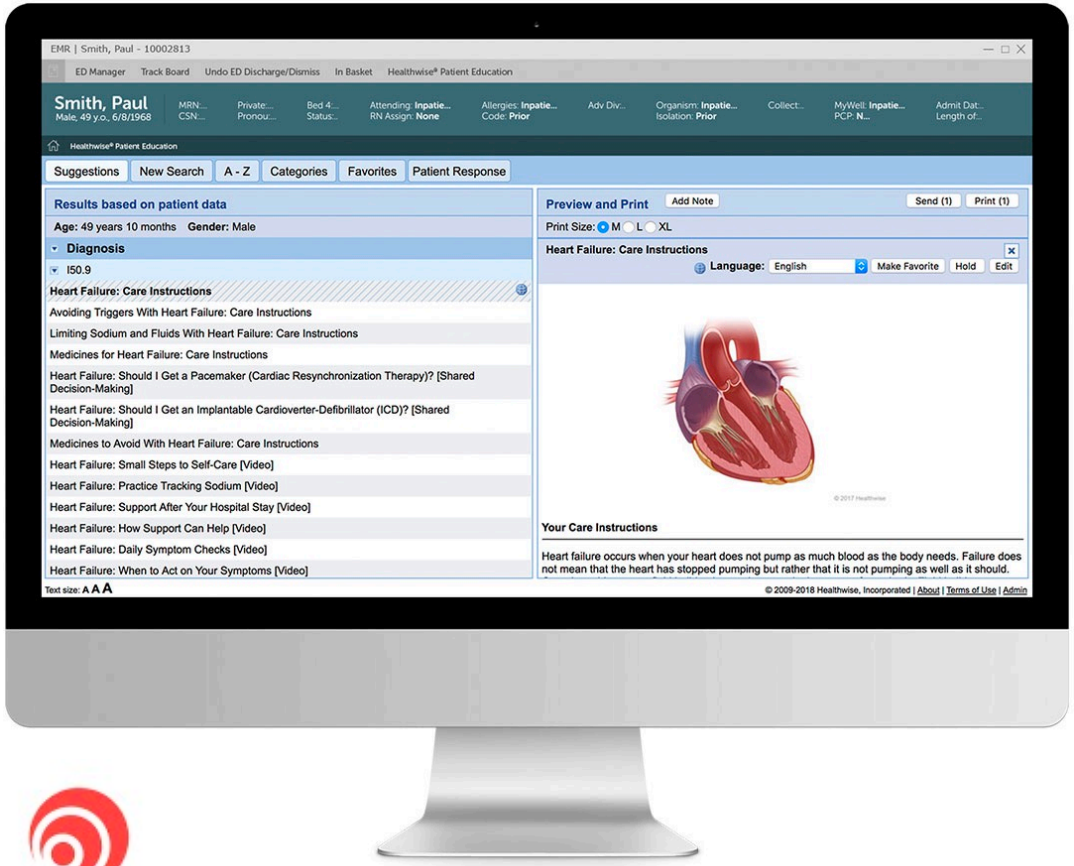
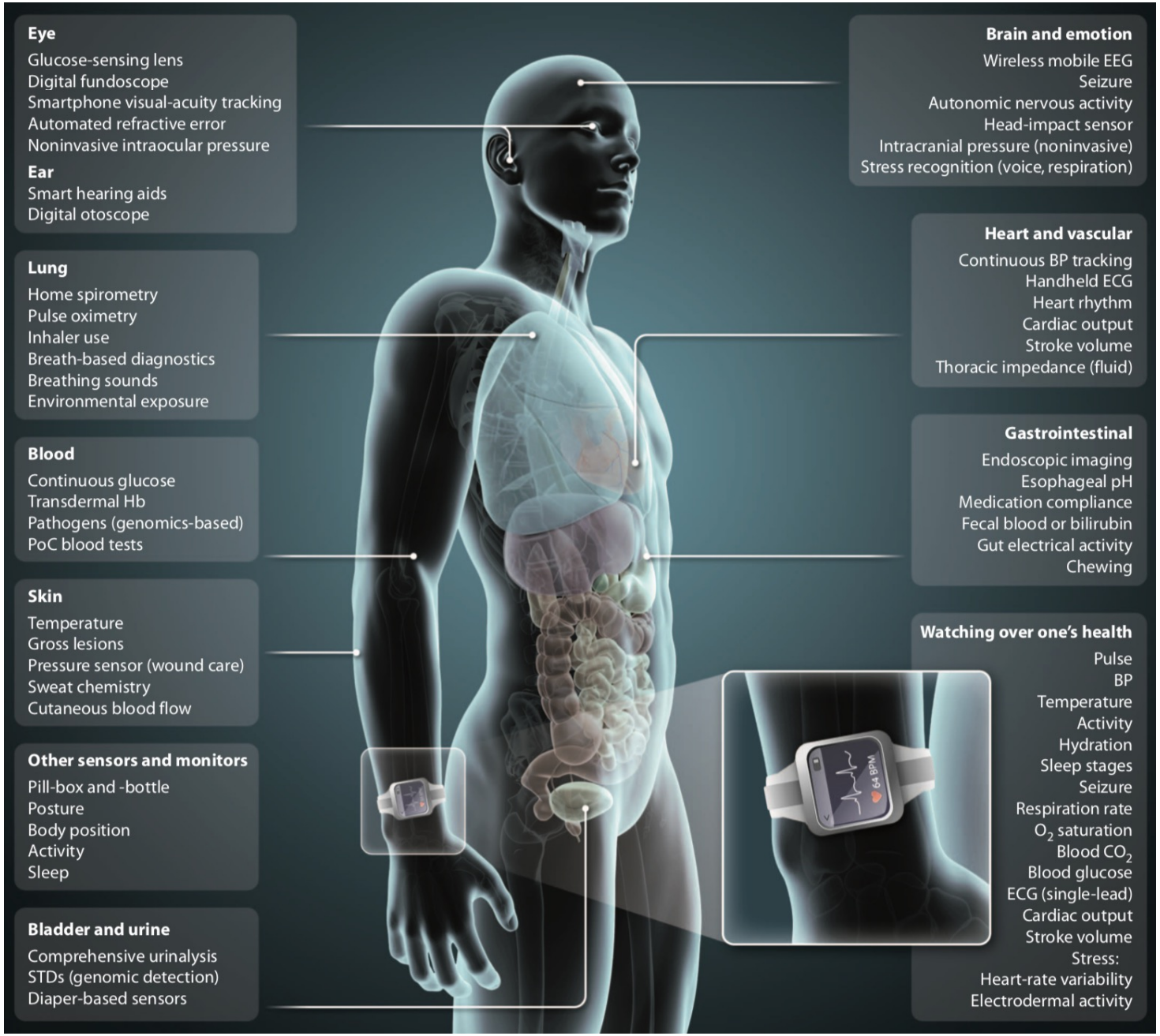
- Customize – merge original content with libraries of existing content
- Searchable by patients
- “Pushable” by clinicians, integrated into workflow
- Track engagement



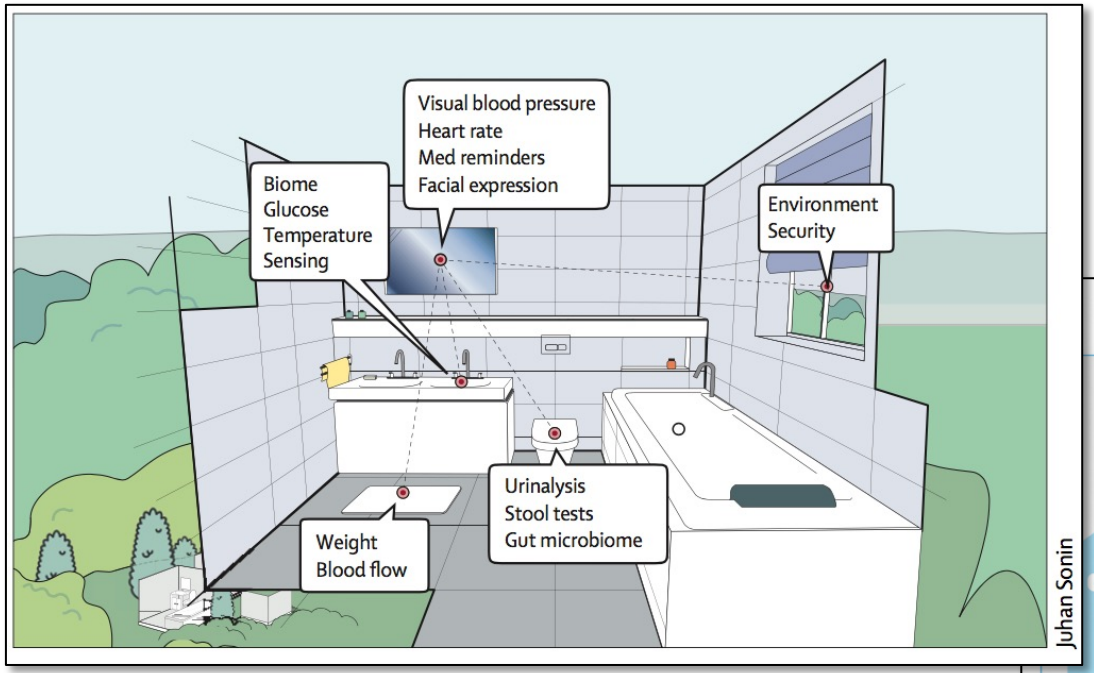
healthwise®
for every health decision®

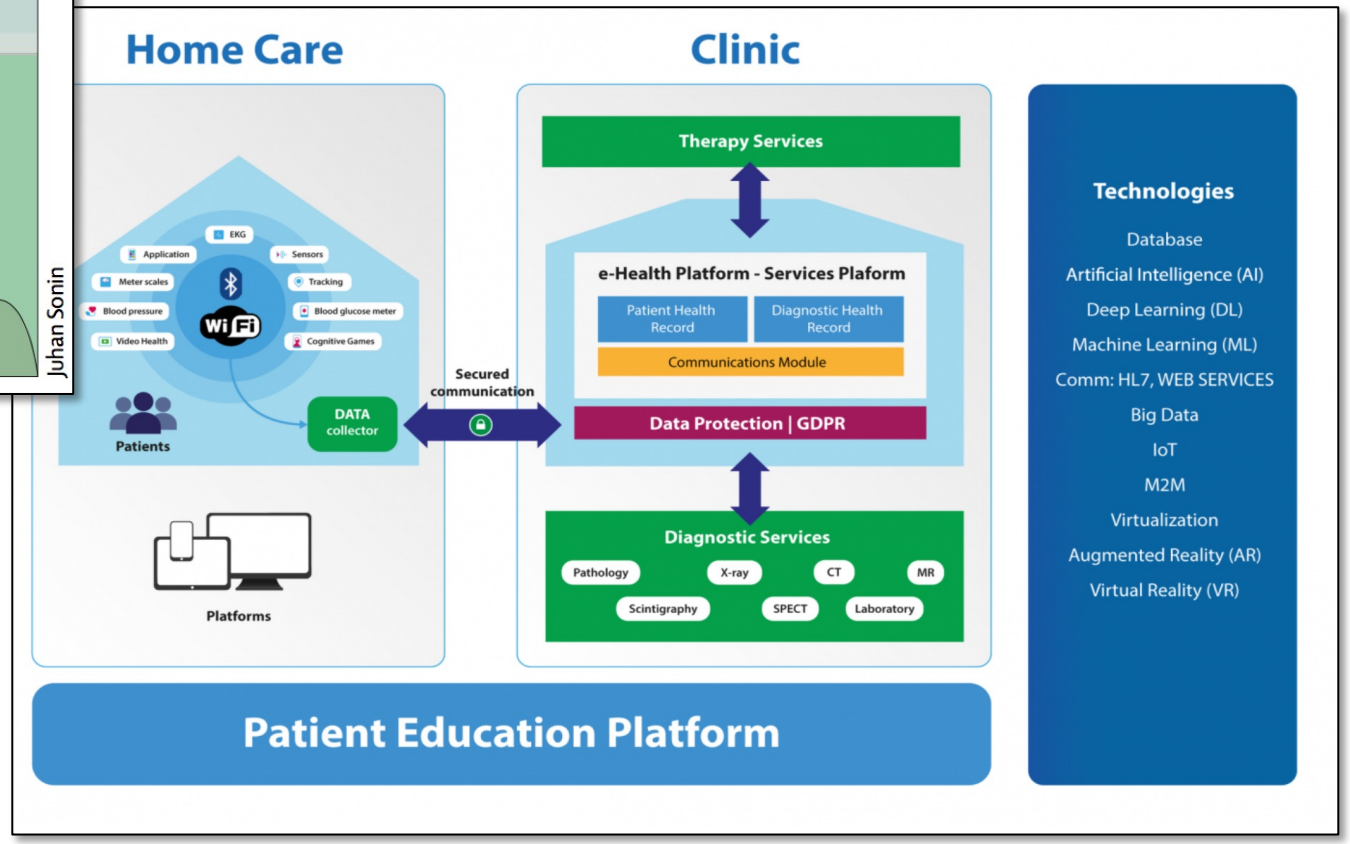
Additional touchpoints: The digital home

Opportunities to use technology to better (i.e., more thoroughly) monitor patient's health



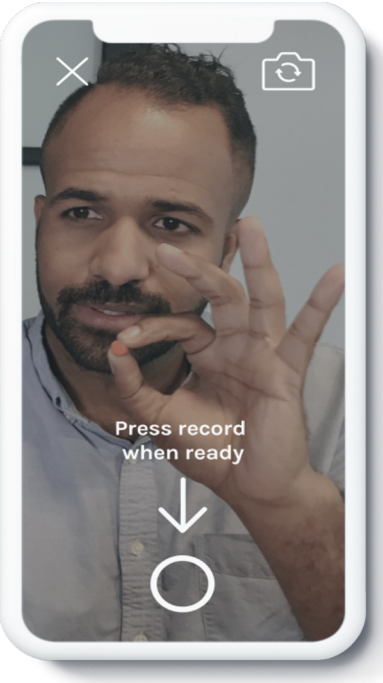
The digital home



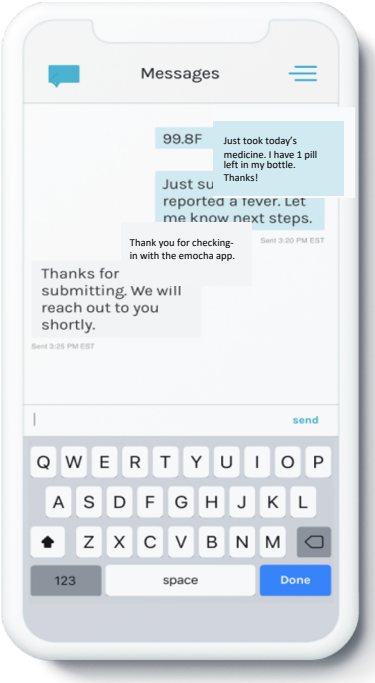


Engagement through health portals: medication adherence

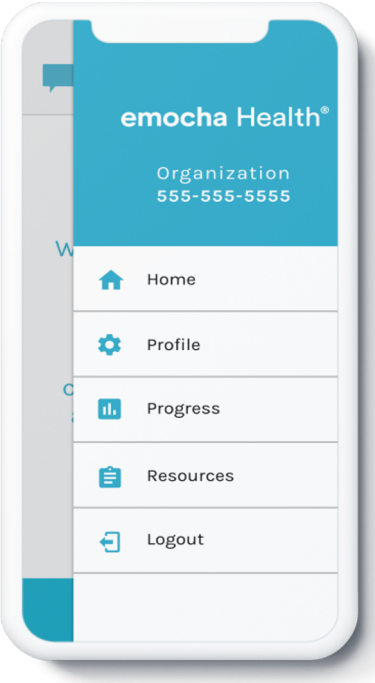
Patients video record taking their medications and then send video to providers



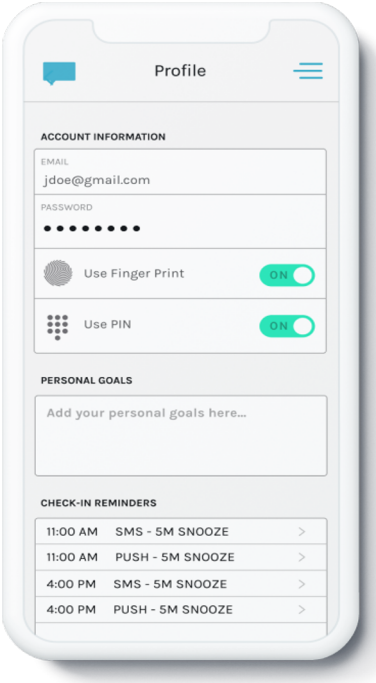
Patient and care team can communicate via secure 2-way messaging



Patient can access their profile, progress, or resources from menu screen

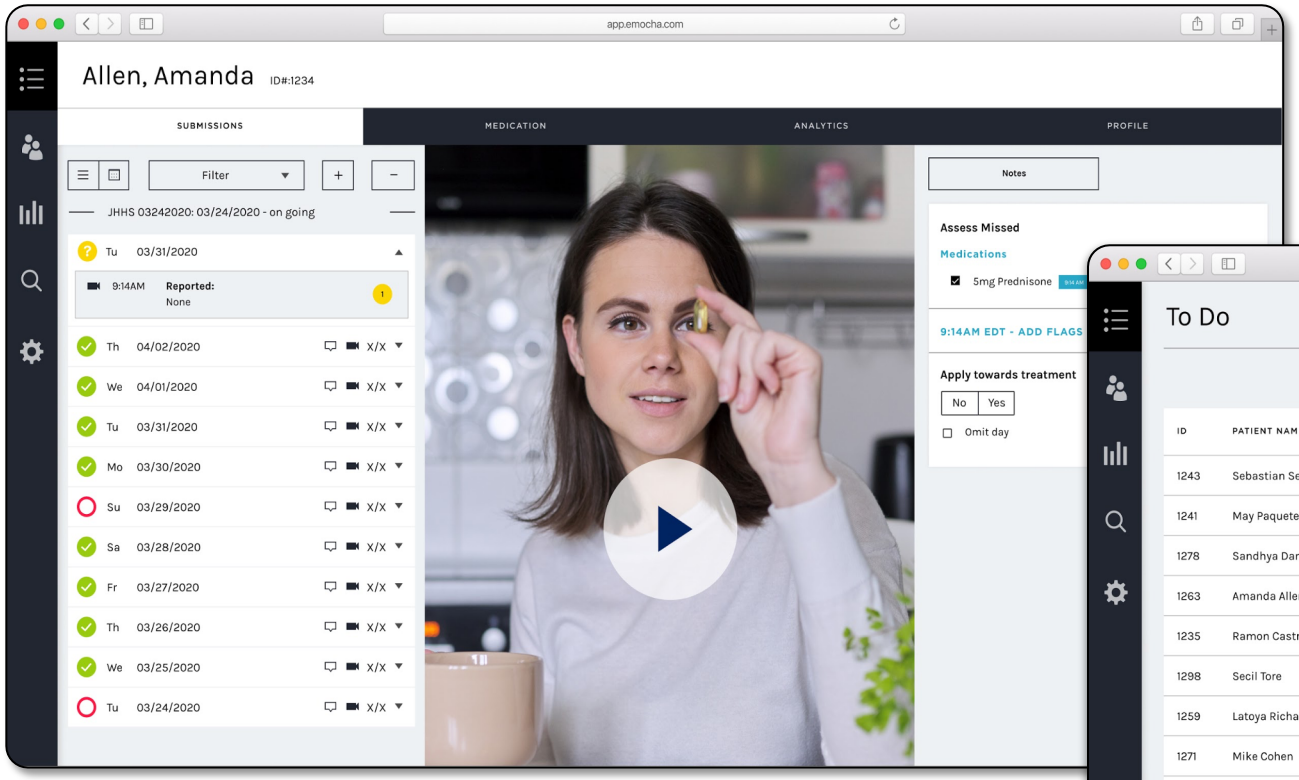


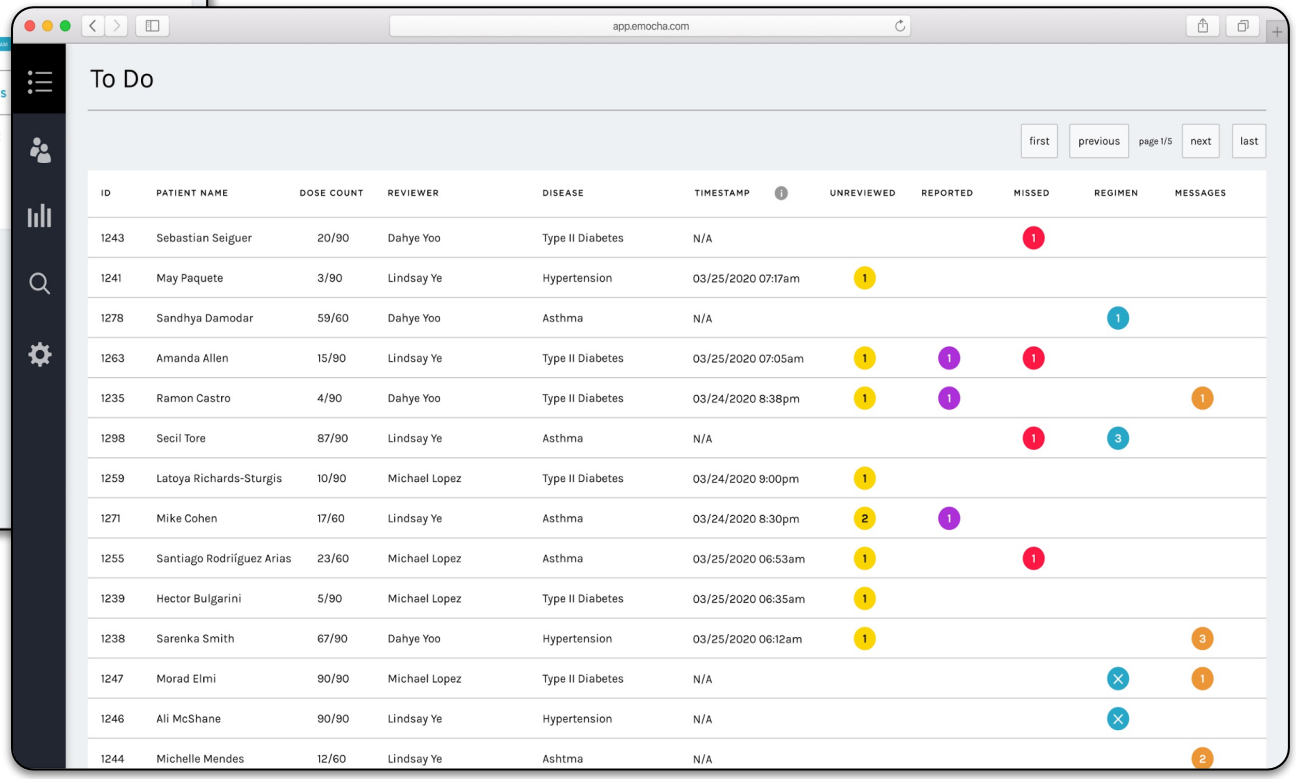
Patient can update their account information, manage their login, and check-in reminders



emocha Health®

Engagement through health portals: medication adherence





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Concluding thoughts

- Providers should familiarize themselves with existing materials so that they can create education plans that address specific patient preference (e.g., pamphlet vs. video vs. other), health literacy.
- Ideal educational tools are ones that can be tailored to the individual including health literacy, education, specific health condition/problem.
- The transplant community should develop state-of-the-art tools in digital technology to better engage and educate our patients.

Resources

Web and printable materials

- UNOS: www.unos.org/resources/education
- UNOS Transplant Living: transplantliving.org/children
- AST Power2Save: power2save.org/community-education
- Nemours KidsHealth: kidshealth.org/en/kids/liver.html
- Starzl Network: starzlnetwork.org
- American Liver Foundation: liverfoundation.org
- CDC (for topics like pets/travel: cdc.gov/healthypets/specific-groups/organ-transplant-patients.html
- International Transplant Nurses Society (for adults, or teenagers): itns.org/education/patient-education

Apps

- University of Michigan Liver Transplant Education (general education)
- Sierra's Journey to Health (school aged learning)
- Liver Transplant from Phoenix Children's Hospital: Interactive education
- Transplant Hero Pill Alarm
- Transplant Care (lab and appointment tracking, etc).

THE Alliance

Advancing Organ Donation & Tranplantation

Questions?

THE Alliance

Advancing Organ Donation & Tranplantation

Thank You!