Cultivating Innovative Data Science Communities

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IRIS INSTITUTE FOR RESEARCH ON INNOVATION & SCIENCE

Producing value and cultivating community since 2015

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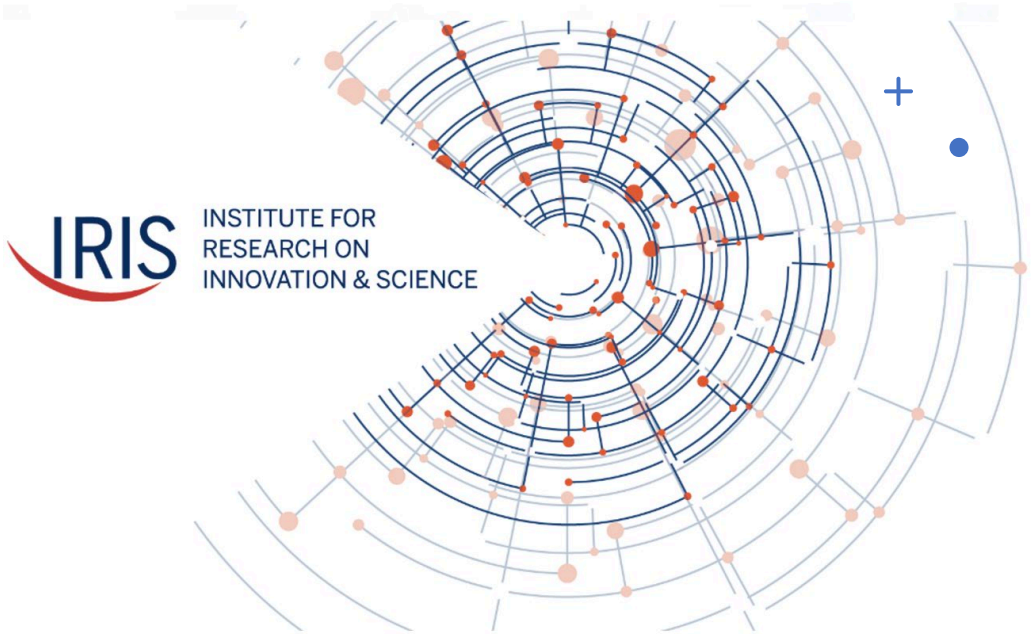
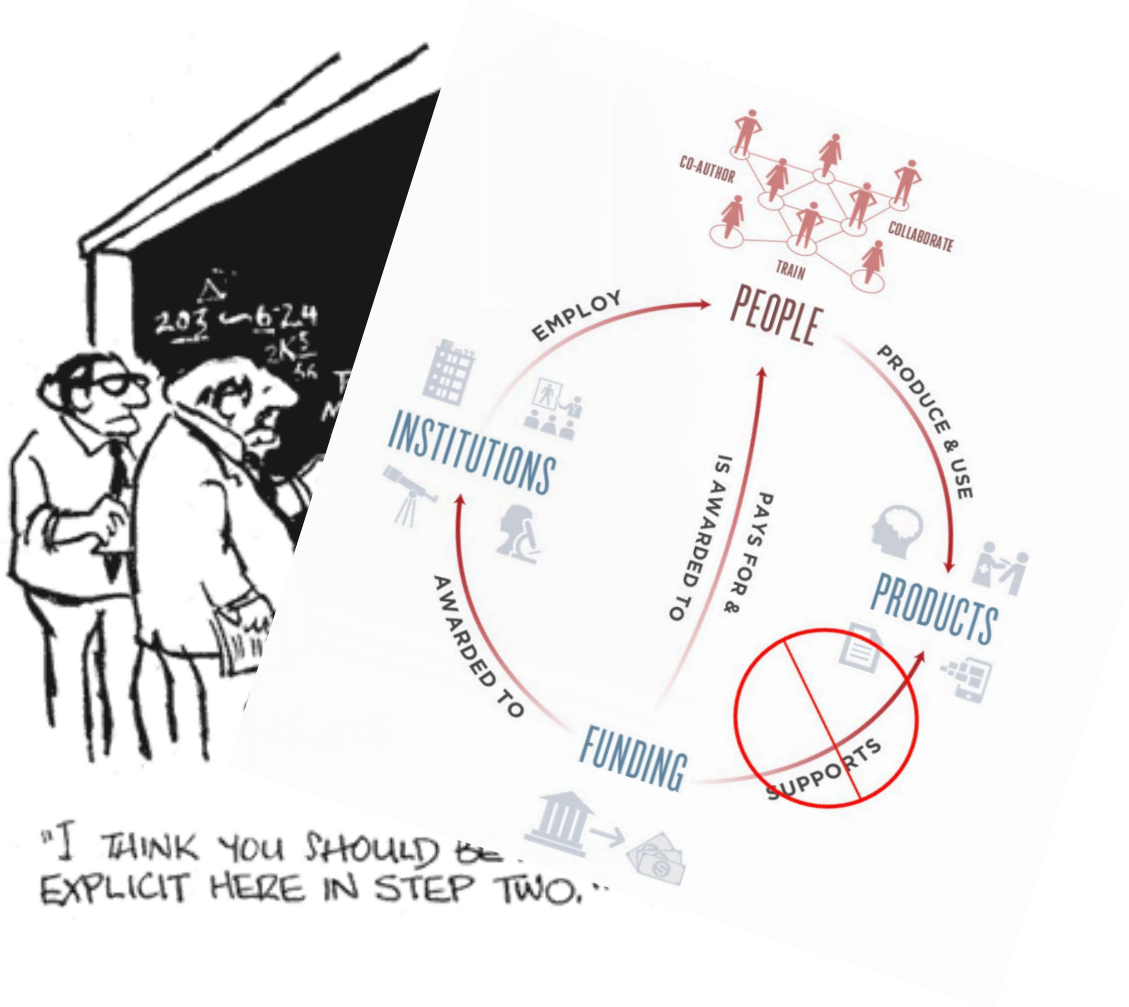


- IRIS Vision and **Value**
- How we achieve it
- Why we do it that way
- Lessons for network anchors

Data to **understand, explain, and improve** the public value of research and higher education

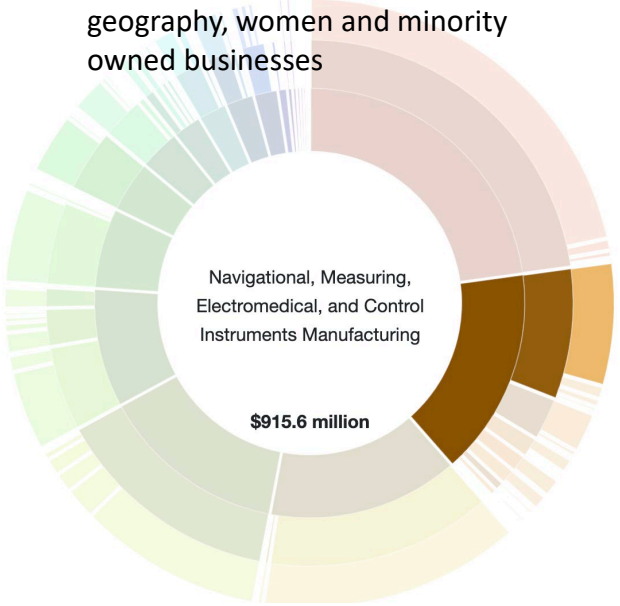
The Promise & The Challenge: understanding, explaining & improving the public value of science

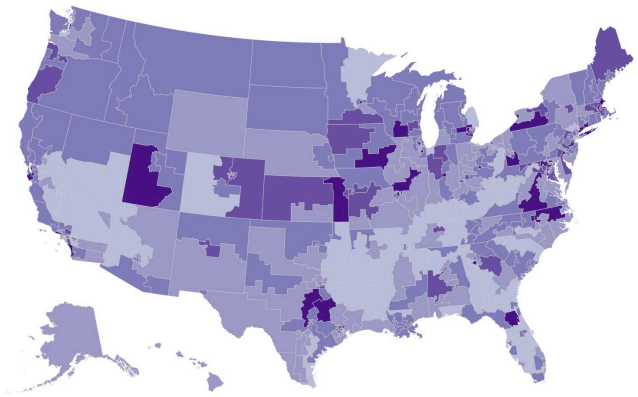


Data Types	Produces/Owners	Restrictions
Grant details	Federal Science Agencies	None for public data
Granular Expenditures	Universities	State & Federal Law, institutional, contractual
Student records & transcripts	Universities, State Higher Education Agencies	State & Federal Law, institutional, contractual
Survey information (e.g. SED, BRDIS)	Federal Statistical Agencies	Federal Law, Human Subjects Protections
Scientific Outcomes	Federal Agencies (USPTO, NLM), Publishers (Elsevier, Clarivate, ProQuest), Repositories, University Tech Transfer Offices	None for public data, proprietary, contractual, institutional policies
Employment & Workforce	State Workforce Agencies, Federal Statistical Agencies, Corporations	Federal & State Law, proprietary

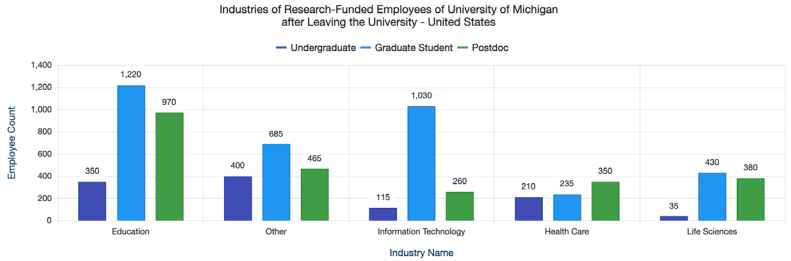
Bare minimum: **9** types of data producers/owners working under **six** types of restrictions with different, sometimes contradictory needs, disparate goals and a challenging history that can breed mistrust are needed to fill in step 2.

Economic impact, industrial relations, and procurement: detailed data on spending and employment by industry, geography, women and minority owned businesses





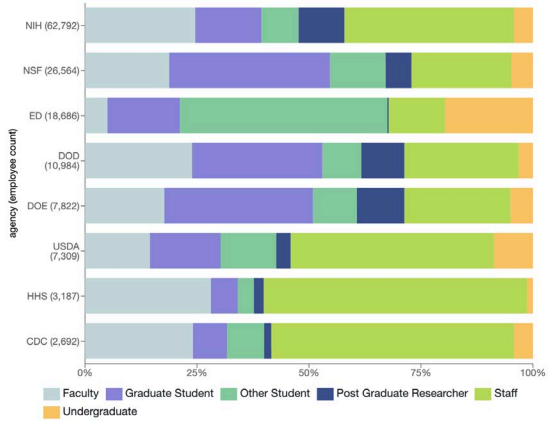
Government Relations: Spending, employment, and economic impact by state & federal congressional district



Improving student outcomes: employment and earnings by industry, geography (down to county) and employers

	KL2 Scholars (n=58)	K Comparison Scholars (n=302)
Faculty	3.7	3.6
Clinician	0.24	0.16
Postdoctoral Researcher	0.40	0.53
Staff	3.9	3.9
Student	1.2	1.2
Average Team Size	9.5	9.4
Gender Composition		

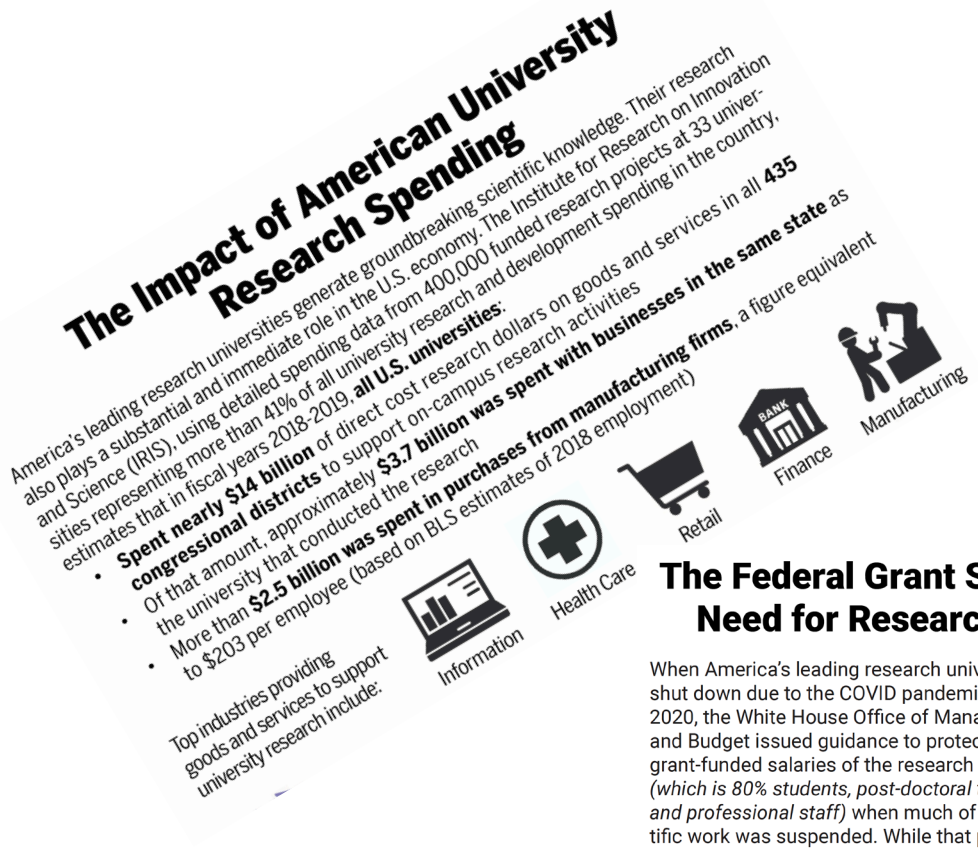
Campus Research Workforce: Planning, bridging funds, development of collaborations

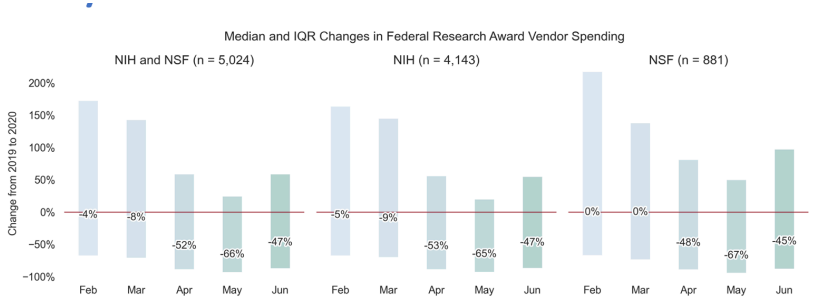


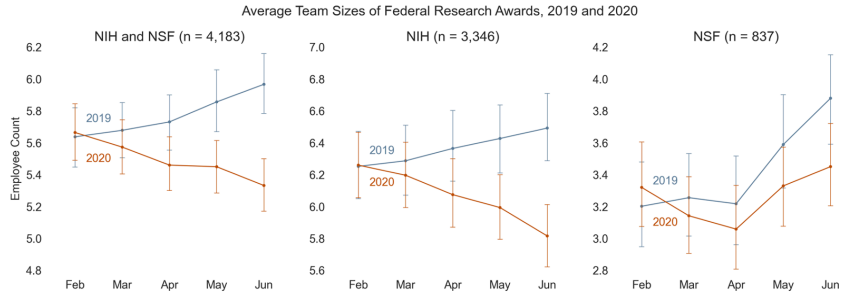
Faculty & Research Development: Funding, transition to independence, research productivity & impact, team science

The Value of Linked Transaction Data

Timely, responsive, and safe production at scale



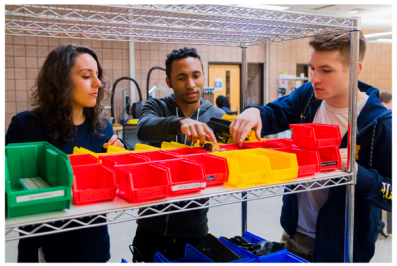




Data and products to track and explain COVID-19 effects

The Federal Grant Salary Gap: An Example of the Need for Research Relief under the RISE Act

When America's leading research universities shut down due to the COVID pandemic in spring 2020, the White House Office of Management and Budget issued guidance to protect the grant-funded salaries of the research workforce *(which is 80% students, post-doctoral trainees and professional staff)* when much of the scientific work was suspended. While that protected more than 90% of research jobs, it also created a **"Salary Gap" for federal grants that are being spent down on salaries while the pandemic slows or pauses active research work.**



If this gap is not addressed, federal funding agencies will be forced to choose between finishing these projects and funding new science. This tradeoff would harm America's standing as a global research leader, and diminish our ability to develop a competitive STEM workforce.

Research-based fact sheets for NSF & members of congress support RISE Act, Endless Frontier Act, and infrastructure funding for research

IRIS Products are driven by linkage across more than *50 data streams*

Advanced Research Computing - scientific impact of cyberinfrastructure

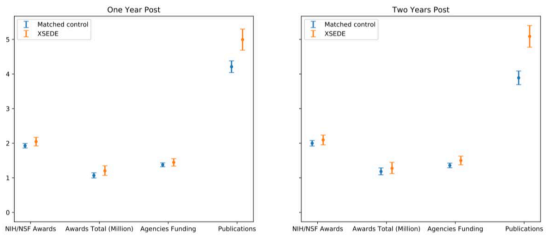
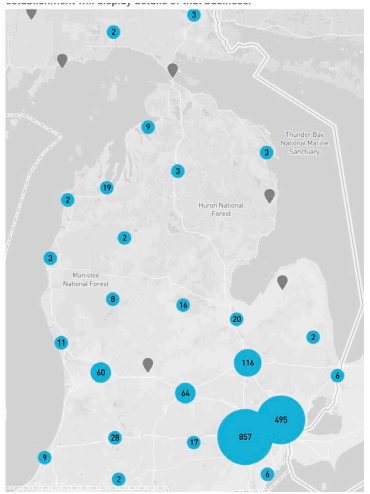


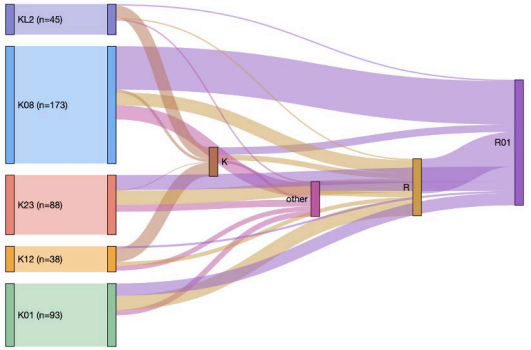
Figure 6. Estimated Marginal Effects of XSEDE Treatment via Regression on Matched Sample

XSEDE



University Government Relations & Communications - the IRIS ImpactFinder

Translational Science – evaluating KL2 & T32 outcomes



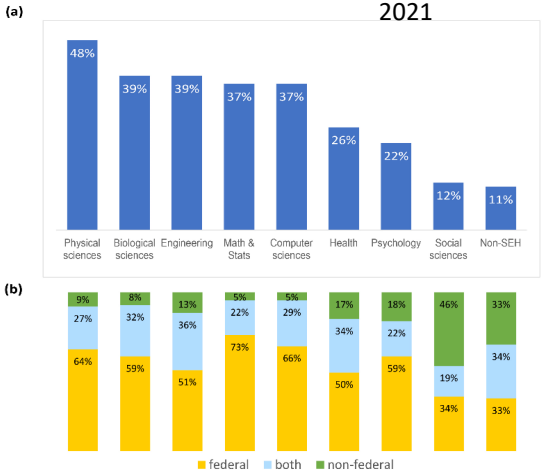
10 CTSA Hubs/NCATS

Improving Science Statistics

NCSES

Linking SED/SDR & UMETRICS

Chang et al, 2021



Strategic partnerships create value for multiple communities and expand benefits of participation

Compelling Stories Grounded in Data

Measuring Impact

Sam Carlin has built 50 pediatric treadmills for U-M researchers so they can study the mobility patterns of children.

The custom exercise equipment helped Professor Dale Ulrich determine that just a few minutes of daily treadmill training can help accelerate the walking habits of children with Down syndrome.

U-M Professor Dale Ulrich determined that just a few minutes of daily treadmill training can help accelerate the walking habits of children with Down syndrome. Photo: U-M School of Kinesiology

"Treadmill training in the home of infants with Down syndrome helps reduce the infants' significant delay in learning to walk," said Ulrich, professor of movement science and health fitness. "Once any infant can walk, we see advancements in their cognitive, social, emotional and physical development because they can explore their environment and learn."

Grants awarded to Ulrich and other U-M researchers covered the $50,000 bill for the pediatric treadmills. And that funding helped Carlin expand his Sturgis, Mich.-based company, which has designed about 350 specialty treadmills for hospitals, schools and families worldwide.

Pediatric Treadmills by Carlin's Creations, L.L.C.

Pediatric Treadmills

Designed for children with developmental difficulties (such as Down Syndrome or Cerebral Palsy)

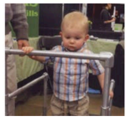
Research by the University of Michigan shows that children with Down Syndrome learn to walk faster and better when using a slow treadmill.

Our Pediatric Treadmill Models are designed for childred weighing- click link for additional information:

- Treadmill 2 & Treadmill 3- under 75 pounds.
- Treadmill 4- under 100 pounds.
- Treadmill 5- under 100 pounds.
- Treadmill 6- under 125 pounds.

Treadmill 3

Treadmill 2



Treadmill training helps babies with Down syndrome walk months earlier

December 17, 2007

Contact: Laura Bailey
baileylm@umich.edu

Share on:

ANN ARBOR—Starting infants with Down syndrome on treadmill training for just minutes a day can help them walk up to four or five months earlier than with only traditional physical therapy, a new study from the University of Michigan says.

The study also suggests that infants who do high intensity treadmill training may walk even sooner.

Getting infants walking is critical because so many other skills arise from locomotion: social skills, motor skills, advancement of perception and spatial cognition, says professor Dale Ulrich of the University of Michigan Division of Kinesiology and principal investigator on the treadmill training project.

"The key is if we can get them to walk earlier and better then they can explore their environment earlier and when you start to explore, you learn about the world around you," Ulrich said. "Walking is a critical factor in development in every other domain."

Infants with typical development learn to walk independently at about 12 months of age. Babies with Down syndrome typically learn to take independent steps at 24-28 months.

In the study, 30 infants were randomly assigned lower intensity, generalized treadmill training, or high intensity, individualized treadmill training, implemented in the homes by their parents. The training was used as a supplement to physical therapy.

Initially, all parents worked with their infants on the treadmill for eight minutes a day, five days a week. The parent sat on a bench that straddled the treadmill and held the infant as the child took steps on the treadmill, Ulrich said. All of the parents began with low intensity training, but after the infant could take 10, 20, and 30 steps per minute, intensity was gradually increased for half the infants, Ulrich said.

High intensity training included increasing the treadmill belt speed, using longer durations, and adding light weights to the ankles, with intensity tailored to each child.

The results suggest that infants in the higher-intensity, individualized training group increased their stepping more dramatically over the course of training, and attained most of the motor milestones at an earlier mean age. The results also provided support for the results of their earlier treadmill training study reported in 2001.

The treadmills are about $1,200 each, and Ulrich said the hope is that more hospitals and parent organizations will rent the equipment to parents.

Down syndrome occurs in about 1 in 700 births, and is one of the few disabilities that causes significant delays in all developmental domains, the paper said.

Treadmill Training of Infants With Down Syndrome: Evidence-Based Developmental Outcomes

Dale A. Ulrich, PhD*; Beverly D. Ulrich, PhD*; Rosa M. Angulo-Kinzler, PhD*; and Joonkoo Yun, PhD‡

ABSTRACT. *Objective.* On average, infants with Down syndrome (DS) learn to walk about 1 year later than nondisabled (ND) infants. The purpose of this study was to determine if practice stepping on a motorized treadmill could help reduce the delay in walking onset normally experienced by these infants.

Methods. Thirty families of infants with DS were randomly assigned to the intervention or control group. All infants were karyotyped trisomy 21 and began participation in the study when they could sit alone for 30 seconds (*Bayley Scales of Infant Development, Second Edition* 1993, item 34). Infants received traditional physical therapy at least every other week. In addition, intervention infants received practice stepping on a small, motorized treadmill, 5 days per week, for 8 minutes a day, in their own homes. Parents were trained to support their infants on these specially engineered miniature treadmills. Every 2 weeks research staff went into the homes and tested infants' overall motor progress by administering the *Bayley Scales of Infant Development, Second Edition*,[1] monitored growth status via a battery of 11 anthropometric measures, and checked parents' compliance with physical therapy and treadmill intervention. The primary measures of the intervention's effectiveness were comparisons between the groups on the length of time elapsed between sitting for 30 seconds (entry into the study) and 1) raising self to stand; 2) walking with help; and 3) walking independently.

Results. The experimental group learned to walk with help and to walk independently significantly faster (73.8 days and 101 days, respectively) than the control group, both of which also produced large effect size statistics for the group differences. The groups were not statistically different for rate of learning to raise self to stand but there was a moderate effect size statistic suggesting that the groups were meaningfully different in favor of the experimental group.

Conclusions. These results provide evidence that, with training and support, parents can use these treadmills in their homes to help their infants with DS learn to walk earlier than they normally would. Current research is aimed at 1) improving the protocol to maximize outcome; 2) determining the impact of treadmill practice on walking gait patterns; 3) testing the application to other populations with a history of delays in walking; and 4) determining the long-term benefits that may accrue from this form of activity. *Pediatrics* 2001;108(5). URL: http://www.pediatrics.org/cgi/content/full/108/5/e84; *motor development, Down syndrome, early intervention, walking.*

ABBREVIATIONS. DS, Down syndrome; ND nondisabled; *BSID-II, Bayley Scales of Infant Development, Second Edition.*

From the *Division of Kinesiology, University of Michigan, Ann Arbor, Michigan; and the ‡Department of Exercise and Sport Science, Oregon State University, Corvallis, Oregon.

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Infants with Down syndrome (DS) begin to walk, on average, about 1 year later than infants who are nondisabled (ND).[2,3] This is part of the sequence of delayed and diminished motor abilities this population faces; the gap between infants with and without DS grows wider with age. Walking is a particularly salient skill for young children because its impact is multidimensional, affecting cognitive, social, as well as subsequent motor development.

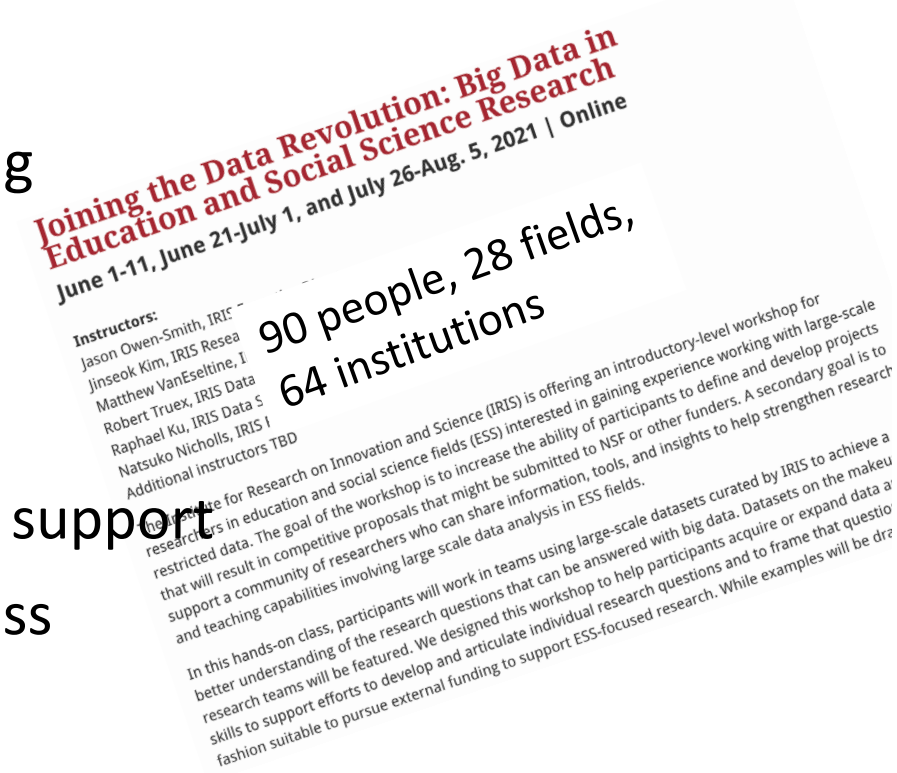
In his editorial in *Developmental Medicine and Child Neurology*, Bax[4] wrote that walking is "more than simply the ability to ambulate . . . it is the ability to stand upright in social situations . . . can be little doubt that it has an effect on body image . . . Standing upright places one on the same plane as the rest of the world, enabling one to be more aware of the importance of his body in relation to other people." When infants with DS begin to walk their opportunities to interact and play with their age-mates increases significantly. Motor activity-play provides exploration and opportunities for new forms of cognitive development to emerge.

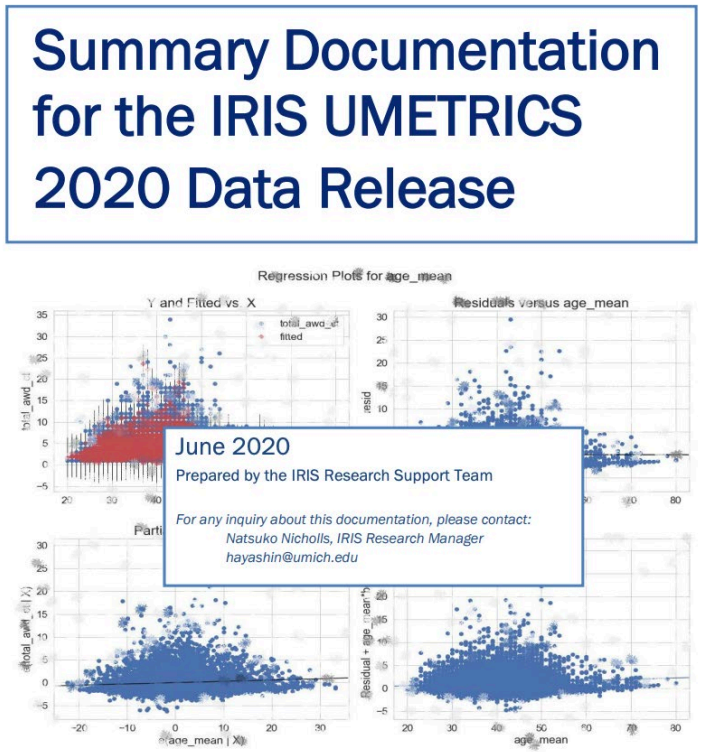
Research involving normally developing infants has demonstrated that the ability to locomote increases children's understanding of depth, locations of objects and themselves in space, and of hidden objects.[5,6] Biringen and colleagues[7] documented, in particular, an increase in affective behavior (positive interactions as well as clashes of will) of both mother and infant with walking onset, particularly for infants who walk earlier, rather than later in age. In her work with preschool-aged children with mobility problems, Butler[8,9] observed an immediate impact when these children learned to use powered wheelchairs. They increased their language, play, and exploration dramatically. Most fascinating were their increased efforts to produce self-propelled locomotion. The rewarding experience of being able to control their own movement in one context motivated them to make further efforts to learn and be active when not in the wheelchair.

Parents of infants with DS identify walking as one of the goals they value most for their young children. Well-intentioned family members and friends repeatedly ask if their child has begun to walk and talk,

Training and support for open, inclusive research communities

- Accessible, effective training
- Discoverable, public documentation
- Facilitating peer learning
- Strong, accessible research support
- Multiple onramps and access points





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Administrative Data Research Facility

FSRDC

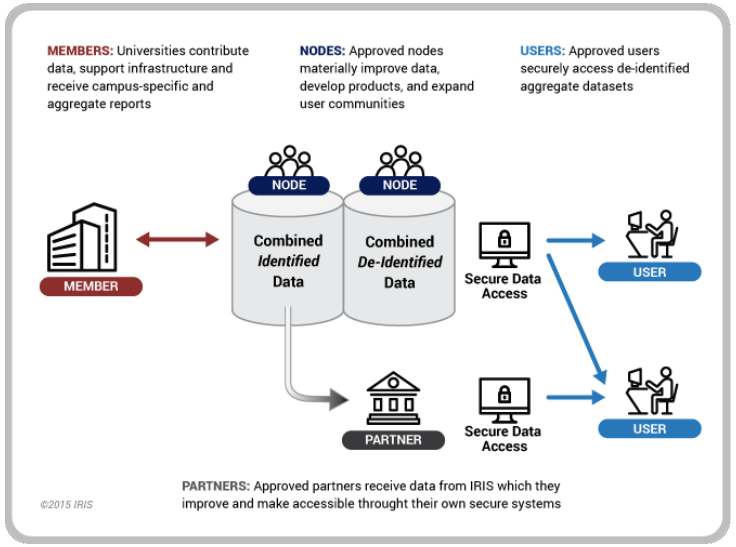
>350 research users from nearly 150 institutions

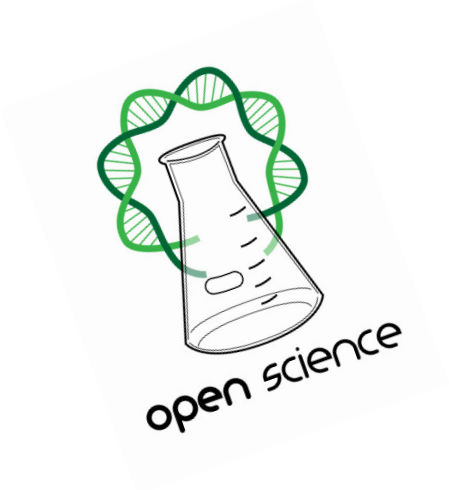
https://doi.org/10.21987/9wyn-8w21

Solving the problem of social organization

Innovative Communities need:

1. Social solidarity - trust, affinity, forbearance, reciprocation, common language
2. Interdependence & Commitment
3. Mechanisms for learning, credit, and credibility
4. Value for all





Generalized exchange – *"each actor gives benefits to another, and eventually receives benefits from another*" but not from the same other (Molm et al 2007)

- Generates more social solidarity than arms-length, tit-for-tat, or restricted pairwise exchange

Network governance – a collection of actors who pursue "*enduring exchange relationships with each other"* but "*lack a legitimate organizational authority"* to resolve disputes and conflicts (Podolny & Page 1998)

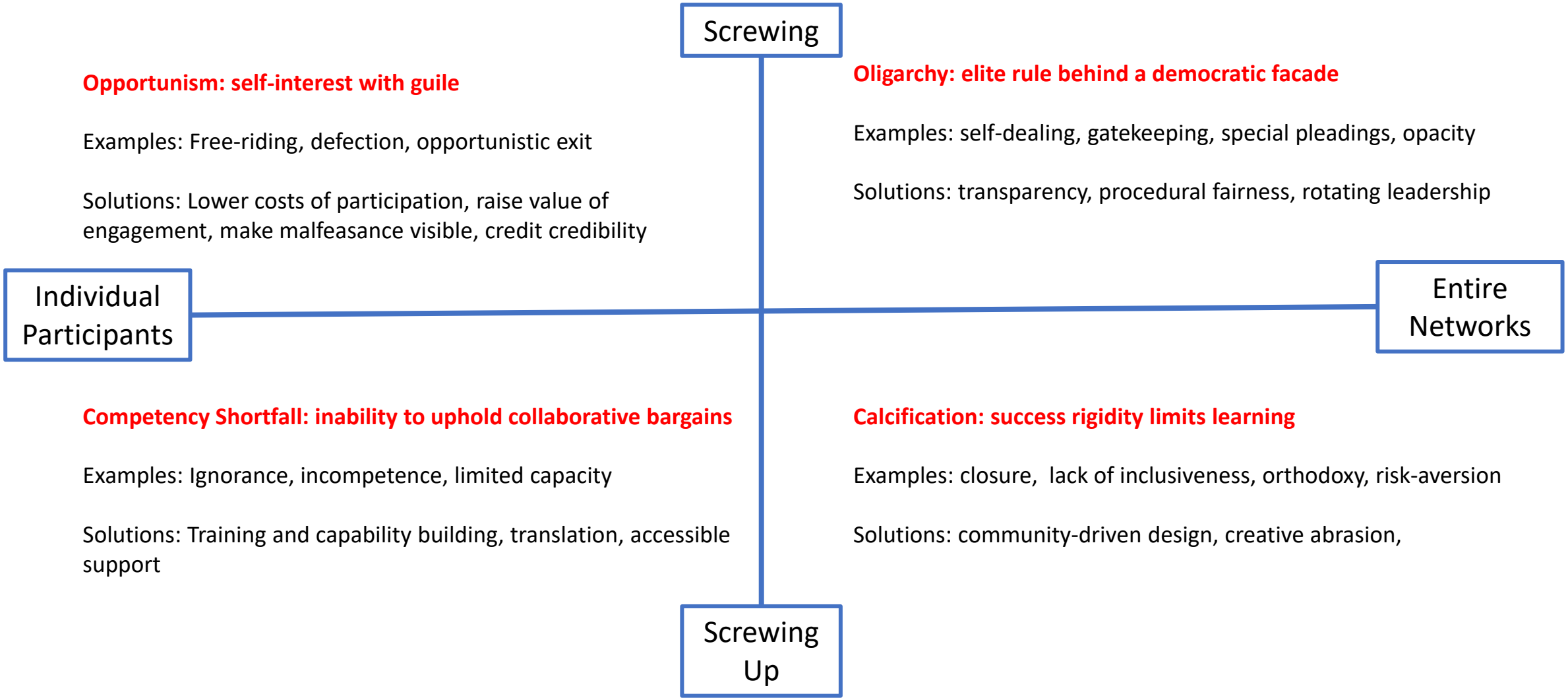
- Nimble, innovative, well-suited to fields where knowledge is rapidly expanding and widely dispersed

- ~~Centralized Hierarchical Authority~~
- ~~Bilateral Exchange and Direct Reciprocity~~
- ~~Altruism~~

Generalized Exchange + Network Governance = Vibrant, Innovative Community

Avoiding the most common pitfalls

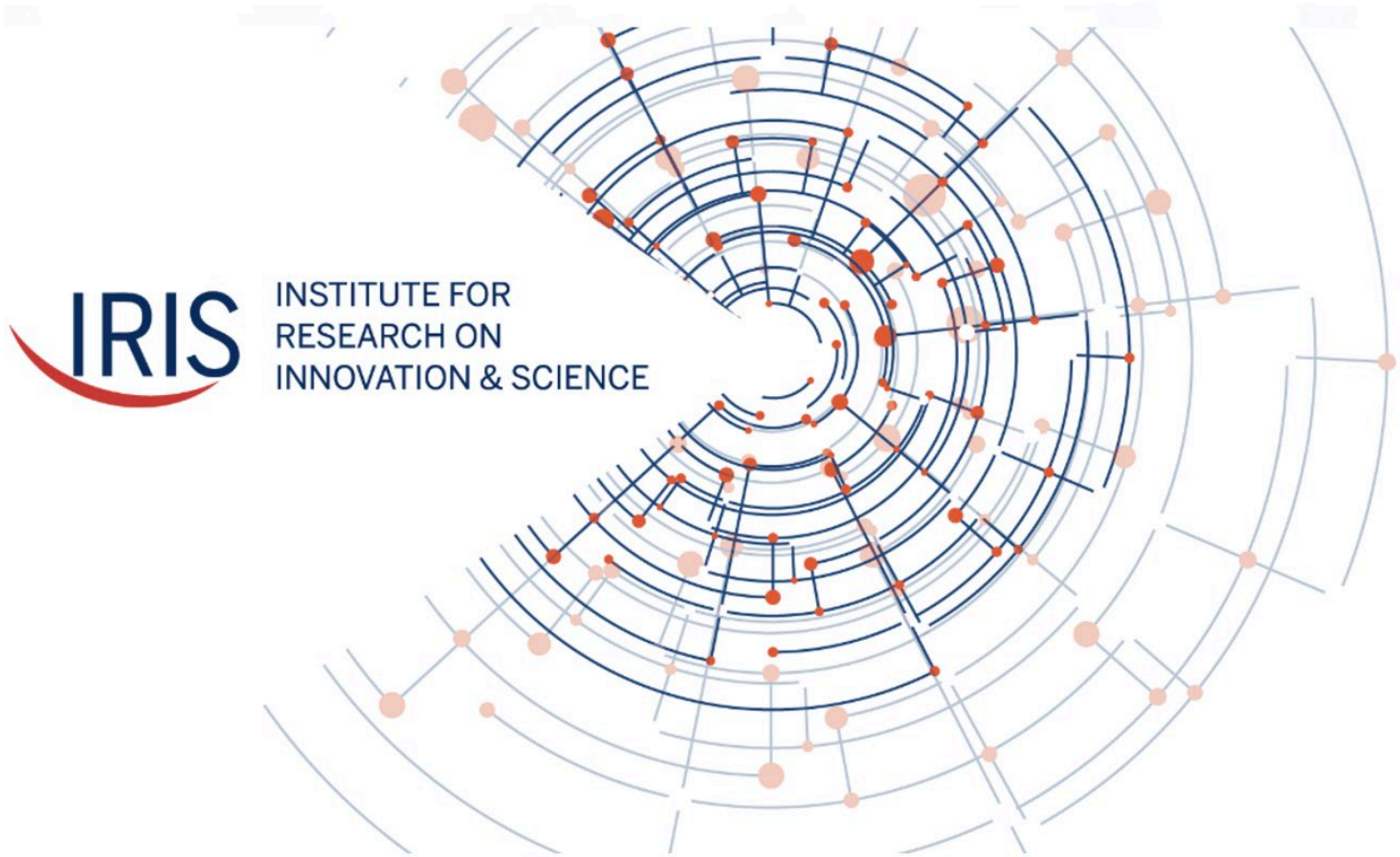
Networks fail when ”partners **screw each other** or **screw up**”
(Schrank & Whitford, 2011)



Lessons from IRIS for Cultivating Community

- **Laser focus on reliability, transparency, timeliness and value**
- **Guard against opportunism and make misbehavior costly**
  - Absorb transaction costs to lower barriers for partners
  - Increase scale and scope of data to raise value through network externalities
- **Accessible, inclusive training and support to increase capacity and decrease the likelihood of screwups**
  - Create multiple onramps and access points
  - Meet communities where they are and help them develop the capabilities they need
- **Transparent, fair and open procedures, dependence on community to avoid oligarchy**
  - All documents and procedures public
  - Dependent on and answerable to community through membership contributions and elected board of directors
- **Partnerships with other community anchors and broad, welcoming outreach to prevent calcification**
  - Integrate with other relevant communities through strategic partnerships and innovative research
- **Make news through sustained, substantive technical and scientific contributions**
  - Research active anchors are necessary for collaborative problem solving

Safe, reliable, open, responsive and innovative data communities create value for all



Data to **understand, explain, and improve** the public value of research and higher education

Thank you!