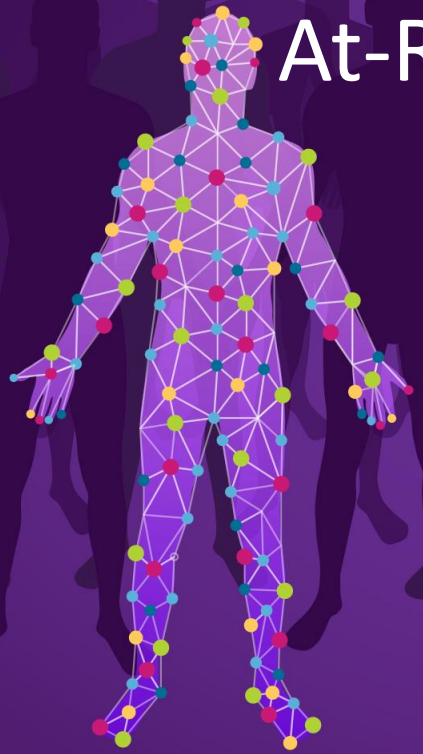
AST | AMERICAN SOCIETY OF TRANSPLANTATION

# Use of Contemporary Technologies to Improve At-Risk Candidate and Recipient Engagement



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CEOT CUTTING EDGE of TRANSPLANTATION

**TRANSPLANT SUMMIT** 2019

***NO SIZE FITS ALL:*** *Uncovering the Potential of Personalized Transplantation*

FEBRUARY 21–23, 2019 • ARIZONA BILTMORE • PHOENIX, AZ

## Disclosure

No financial conflicts to disclose.

# Learning Objectives

1. To define “personalization” in the context of designing health behavior interventions
2. To explain how innovative technologies foster engagement and increase access to transplantation for minority populations
3. To describe benefits of culturally targeted interventions and care

# Who are '**at risk**' populations?

Groups with disproportionately low access to tx or living donor tx, poor tx outcomes, or who assume greater risks

- African Americans, Hispanics, other ethnic minority groups
- Live liver donors
- Candidates considering increased risk donors
- Pediatrics
- Highly sensitized patients
- HIV+ candidates
- Candidates participating in deceased donor intervention research

# What does **personalized** mean?

National Research Council:

- **Personalized Medicine**: older, similar term; “could be misinterpreted to imply that treatments and preventions are being developed uniquely for each individual” (**tailored**)
- **Precision Medicine**: “focus on identifying which approaches will be effective for which patients based on genetic, environmental, and lifestyle factors” (**targeted**)
- Terms still used interchangeably

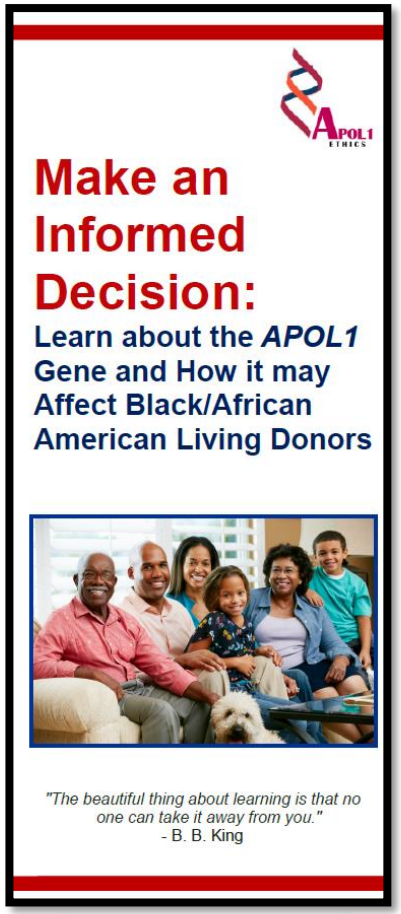
https://ghr.nlm.nih.gov/primer/precisionmedicine/precisionvspersonalized

# So, how do we **personalize care**?

- Genetic testing
- Culturally competent interventions (targeted)
  - focus on reducing disparities for specific cultural groups
- Addressing information needs for specific patients (tailored)

# Personalized Strategies by **Culture**

- *Infórmate* website
- *APOL1* brochure
- *Promotoras de Donación* training module




Original Investigation AJKD Vol 72 | Iss 6 | December 2018 AJKD

## African American Living Donors' Attitudes About *APOL1* Genetic Testing: A Mixed Methods Study

*Elisa J. Gordon, Daniela Amórtegui, Isaac Blancas, Catherine Wicklund, John Friedewald, and Richard R. Sharp*

Gordon EJ, et al. A Focus Group Study on African American Living Donors' Treatment Preferences, Sociocultural Factors, and Health Beliefs about *Apolipoprotein L1* Genetic Testing. Progress in Transplantation 2019;June.

- **Surface structure**: photographs of AAs, preferred terminology, content order
- **Deep structure**: cultural concerns about genetic testing and representations of disparities

(R03 AI126090-01 to EJ Gordon)


**A Culturally Targeted Website for Hispanics/Latinos About Living Kidney Donation and Transplantation: A Randomized Controlled Trial of Increased Knowledge**

Elisa J. Gordon, PhD, MPH,[1] Joe Feinglass, PhD,[2] Paula Carney, PhD,[3] Karina Vera, BA,[4] Maria Olivero, BA,[5] Anne Black, CEO,[5] Kate O'Connor, CEO,[6] Jessica MacLean, BA,[7] Shari Nichols, CCRP,[8] Junichiro Sageshima, MD,[8] Luke Preczewski, BA,[9] and Juan Carlos Caicedo, MD[10]

(*Transplantation* 2016;100: 1149–1160)

JMIR Res Protoc. 2015 Apr-Jun; 4(2): e42. PMCID: PMC4419196
Published online 2015 Apr 20. doi: 10.2196/resprot.3838: 10.2196/resprot.3838 PMID: 25896143

**An Interactive, Bilingual, Culturally Targeted Website About Living Kidney Donation and Transplantation for Hispanics: Development and Formative Evaluation**

Monitoring Editor: Gunther Eysenbach

Reviewed by Milda Saunders

Elisa J Gordon, MPH, PhD,[✉1] Joe Feinglass, PhD,[2] Paula Carney, PhD,[3] Daney Ramirez, MPH,[4] Maria Olivero, BA,[5] Kate O'Connor, BS,[6] Jessica MacLean, BA,[7] James Brucker, MSLIS,[8] and Juan Carlos Caicedo, MD[9]

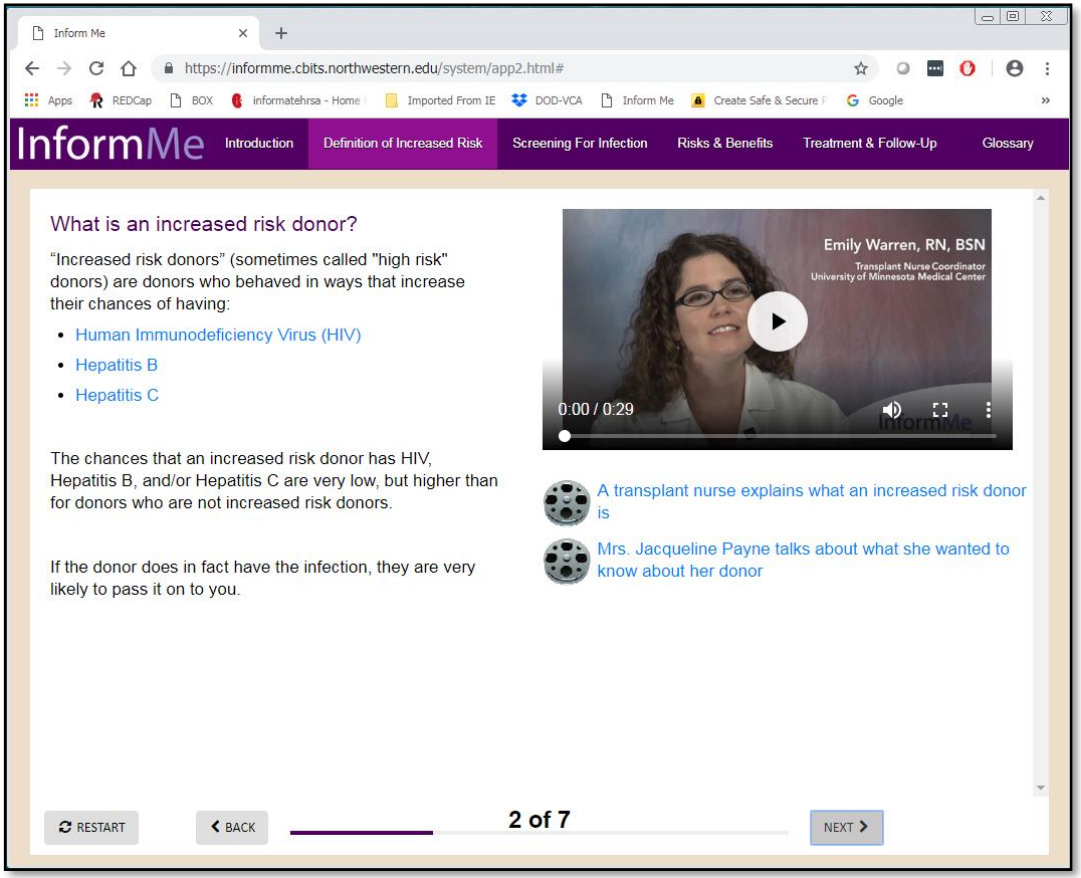
- Surface structure
- Deep structure
- Linguistic congruence

# Personalized Strategies by **Information Needs**

- **Inform Me** web-based app

https://informme.cbits.northwestern.edu/system/

- Evaluation of Donor Informed Consent Tool (EDICT)




**Effect of a Mobile Web App on Kidney Transplant Candidates' Knowledge About Increased Risk Donor Kidneys: A Randomized Controlled Trial**

Elisa J. Gordon, PhD, MPH,[1,2,3] Min-Woong Sohn, PhD,[4] Chih-Hung Chang, PhD,[5,6] Gwen McNatt, RN, PhD,[7] Karina Vera, BA,[1] Nicole Beauvais, PA-C,[7] Emily Warren, RN, BSN,[8] Roslyn B. Mannon, MD,[9] and Michael G. Ison, MD[2]

(*Transplantation* 2017;101: 1167–1176)

- Computer adaptive learning
- Layering information

# Can you still personalize interventions while standardizing them?

# Standardization and Personalization

- Providing all tx candidates the same minimum essential information that all tx candidates should receive
- Important for providing a consistent message to candidates across tx providers and tx centers, given the multidisciplinary process of informed consent
- Variation in the informed consent process across tx providers and tx centers may introduce inadvertent bias in the disclosure of risks and limit candidate/donor comprehension

# Benefits of Personalized Care

- In general, reduce health disparities
- In transplantation, the few interventions done have effectively increased rates of LDKT, increased knowledge for decision-making
  - e.g., home-based education, social worker communication, or public media campaigns

# Do culturally targeted interventions work?

- Interventions targeting a particular cultural group, and have greater cultural congruence, are more likely to be effective

- But, systematic reviews of culturally competent interventions report mixed or inconclusive results that preclude drawing firm conclusions

Alizadeh S, Chavan M. Cultural competence dimensions and outcomes: a systematic review of the literature. Health and Social Care in the Community. 2016;24(6):e117–e130.
Butler M, McCreedy E, Schwer N, et al. Improving Cultural Competence to Reduce Health Disparities. In: Agency for Healthcare Research and Quality (US); Mar. Report No.: 16-EHC006-EF ACER, ed. Rockville (MD), 2016.
Hasnain R, et al. Do cultural competency interventions work? A systematic review on improving rehabilitation outcomes for ethnically and linguistically diverse individuals with disabilities. FOCUS Technical Brief, (31). Austin, TX: SEDL, National Center for the Dissemination of Disability Research, 2011.

# Challenges with Culturally Targeted Care

- Studies use different measures of “cultural competency”
- Studies focus on educating providers about culture, but not on changing provider behavior or organizational microsystems
- Studies don’t use culturally targeted components
- Few studies evaluate the fidelity of intervention implementation

# Lack of Implementation Evaluation

- Disparities in access to KT and LDKT still remain!
- Despite effectiveness of various interventions, few are implemented into routine practice.
- **17 years for uptake!** (Morris et al. J R Soc Med 2011;104:510-520)
- Few **LDKT** interventions evaluate the implementation of their intervention.

# What is Implementation Science Research?

"Implementation research is the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services. It includes the study of influences on healthcare professional and organisational behaviour."

Eccles MP, Mittman BS. Welcome to Implementation Science. Implementation Science 2006; PMC1436009.

# Why should transplant programs care about reducing disparities?

Healthcare organizations and providers have a responsibility to reduce racial/ethnic disparities in health **to improve equity** as part of quality improvement initiatives.


Chin MH, et al. A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. J Gen Int Med 2012;27:992.

# How should transplant programs proceed?

**Robert Wood Johnson's** Finding Answers: Disparities Research for Change program identified best practices for implementing interventions into health care settings to reduce health disparities:

"1) Recognize disparities and commit to reducing them
2) Implement a basic quality improvement structure and process
3) Make equity an integral component of quality improvement efforts
4) Design the intervention(s)
5) Implement, evaluate, and adjust the intervention(s)
6) Sustain the intervention(s)."

Chin MH, et al. A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. J Gen Int Med 2012;27:992.

# Conclusions

- Many culturally and linguistically congruent and targeted interventions exist!
- We just need to implement them, and do so in the way that they were tested, in order to increase access to KT and LDKT
- More research on implementation science of effective culturally targeted, personalized interventions is needed to reduce health disparities

# Thank you

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# Multiple Choice Question

What is **true** about most interventions designed to reduce racial/ethnic disparities? They…

a) Exclude culturally targeted components

b) Evaluate the fidelity of their intervention implementation

c) Target changing health provider behavior or organizational microsystems

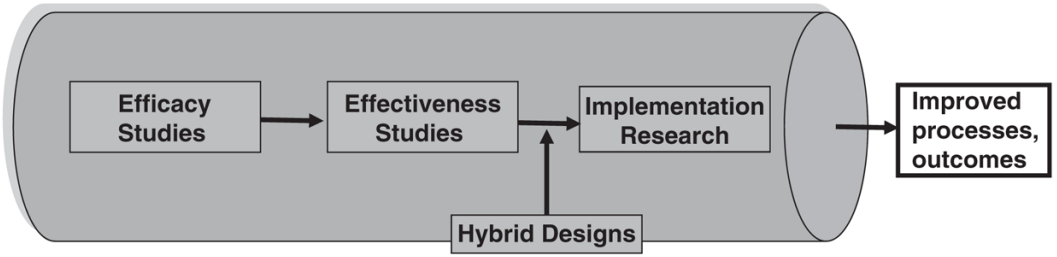
d) All of the above

# Implementation Science is Needed!

- Almost all interventions did not use implementation science or a hybrid study design to evaluate the effectiveness of the intervention implementation process.

- Implementation science can identify factors that influence the uptake of interventions so that other organizations can achieve comparable effective results.






Curran GM et al. Effectiveness-Implementation Hybrid Designs. Med Care. 2012;50(3): 217–226.

# Need for Cultural Competence

The American Society of Transplant-sponsored Living Donor Community of Practice Best Practices Consensus Conference recommended culturally competent educational interventions to reduce ethnic/racial disparities in LDKT.

Rodrigue JR, Kazley AS, Mandelbrot DA, Hays R, LaPointe Rudow D, Baliga P. Living donor kidney transplantation: overcoming disparities in live kidney donation in the US—recommendations from a consensus conference. Clin J Am Soc Nephrol 2015;10(9):1687–1695.

# How well are transplant programs doing in delivering CLAS?

Could be better!

Our survey of 280 U.S. kidney transplant administrators found that most transplant centers:

- Relied on interpreters (82%) rather than bilingual staff
- Provided no routine transplant education in Spanish (61%)


Gordon E, et al. Transplant Center Provision of Education and Culturally and Linguistically Competent Care: A National Study. American Journal of Transplantation 2010;10(12):2701-2707.

# What is “culturally competency”?

“A set of values, principles, behaviors, attitudes, policies, and structures that enable organizations and individuals to work effectively in cross-cultural situations.”

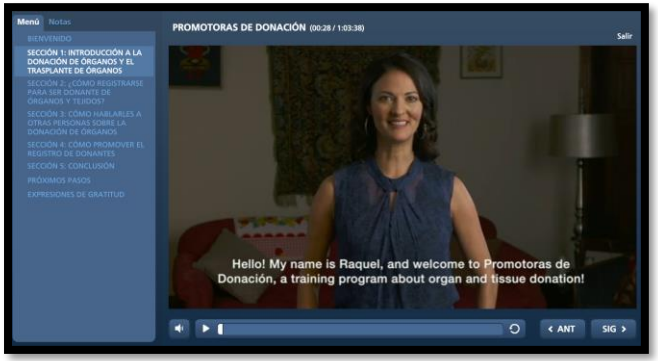
Debate over “cultural competency” discourse:

– Cultural sensitivity
– Cultural **congruence**
– Cultural **targeting**


U.S. Department of Health and Human Services, Office of Minority Health. National Standards for Culturally and Linguistically Appropriate Services in Health Care Final Report. Washington, D.C., 2001.; Leininger M. Culture Care Diversity and Universality: A Theory of Nursing. New York: National League for Nursing; 1991.; Goode T, Jones W. National Center for Cultural Competence, Georgetown University Center for Child & Human Development. http://www11.georgetown.edu/research/gucchd/nccc/documents/Definition%20of%20Linguistic%20Competence.pdf [Accessed 2-18-14]. 2009.; Schim SM, Doorenbos AZ. A Three-dimensional Model of Cultural Congruence: Framework for Intervention. J Soc Work End Life Palliat Care 2011;6(3-4):256–270.; Kreuter M, et al. Achieving cultural appropriateness in health promotion programs: A targeted and tailored approach. Health Education & Behavior 2003;30:133-146.; Hunt LM, de Voogd KB. Clinical myths of the cultural "other": implications for Latino patient care. Acad Med 2005;80(10):918-924.; Helman C. Culture, Health and Illness, Fifth Edition. London, UK: Hodder Arnold; 2007.

# Dimensions of Culturally Competent Care

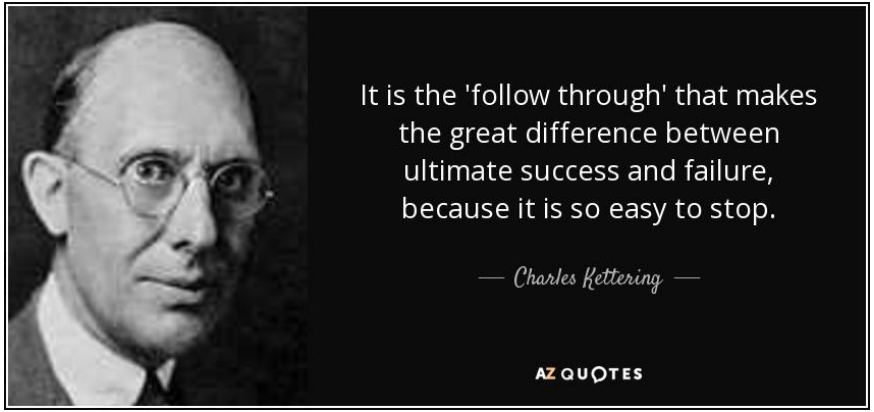
- Address cultural values, beliefs, practices
- Delivery strategies (radio, churches, barber)
- Congruence in personnel
- Linguistic
- Training of providers


*Promotoras de Donación*
HRSA R39OT29878, PI: Gardiner

# Fidelity

**“The extent to which the intervention was delivered as planned. It represents the quality and integrity of the intervention as conceived by the developers.”**




Allen JD, et al. Fidelity and its Relationship to Implementation Effectiveness, Adaptation, and Dissemination. In Dissemination and Implementation Research in Health. Brownson RC, Colditz GA, Proctor EK (Eds.).New York: Oxford Univ Press, 2012.

# Why is Fidelity important?

- Can we attribute effectiveness to the intervention or to other external factors?
- Can we attribute failure of the intervention to the intervention itself or to not rolling it out the right way?
- Does the intervention work in the real world?

Allen JD, et al. Fidelity and its Relationship to Implementation Effectiveness, Adaptation, and Dissemination. In Dissemination and Implementation Research in Health. Brownson RC, Colditz GA, Proctor EK (Eds.).New York: Oxford Univ Press, 2012.

# What is Culture?

The **pattern** of knowledge, beliefs, morals, customs **shared** among a group based on **common identity** through nationality, heritage, language, gender, religion (Tylor 1871)

# Culturally and Linguistically Appropriate Services (CLAS)

"Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation."


*Federal Register 65, no. 247 (22 December 2000): 80865;* U.S. Department of Health and Human Services, Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health Care Final Report. Available at [www.omhrc.gov/clas/].* Washington, D.C. 2001. ; Youdelman MK. The Medical Tongue: U.S. Laws And Policies On Language Access. Health Aff 2008;27:424-433.