Integrating Social Determinants of Health into the EHR: Ethical and Social Justice Issues

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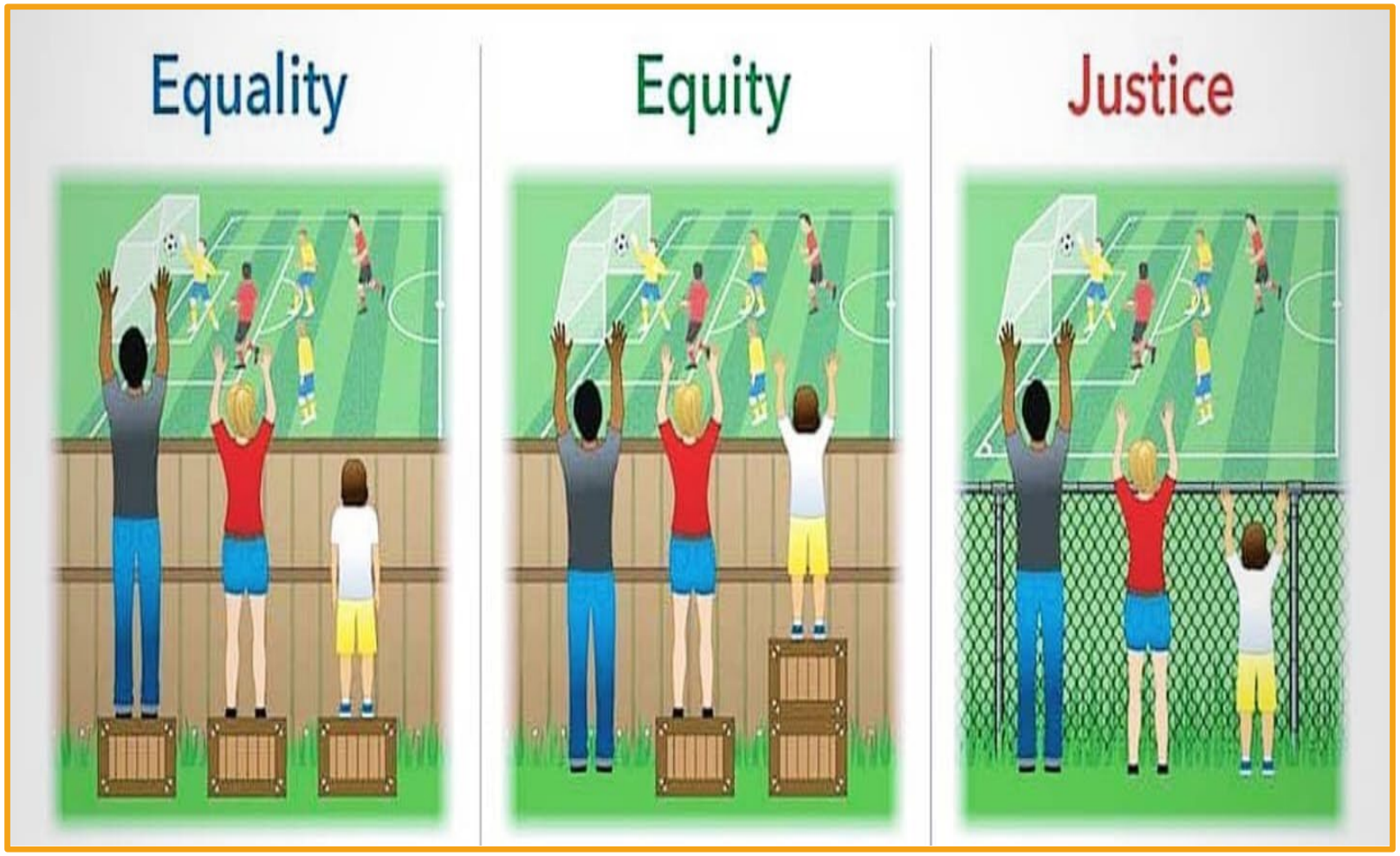
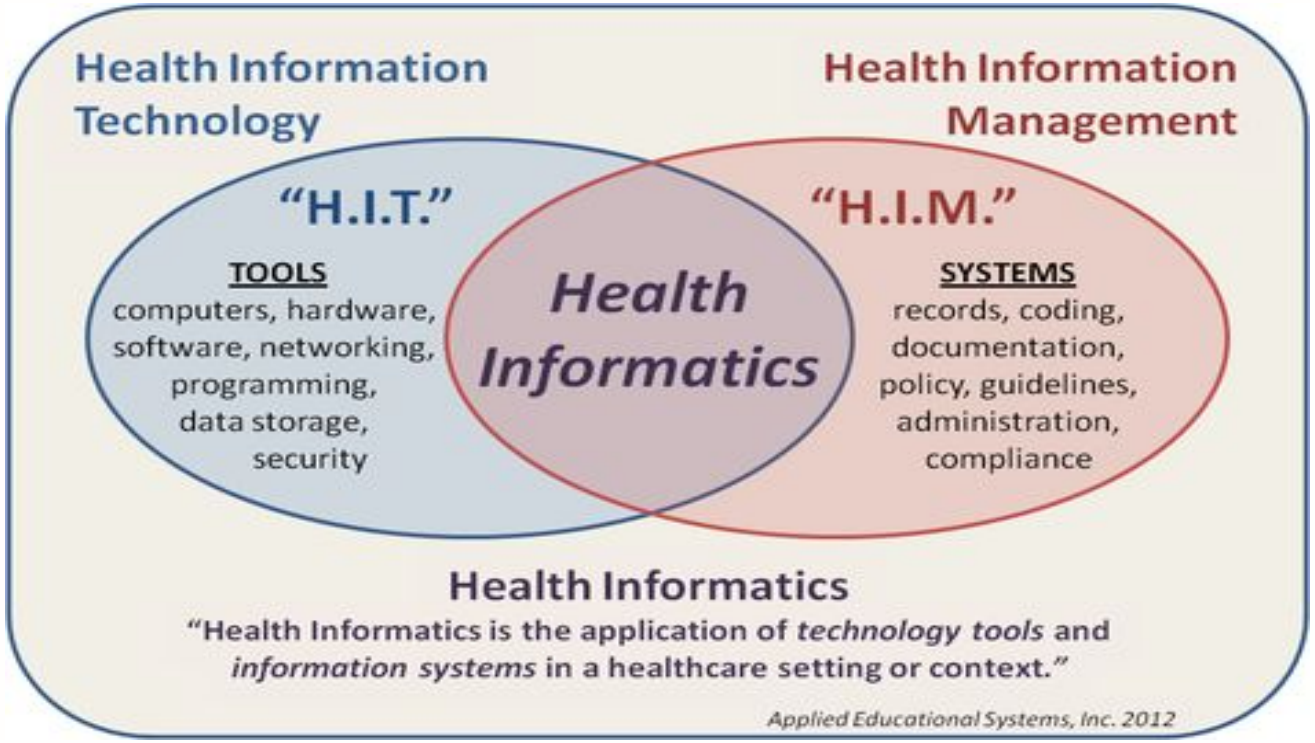
Vision for Cancer Health Equity



Promote equity through effective approaches for early detection, prevention, and treatment



Electronic Health Records

- Improve Health Care Quality
- Enhance Patient-Provider Communication
- Increase Patient Engagement
- Facilitate Research in Minority Health and Cancer Health Disparities

Ethical and Social Justice Issues in Electronic Health Records

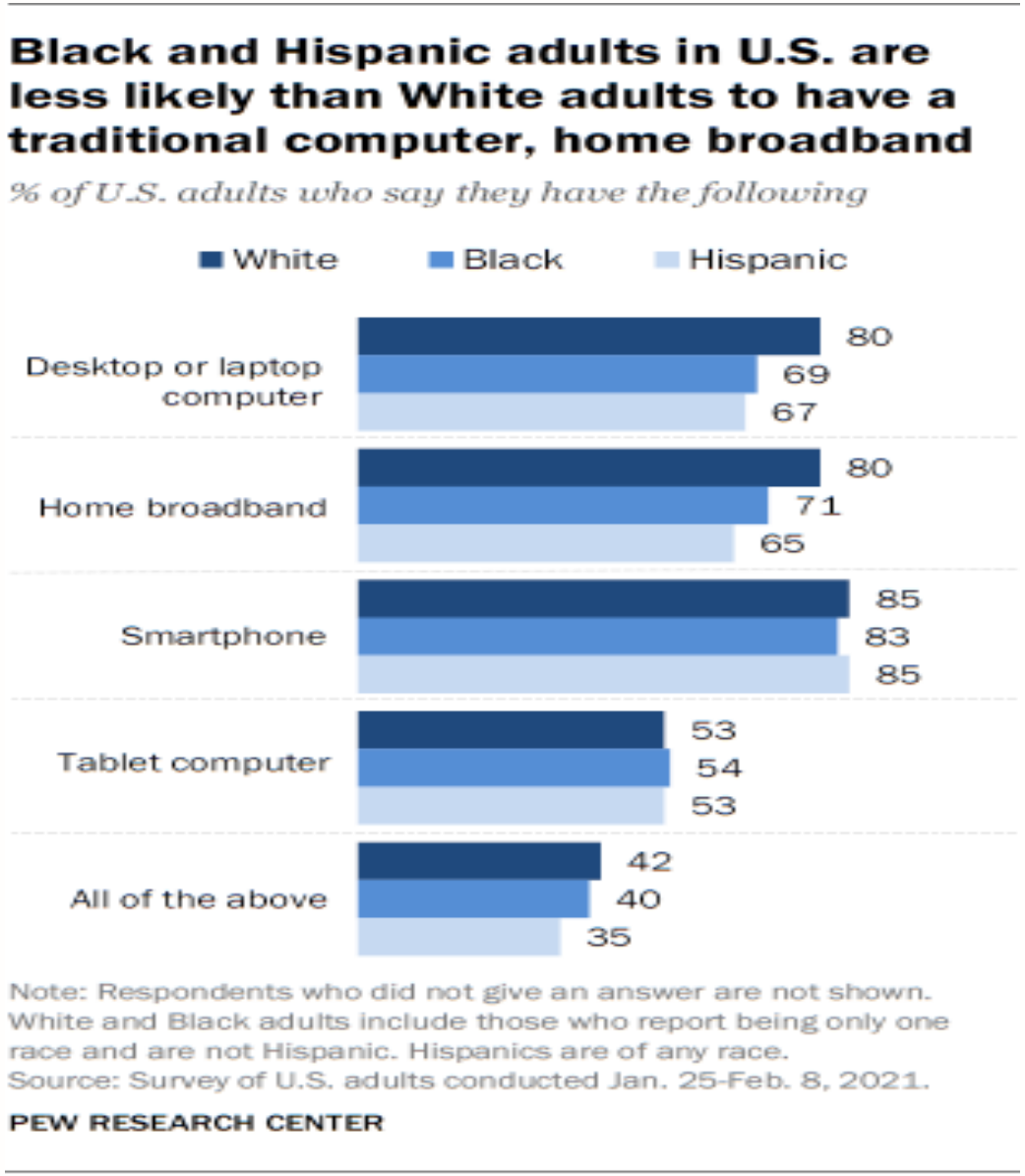
- Privacy and Confidentiality
- Beneficence
- Non-maleficence
- Justice

JAMA Network Open

Original Investigation | Health Policy

Examination of Stigmatizing Language in the Electronic Health Record

Gracie Himmelstein, MD; David Bates, MD, MS; Li Zhou, MD, PhD



"Create social, physical, and economic environments that promote attaining the full potential for health and well-being for all." *Healthy People 2030*

Transdisciplinary Collaborative Center in Precision Medicine and Minority Men's Health

- Multi-regional consortium
- Translational research on biological, social, psychological, and clinical factors
- Dissemination and implementation
- Data integration

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Low Country AHEC
National Black Leadership Initiative on Cancer
Hope Institute, LLC
Southeastern Health Equity Council

Scientists, scholars and champions of health equity for all people.

Keck School of Medicine of USC
Department of Population and Public Health Sciences

Data Integration Core

Develop Natural Language Processing (NLP) tools to identify and extract data on social determinants from clinical notes in the electronic health record to leverage the clinical information that is stored in clinical narratives

Population and Behavioral Sciences

- What social determinants are most important to identify and extract
- How are these domains likely to be represented in clinical narratives
- Ethical, legal, and social issues

Machine Learning/Informatics

- Expertise to develop algorithms for NLP and deep learning
- Evaluation of how the tools perform
- GIS expertise to obtain community level data on social determinants

Social Isolation

Objective measure

- Lack of social contacts and limited interaction with others on a regular basis

Loneliness

Subjective measure

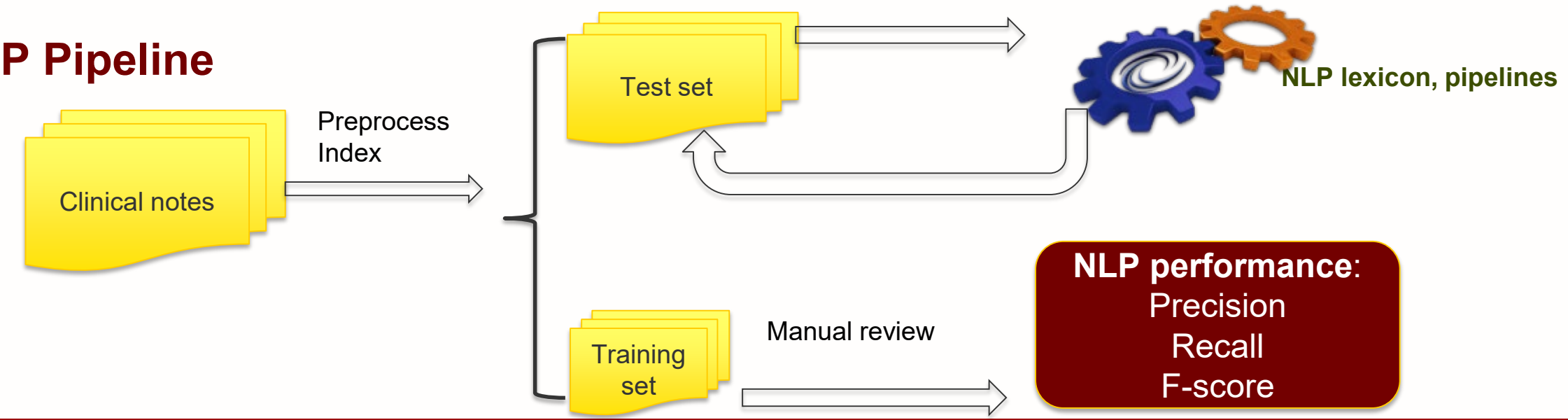
- Perceptions about the quality of social connections (e.g., being alone or separated)

Machine Learning/Informatics: Data Source and NLP Process

Data Source

- MUSC Research Data Warehouse (RDW): a copy of MUSC Epic data warehouse for research
- Cohort sample: 4,195 MUSC prostate cancer patients with age >= 18 years
  - Training set: 3,138 subjects (197,346 notes)
  - Test set: 1,057 subjects (72,040 notes)
- Time period: July 1, 2014 until May 31, 2017

NLP Pipeline



Social Isolation Lexicon

- Developed by transdisciplinary MUSC TCC team
- Conceptual models of population health and behavioral science
- Concordance with validated instruments

Zhu *et al. BMC Medical Informatics and Decision Making* (2019) 19:43
https://doi.org/10.1186/s12911-019-0795-y

BMC Medical Informatics and Decision Making

RESEARCH ARTICLE Open Access

Automatically identifying social isolation from clinical narratives for patients with prostate Cancer

Vivienne J Zhu[1*], Leslie A Lenert[1], Brian E Bunnell[1], Jihad S Obeid[1], Melanie Jefferson[2] and Chanita Hughes Halbert[2]

Zhu et al., 2019

Natural Language Processing for Social Isolation

Terms of social isolation	Frequency		Terms of social isolation	Frequency		I2E Pre-negation	
lack of social support	52	19.5%	Limited social support	3	1.1%	but *	3
lonely	41	15.4%	feel isolated	3	1.1%	all family*	2
no friends	35	13.2%	no family support	3	1.1%	her husband	1
loneliness	29	10.9%	isolation and loneliness	2	0.8%	Discussed*	1
Social withdraw	26	9.8%	Socially withdrawn	2	0.8%	However*	1
socially isolated	22	8.3%	socially isolating	2	0.8%	is still*	1
social isolation	9	3.4%	Social isolation	2	0.8%	still has*	1
feels isolated	8	3.0%	Limited social support	2	0.8%	But*	1
Lonely	6	2.3%	limited social connection	1	0.4%		
lack of social supports	6	2.3%	Limited social network	1	0.4%		
no social support	5	1.9%	lack in social support	1	0.4%		
Loneliness	4	1.5%	loss of social network	1	0.4%		

Clinical Negations v..	social isolation	Post-Negation no	#Docs	Doc	#Hits	Hit
	no friends		12	25949	1	He reports having no friends in very little social support ...
	loneliness		10	98861	2	... , lack of concentration, loneliness, grandiosity, impulsive thinking ...
	lack of social support		23	18692	1	... cardiac transplantation d/t lack of social support.
	loneliness		8	108619	2	... he has felt anger and loneliness almost to the point of ...
	feels isolated		6	66779	1	... lives nearby, Mr. Turner feels isolated, helpless, lonely, ...
	socially isolated		7	13912	1	He is socially isolated and uses avoidance as a ...
	lack of social support		3	70647	1	... and Adams about Mr. Ackerman's lack of social support.
	lonely		3	132977	1	... Pt appears to be very lonely.
	socially isolated		2	80865	2	He is increasingly socially isolated, stating that he "...
	limited social network		1	135392	1	... pain, financial stress, limited social network Axis V: GAF-current: ...
	Loneliness		1	64980	1	... Conflict/arguments with others Loneliness x Boredom Physical pain Fatigue ...
BUT	no friends		1	124847	1	... leaving him alone at home BUT so far no friends or family members have been ...
	social isolation		1	146849	1	... decreased appetite, irritability, social isolation, guilt and anhedonia.

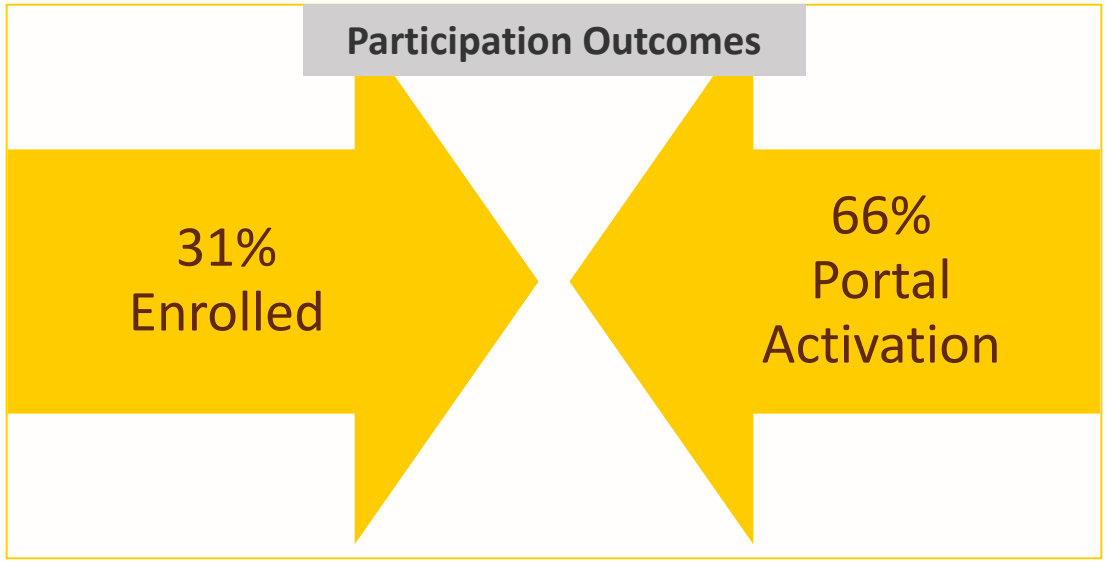
Social Deprivation and Participation in Precision Medicine Research in African American Prostate Cancer Survivors

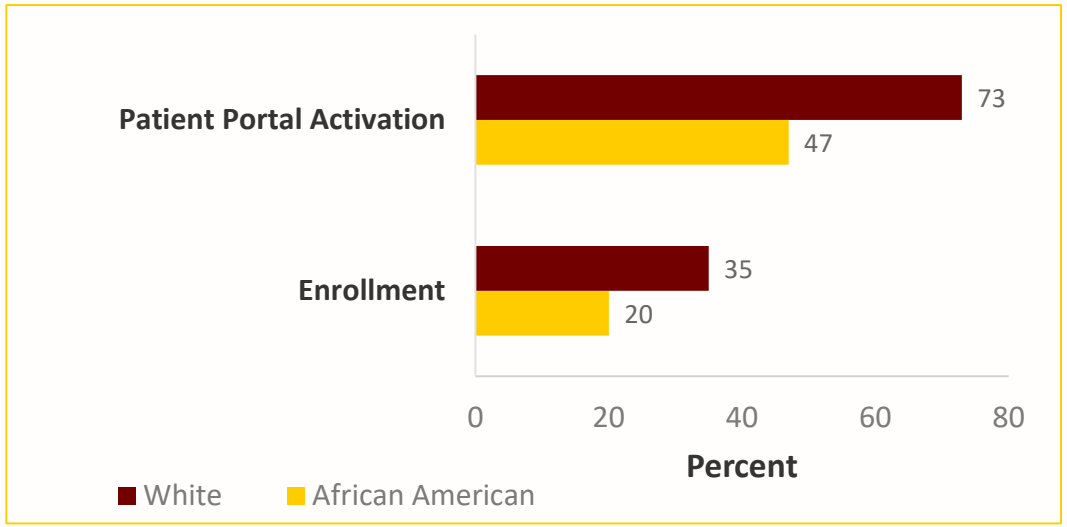
JCO™ CLINICAL CANCER INFORMATICS
An American Society of Clinical Oncology® journal

Defining an Integrated Allostatic Load Index with Immune and Tumor Microenvironment Factors

Participants: Prostate cancer patients identified from biorepository and tissue analysis core at HCC (n=218)

Outcomes: Enrollment in social determinants study and activation of patient portal





Social deprivation associated with a significantly reduced likelihood

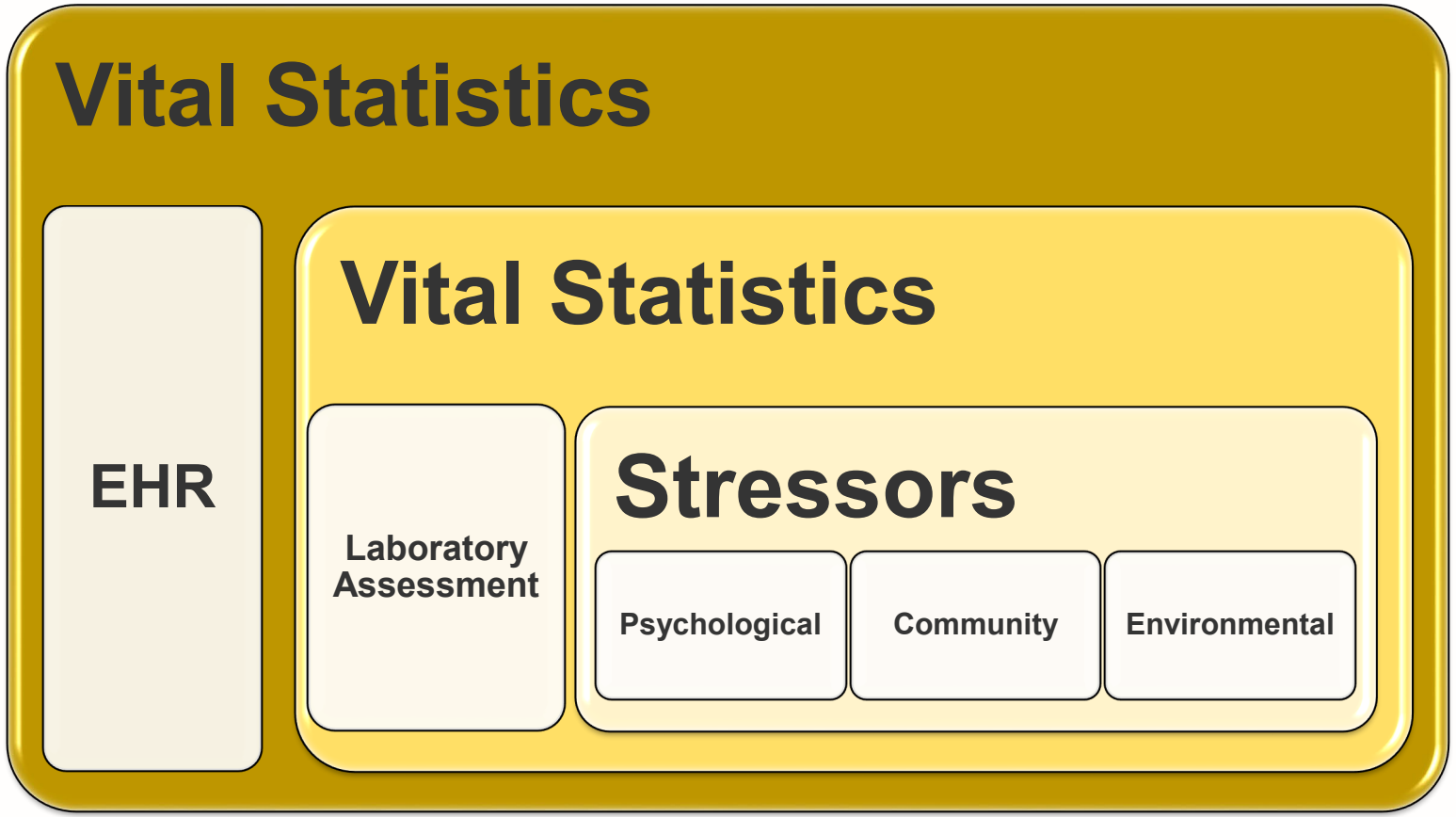
Variable	Odds Ratio	95% Confidence Interval
Enrollment	0.70	0.50, 0.98*
Patient portal activation	0.58	0.42, 0.82*

*p between 0.01 and 0.05

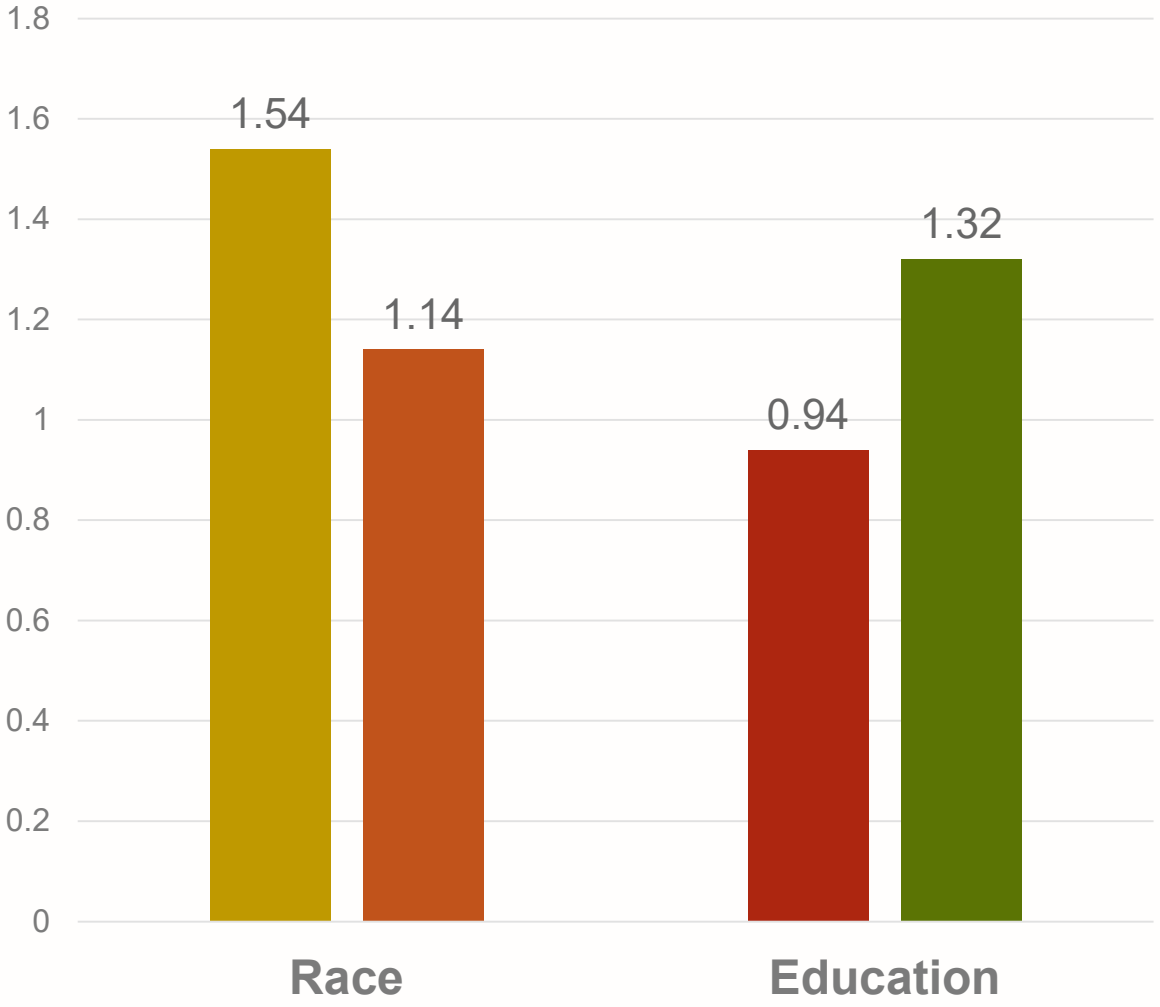
Halbert CH et al. 2021 ;5:768-774

Allostatic Load and Cancer Health Disparities

Allostatic load reflects physiological responses to stress



Allostatic Load in Prostate Cancer Survivors



Allostatic Load: Clinical Model (n=392)			
Variable	Level	OR	95% CI (p-value)
Race	African American White	1.78	1.15, 2.77 (0.01)
PSA	***	1.05	1.02, 1.08 (0.001)
Age	***	0.98	0.95, 1.01 (0.22)
Stage	T2 T3	0.98	0.61, 1.58

Public Health and Clinical Priorities for Social Determinants of Health

- Continued efforts are needed to understand the effects of multilevel social determinants on cancer health disparities
- SDOHs should be measured and addressed as part of cancer care
- Additional research is needed to evaluate the effects of SDOH interventions on cancer outcomes
- Ethical, legal, and social impact of documenting SDOH in electronic health record should be examined