WORKSHOP FOR ACCELERATING INCLUSIVE RESEARCH RECRUITMENT OR HOW TO FAIL AT SCIENCE

JONATHAN JACKSON, PHD
“Men are born to succeed, not fail.”

Henry David Thoreau
IF YOU BELIEVE
YOU WILL SUCCEED
I live to succeed, not to please you or anyone else.

Marilyn Monroe
ATELOPHOBIA

n. a fear of imperfection
WRITE A PAPER THE DAY BEFORE IT'S DUE

ACE IT
A PARTIAL LIST OF JONATHAN’S COLLEGIATE FAILURES (FIRST SEMESTER)

1. Scored a 10 on a Math 101 test. Out of 100.
2. Sat in 2nd row for Psych 101. Fell asleep every class.
4. Asked one question in Philosophy 103 - prof’s age.
COLLEGE
You only can choose two

GRAD SCHOOL
Pick one and expect to fail at it
A PARTIAL LIST OF JONATHAN’S GRAD SCHOOL FAILURES

1. Overpromised, underdelivered on every project.

2. Left after 3 years. Couldn’t get job, had to return.

3. Routinely put faculty to sleep during talks.

4. Dissertation is 125 pages of stuff that didn’t work.
Mind-Wandering in Younger and Older Adults: Converging Evidence From the Sustained Attention to Response Task and Reading for Comprehension

Jonathan D. Jackson and David A. Balota
Washington University in St. Louis

Can mind-wandering be timeless? Atemporal focus and aging in mind-wandering paradigms

Jonathan D. Jackson\(^1\)*, Yana Weinstein\(^2\) and David A. Balota\(^1\)

Mind-Wandering in Healthy Aging and Early Stage Alzheimer’s Disease

Mate Gyurkovics
University of Sheffield

David A. Balota
Washington University in St. Louis

Jonathan D. Jackson
Massachusetts General Hospital, Harvard Medical School
Table 1. Percent Participation in Clinical Trials by Subpopulation* for New Molecular Entities and Therapeutic Biologics Approved in 2020

<table>
<thead>
<tr>
<th></th>
<th>WOMEN</th>
<th>WHITE</th>
<th>BLACK or AFRICAN AMERICAN</th>
<th>ASIAN</th>
<th>HISPANIC</th>
<th>AGE 65 AND OLDER</th>
<th>UNITED STATES</th>
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<tbody>
<tr>
<td><strong>AVERAGE</strong></td>
<td>56%</td>
<td>75%</td>
<td>8%</td>
<td>6%</td>
<td>11%</td>
<td>30%</td>
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<tr>
<td>WOMEN</td>
<td>50.8%</td>
<td>76.5%</td>
<td>13.4%</td>
<td>5.9%</td>
<td>18.3%</td>
<td>16.0%</td>
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<td>WHITE</td>
<td>55%</td>
<td>78%</td>
<td>3%</td>
<td>5%</td>
<td>8%</td>
<td>11.5%</td>
<td>36%</td>
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<tr>
<td>BLACK or</td>
<td>0.47</td>
<td>0.35</td>
<td>1.64</td>
<td>1.44</td>
<td>0.85</td>
<td>1.10</td>
<td>0.80</td>
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<tr>
<td>AFRICAN AMERICAN</td>
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</table>
Diversity in GWAS Databases

Overall | All Cancer | Cardiovascular | Neurologic | Respiratory | Reproductive

European | Asian | "Other"

% Distribution:
- Overall: European 80%, Asian 20%
- All Cancer: European 70%, Asian 30%
- Cardiovascular: European 60%, Asian 40%
- Neurologic: European 90%
- Respiratory: European 70%, Asian 30%
- Reproductive: European 70%
What differentiates these events?
A PARTIAL LIST OF JONATHAN’S CAREER FAILURES AND SHORTCOMINGS

1. Couldn’t get anyone to care about attentional control.
2. Published too slowly.
3. Difficult cultural fit with colleagues.
4. Spent way too much time in the community.
Why can’t we engage representatively?

1. Lack of awareness of research opportunities
2. Deep mistrust of scientific sectors and research studies
3. Confusion and concern over what research is
4. Limited transportation options / times
5. Inclusion / exclusion criteria (especially hidden participation criteria)
6. Lack of plain language use in documents
7. Fear of placebo / fear of intervention
8. Health insurance coverage
9. Limited diversity on study staff
10. Poor targeting within catchment area
11. Insufficient return of value

Selected references:
- Bonevski 2014 | BMC Med Res Method
- Dunbar 2019 | Ped Neur
- Ejioagu 2011 | The Gerontologist
- George 2014 | Am J Public Health
- Gilmore-Bykovskyi 2019 | Alz & Dem: TRCI
- Gul & Ali 2010 | J Clin Nursing
- Howell 2020 | Alz & Dem
- Indorewalla 2021 | J Alz Dis
- Oh 2015 | PLoS Medicine
- Otado 2015 | Clin Trans Sci
- Probstfield & Frye 2011 | JAMA
- Robinson & Trochim 2007 | Ethn Health

Jonathan Jackson | jjackson31@partners.org
Representation as a selection problem

Sampling frame
- Lack of awareness of research opportunities

Awareness
- Deep mistrust of healthcare system and research
- Confusion and concern over what research is

Trust/Engagement
- Limited transportation options / times
- Inclusion / exclusion criteria

Literacy/Motivation
- Lack of plain language use in documents
- Fear of placebo / fear of intervention

Equity/Return of Value
- Health insurance coverage
- Limited diversity on study staff
- Poor targeting of catchment area
- Insufficient return of value

Screening

Setting

Implementation

Retention

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Sampling Frame
Awareness
Trust & Engagement
Literacy & Motivation
Equity & Return of Value
Screening & Inclusion
Research Setting
Implementation
Retention
“Diversity” as a coal-mine canary

Essentialized / Biological Disparities

Selection Biases → Measurement Error → Implementation & Design Biases → Social / Environmental Inequities → Biological Disparities

Social / Environmental Inequities → Biological Disparities

Jonathan Jackson | jjackson31@partners.org
What does it mean to fail?

<table>
<thead>
<tr>
<th>Measure</th>
<th>Caucasian</th>
<th>Caucasian (matched sample)</th>
<th>African-American</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (female)</td>
<td>242 (139)</td>
<td>47 (26)</td>
<td>47 (36)</td>
</tr>
<tr>
<td>Age</td>
<td>73.8 (6.2)</td>
<td>74.6 (6.8)</td>
<td>73.3 (6.4)</td>
</tr>
<tr>
<td>Education*</td>
<td>16.1 (3.1)</td>
<td>13.8 (3.2)</td>
<td>14.0 (2.9)</td>
</tr>
<tr>
<td>Mini-Mental State Exam*</td>
<td>29.1 (1.0)</td>
<td>28.7 (1.1)</td>
<td>28.4 (1.4)</td>
</tr>
<tr>
<td>American National Adult Reading Test*</td>
<td>122.6 (7.8)</td>
<td>110.0 (6.6)</td>
<td>111.0 (11.9)</td>
</tr>
<tr>
<td>Hollingshead index*</td>
<td>26.3 (14.7)</td>
<td>33.9 (14.6)</td>
<td>36.1 (15.9)</td>
</tr>
<tr>
<td>Geriatric depression scale</td>
<td>2.4 (2.4)</td>
<td>1.8 (2.0)</td>
<td>2.5 (3.2)</td>
</tr>
<tr>
<td>Memory factor score*</td>
<td>5.7 (2.1)</td>
<td>4.4 (1.8)</td>
<td>4.1 (2.0)</td>
</tr>
<tr>
<td>Subjective cognitive concerns composite</td>
<td>0.0 (0.7)</td>
<td>0.0 (0.7)</td>
<td>0.2 (1.0)</td>
</tr>
</tbody>
</table>

*P < 0.05 between full Caucasian sample and African-Americans, Mann–Whitney U.
2018 ACCRUAL TO DIGITAL STUDY

- White: 88.8%
- Hispanic: 7.6%
- Asian: 1.4%
- Multi-Racial: 1.1%
- Prefer Not to Answer: 0.2%
- Black or African American: 0.7%
- American Indian: 0.2%
- Native Hawaiian or Other Pacific Islander: 0.1%
EDUCATION LEVEL FOR DIGITAL STUDY

- Bachelor's Degree: 31.0%
- Master's Degree: 24.9%
- Some College: 14.7%
- Associate's Degree: 9.6%
- High School Degree: 6.5%
- Profession School Degree (MD, DDC, JD): 5.5%
- Doctorate Degree: 6.1%
- Less Than High School Degree: 11.1%
- Prefer Not to Answer: 0.6%

Courtesy Michael J Fox Foundation
According to US Census Bureau data, the median US household income is ~$57,000.

Courtesy Michael J Fox Foundation
The FIRE-UP PD Study

Sampling selection
Awareness
Trust/Engagement
Literacy/Motivation
Return of Value
Screening
Setting
Implementation
Retention

- Study designed to focus on multiple barriers
  - Powered primarily for engagement metrics, cost
  - Can assess dependent nature of framework
  - Preliminary assessment of comparative effectiveness
- Broad definition of “minority”
  - Race, ethnicity, gender, education, income, rurality
- Strong focus on sampling frame, protocol
  - Which minorities can or want to access Fox Insight?
  - Detailed engagement protocols help clarify “we’ve done that” or “charismatic individual” effects

Sanchez 2022 | Contemp Clin Tri
Accrual to Digital Study

- Nonwhite
- Hispanic / Latino
- Low Income
- Low Education

Baseline, Control, Intervention
A CONTINUING LIST OF JONATHAN’S CAREER FAILURES AND SHORTCOMINGS

1. (Still) Publishing too slowly.
2. Terrible leader for first 18 months at CARE.
3. Slow to pursue academic promotion.
4. I have no idea what I’m doing.
Wave 1
- Fast (days to weeks)
- Short duration
- Highly privileged
- Low representativeness
- Low researcher effort

Wave 2
- Less fast (weeks)
- Middling duration
- Somewhat privileged
- Better representativeness
- Modest researcher effort

Wave 3
- Slow (months)
- Prolonged duration
- Modest privilege
- Best representativeness
- Significant researcher effort
DEWEY DEFEATS TRUMAN

G. O. P. Sweep Indicated in State; Boyle Leads in City

REPUBLICAN TICKET AHEAD OF 1944 VOTE

Tops Coghlan in Hot Race for Attorney

RECORD CITY VOTE SEEN IN LATE TALLIES

Suburban Ballot Near 375,000

BULLETS ON ELECTIONS

Cook County

Superintendent of Elections-

Chief Clerk

Secretary of State

NATION

North Carolina

voting places of 0.71

221,273, Wallace 3,184, Leuzech D, 978.

Early Count Gives G. O. P. Senate Edge

PUTS G.O.P. BACK IN THE WHITE HOUSE

Sizable Electoral Margin Seen

by Arthur Hare Keesing

Early results indicate a sweeping victory in the presidential election yesterday.

The early returns

Chicago Daily Tribune

THE WORLD'S GREATEST NEWSPAPER

WEDNESDAY, NOVEMBER 3, 1948

...FOUR CENTS-PAY NO MORE
The crisis of diversity is ultimately a symptom of a crisis of scientific rigor.

Effectively addressing one requires addressing the other.
# Additional metrics of equity

<table>
<thead>
<tr>
<th>Traditional Metrics</th>
<th>Equity Metrics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HEALTH CARE SYSTEMS</strong></td>
<td><strong>HCS</strong></td>
</tr>
<tr>
<td>Nursing Homes</td>
<td>Demography (within / among HCS)</td>
</tr>
<tr>
<td>Assisted Living</td>
<td>Representativeness (census, disease burden, community)</td>
</tr>
<tr>
<td>Home Health</td>
<td></td>
</tr>
<tr>
<td>Rehab Hospice Hospital</td>
<td></td>
</tr>
<tr>
<td><strong>DATA SOURCES</strong></td>
<td><strong>DATA SOURCES</strong></td>
</tr>
<tr>
<td>Medicare MDS EHRs</td>
<td>Missingness &amp; gaps in data sources</td>
</tr>
<tr>
<td>Identifying PLWD</td>
<td>Stakeholder outcomes</td>
</tr>
<tr>
<td><strong>ETHICS/REG</strong></td>
<td><strong>ETHICS/REG</strong></td>
</tr>
<tr>
<td>Vulnerable Population</td>
<td>Engagement metrics for vulnerable populations</td>
</tr>
<tr>
<td>Consent Capacity</td>
<td>Consent language &amp; format</td>
</tr>
<tr>
<td>Federal Wide Assurance</td>
<td></td>
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<tr>
<td><strong>OUTCOMES</strong></td>
<td><strong>OUTCOMES</strong></td>
</tr>
<tr>
<td>Relevant to AD/ADRD Caregivers HCS</td>
<td>Triangulation and alignment of outcomes across all stakeholder groups</td>
</tr>
<tr>
<td>Ascertained from particular datasets</td>
<td>Consistency among data sources</td>
</tr>
<tr>
<td><strong>DESIGN/STATS</strong></td>
<td><strong>DESIGN/STATS</strong></td>
</tr>
<tr>
<td>Cluster RCT Dyadic Loss to F/U</td>
<td>DAGs Quantitative bias analyses (modified E-value)</td>
</tr>
<tr>
<td></td>
<td>Floating catchment area metrics</td>
</tr>
<tr>
<td><strong>IMPLEMENT</strong></td>
<td><strong>IMPLEMENT</strong></td>
</tr>
<tr>
<td>Complex Interventions</td>
<td>GOI Score</td>
</tr>
<tr>
<td>Challenging Settings</td>
<td>CFIR analyses</td>
</tr>
<tr>
<td>Adherence</td>
<td>Positive / negative adaptation</td>
</tr>
</tbody>
</table>
uh, how do we operationalize equity in research?

it seems

so. hard.
What I learned from failure

• Separate catchment area from sampling frame
  • Who can *really* participate in that protocol, given its design?
  • Helps avoid fallacy of overestimating participant willingness (Lasagna’s Law)
• Be thoughtful before implementing quick fixes from other sites
  • Don’t recruit in Black churches unless you have time to spend in Black churches
  • There are no cultural monoliths, so it’s always better to trust local input
• You probably have an awareness problem that needs fixing
  • Failing to solve for this barrier tends to negate other efforts
• If you want to get new folks in your study, you have to do new things
  • Diverse participation in research is a workflow problem, not a scaling problem
• Trust the experts - your CRCs and RAs
  • They can clearly see the barriers and effective solutions
  • When in doubt, be scientific - *go out and measure some stuff*
What I learned from failure

• Use plain language for everything, including your ICF
  • Language equity shouldn’t be the problem it is, but let’s at least get English right
  • Aim for 5th grade reading level, but no higher than 8th
• Use clinician champions and research ambassadors
  • This becomes easier if you have a solid clinic / community presence
  • Think about what you can offer clinicians to support research (hint: your expertise)
• Design for a strong return of value
  • Beyond return of results - make it easy / free / fun to participate
  • If you can’t return any results or decent compensation, do participant celebrations
• Sustained community entrenchment works but takes time
  • Can’t float in and out, magic number seems to be around 7 years
  • Talk to communities and families, not just prospective participants
What I learned from failure

• Schedule visits with the patient in mind
  • Low-traffic times of day, maintain familiar faces for study visits
  • Thank them often, build in extra time to explain study and novel findings

• Make sure there are participation options for screen-fails
  • Other studies should be offered, even outside your study team
  • At least build a database or registry for recontact
  • Retain them as ambassadors because they’re already engaged

• Do some social, digital, and traditional media
  • Your CRCs and RAs are better at this than you
  • Media presence gives you solid set of engagement metrics

• Diversify your team. At all levels
  • Look for local voices, not just faces that reflect the group you want
So...what does all this mean.

- Diversity is a stopgap for inclusion on the way to representation
  - The terms have never been interchangeable
  - “Diversity” is a floor, not a ceiling
  - We have work to do within science before we blame larger societal failures
- JEDI needs quantification to fit in our worlds of science
  - Dire need for creation of CDEs, workflows, and protocols
  - Precision measurement and intervention is within reach
  - Convergent compatibility with thoughtful statistical theory
  - Potential for reconciling health equity & global health fields
- This is just the tip of the iceberg
  - Resources from market research, epidemiology, LIS, bioethics, social theory
  - Possible new field of research, between pop health and clinical research
  - Glimmers from pragmatic trials, imp sci, learning networks
- Equity will soon be the primary driver of scientific innovation
  - The emergence of precision approaches, -OMICs requires it
  - All rigorous science and policy must necessarily be equitable

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HOW TO FAIL:

1. Simplify your goals. Stay true to them.
2. Let go of a need to achieve for its own sake.
Justice as a *liberation* problem

- Is a *just* science a *better* science?
  - Equity considerations at macro-, meso-, micro-domains

- Limits of colonial frame in clinical research
  - Solving for representation won’t fix our problems
  - Barriers towards inclusion are symptomatic of larger limitations
  - Using white people as a default does us no favors
  - Must address gaps in analysis, data ownership, innovation

- Fundamental need to *decolonize* science
  - Add *context* to our process of truth-seeking
  - Simultaneously addresses all four frames of justice
  - Takes the pressure off the ivory tower to build datasets that cover everyone
  - Leverage designs like Learning Health Networks
    - Mitigates tension between science and impact
    - A new kind of science emerges, between urbanized public health and clinical research
Centering equity in research and justice

• Strengthen compliance, reporting, transparency
  • Demographic / subgroup data often unreported, missing, despite requirements
  • Develop detailed, transparent reporting as well as accountability (enforcement)
  • End ongoing research abuses (yes, even after Belmont)

• Identify, measure, systemically address exclusionary research
  • Assess and address data burden
  • Model overlapping, currently unmeasured selection biases
  • Promote language equity, even for English speakers
  • End practices that exclude on the basis of researcher / clinician convenience

• Move beyond proportional representation
  • No scientific basis for representation at the level of census tracts
  • Focus on disease risk or burden
  • No basis for Whites as referent group
Centering equity in research and justice

• Build sustained, reciprocal relationships with marginalized communities
  • Stop centering research goals on researcher / clinician / institution
  • Develop broader experience metrics (e.g., for research participants, for care partners)
  • Broaden definition of “participation” in research
  • Don’t lament mistrust – become trustworthy

• Develop sciences of research participation and inclusion
  • Build evidence-based, mechanistic guidance for study design, recruitment, retention
  • Systemically identify and address research barriers
  • Remember that the plural of anecdote is not data, even for diverse recruitment

• Recognize connection between research and health inequities
  • Without justice in research, we cannot solve health inequities
  • Build an infrastructure to support measurement and intervention on justice pillar
  • If successful, will create daylight between inequities and disparities