

What Patients are Interested in When it comes to Data Sharing

Spoiler alert...
Transparency is Key!

2026 PHUSE
Data Transparency
Pavilion, Session 2



Deborah Collyar
President
Patient Advocates In Research (PAIR)
"Where Research Meets Reality"

You've just been diagnosed with *Unamit*, a Serious Cancer



Your treatment options are:

- xyzimab + udonwonit - OR – wutzmortoxinib

Or a new clinical trial with:

- WOWzer immunotherapy $\pm$ either treatment

Which would you like?

Who doesn't want to be in that room?

The U.S. ~~healthcare~~ sick care system

Patients are PEOPLE

Who just landed on a new planet with:

- No roadmap
- No dictionary
- No survival training

YOU CAN HELP!



Image tweeted by @NASAExoplanets

What is missing for people?

CONTEXT



Patients,
Caregivers,
Public
+
Other fields

How to include patient needs & preferences? Just WIIFP*



* What's In It For Patients?

How will they get better results?



Before product or data focus

Cool science & profits aren't enough



Before protocol & regulatory focus

What works for better patient outcomes = reimbursement



This can be a win/win!

What do patients want to know?

- ✓ I am **not** alone (others before me)
- ✓ **Why** are you doing this?
 - What is known/unknown
- ✓ What to **expect**
 - Exploratory v. validated
 - What happens to my data?
- ✓ Is it **better** or just 'more' treatment?
- ✓ How bad can it get... '**safe**' word?
- ✓ What happens **after**?



MORE THAN INFORMED CONSENT

Examples...



Words



Matter



PAIR 102

Term	Scientific/Medical	Patients & Public
Immunotherapy	Focused on immune system	Therapy to fix cancer
Informed consent	Legal paperwork	Understandable info
Efficacy	Drug evaluation	Effective for me
Tumor Mutation Burden	Good!	Bad?
Vaccine	Vehicle for immunotherapy	Prevention
Cytokine Release Syndrome	Systemic inflammatory response	Death Star?
Direct/digital clinical trial (DCT)	COVID-related study	Study that thinks about me
Artificial Intelligence (AI)	Machine learning, algorithms	Robots on steroids?
RWD	Real World Data	Is that mine? How to fix?

Why we need each other...

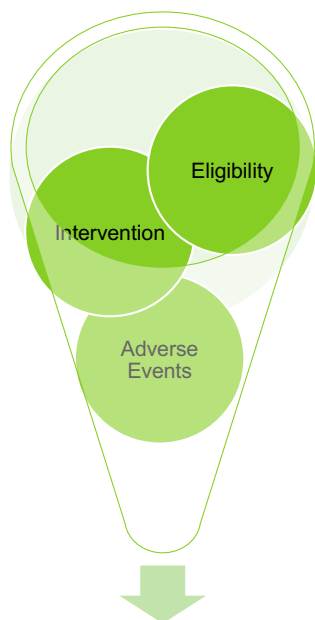
Scientists/researchers:
experts on the letter “i”



Patients & Advocates:
whole alphabets

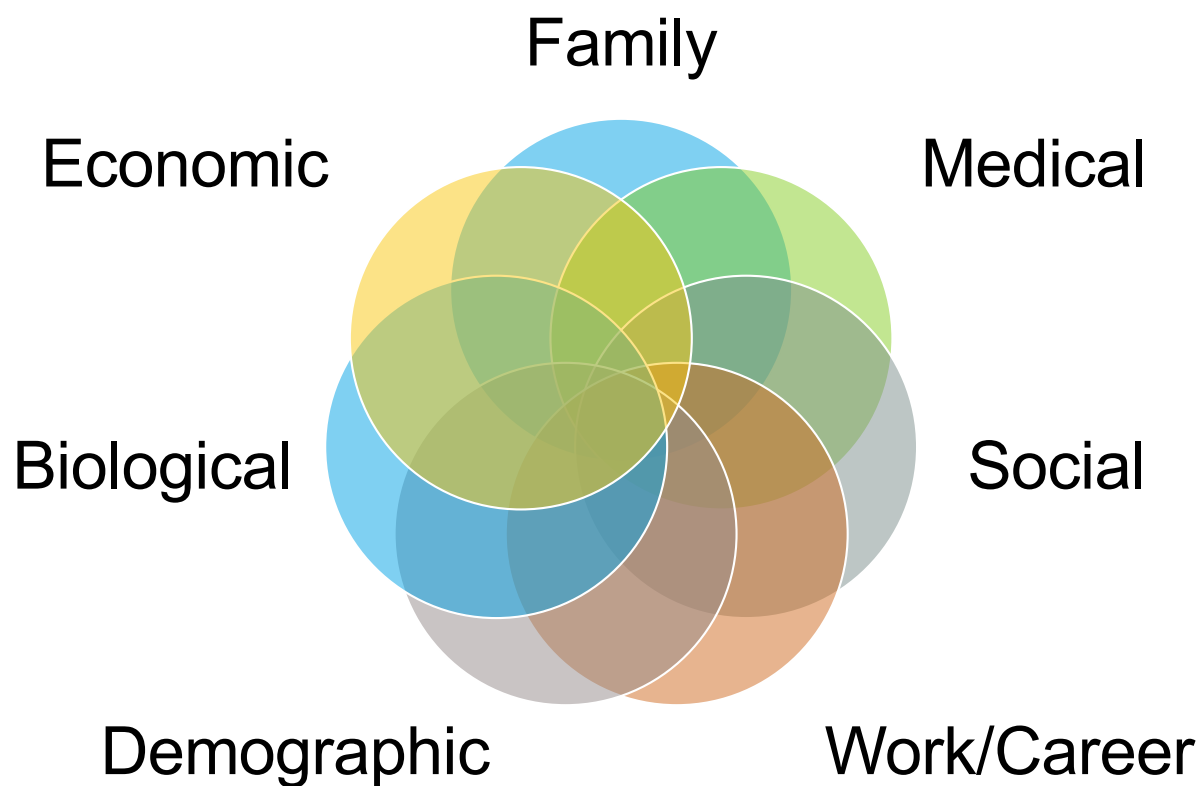
ex: Traditional data...

Clinical Trial Data



All other 'Patient' data

- THIS is real world! SDOH



<https://www.cdc.gov/socialdeterminants/index.htm>

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Diversity, Equity, Inclusion, & Accessibility
aren't just words. They are **realities**.

- What is each person's reality?

Biobanks: Equity starts with Data

Need representative **biospecimens + data**

✓ **Preanalytics** – getting it right

How to:

- ✓ Get **patients** to donate
- ✓ Get pathologists & institutions to **share** tissue + data
- ✓ Protect **privacy** without re-consents
- ✓ Tie critical patient information, research data, & imaging to tissue

- <https://globalforum.diaglobal.org/issue/october-2022/representation-bias-in-genomic-research-data-propagates-structural-inequity-in-cancer-care/>
- <https://commoncancertestingterms.org>
- <https://cancerprecisionmedicinecommons.org>

Representation Bias in Genomic Research Data Propagates Structural Inequity in Cancer Care

Lynda Chin

Dell Medical School, UT Austin
Apricity Health



Common Cancer Testing Terminology

Background

Use Cases

Participating Organizations

The Consistent Testing Terminology Working Group is composed of more than 40 patient advocacy organizations from solid tumors and hematologic malignancies, professional societies, pharma, biotech, diagnostics companies, and testing laboratories committed to clarifying and promoting consistent use of common terms for biomarker and germline genetic testing.

BACKGROUND

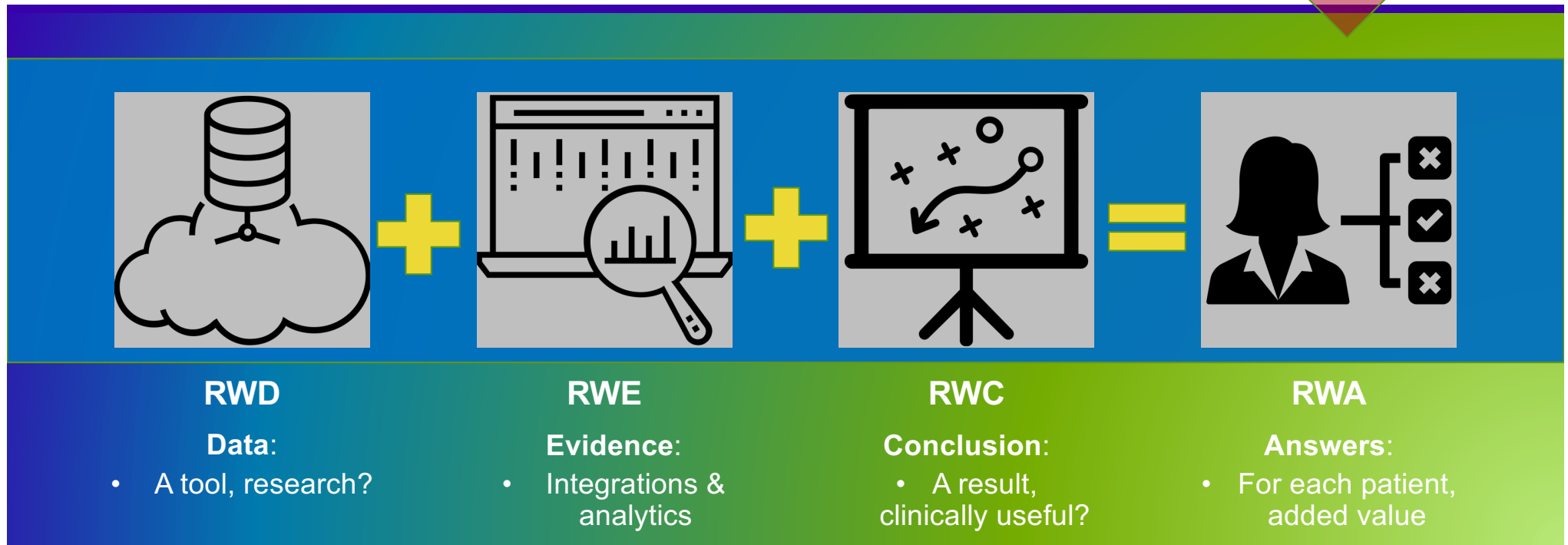
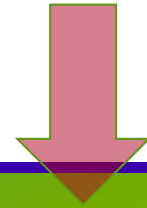
Research shows that despite widespread acceptance of the importance of testing, actual testing rates lag far behind best-practice recommendations for both biomarker testing for somatic (acquired) mutations and other biomarkers, and for germline genetic testing for identification



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RWD & eHRs?

No, WIIFP: What's In It For Patients?



RWD = real world data; eHRs = electronic health records

Know the “why” + “what” + “who” + “how” + “WIIFP”

- What are acceptable **patient benefits**?
 - *E.g., aggregate + individual results*
- Somatic vs. germline vs. immune **mutations**?
- Community leaders + Patient Advocates = **KOLs**
- Include **all patients** for each subtype
 - *E.g., geography, ethnicity, genetic ancestry, immigrant status, culture, gender, sexual orientation, socioeconomic class, age, other factors*
- **Plan** for issues in recruitment, etc.
 - *E.g., access, culture, financial toxicity, comorbidities, environmental issues, chronic stress*
- **Measure** change + lessons **learned** + **communicate**

PROMISE + PRECISION = SUCCESS

Patient-Reported Outcomes (PRO) = results

**“Median overall survival in the
PRO intervention arm was
5 months longer
than the control arm.”**

- Basch EM et al. JAMA & JCO, 2017



- 2007-2011, multiple advanced cancer patients (n=766)
- Wins for patients & system

<http://jamanetwork.com/journals/jama/fullarticle/2630810>

<https://pubmed.ncbi.nlm.nih.gov/30905677/>

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7180512/>

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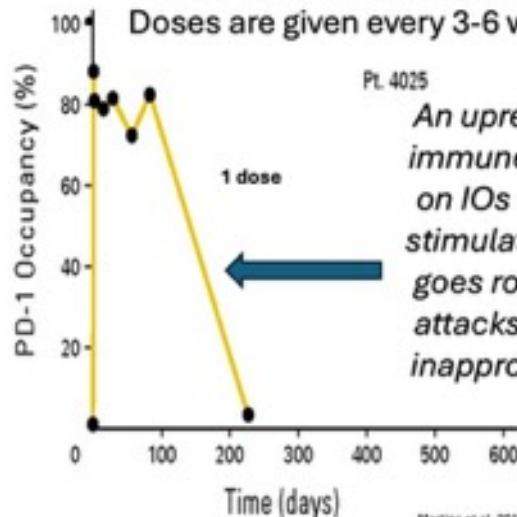
Ex: People want longer AND better quality of lives!

Immune System Changes Linger, Risking Autoimmune Syndromes:

Immune Related Adverse Events (irAEs)

Nivolumab Receptor Occupancy:

- 1 dose blocks the receptor >200 days
- Doses are given every 3-6 weeks



An upregulated immune system on IOs is easily stimulated, then goes rogue and attacks the self inappropriately.

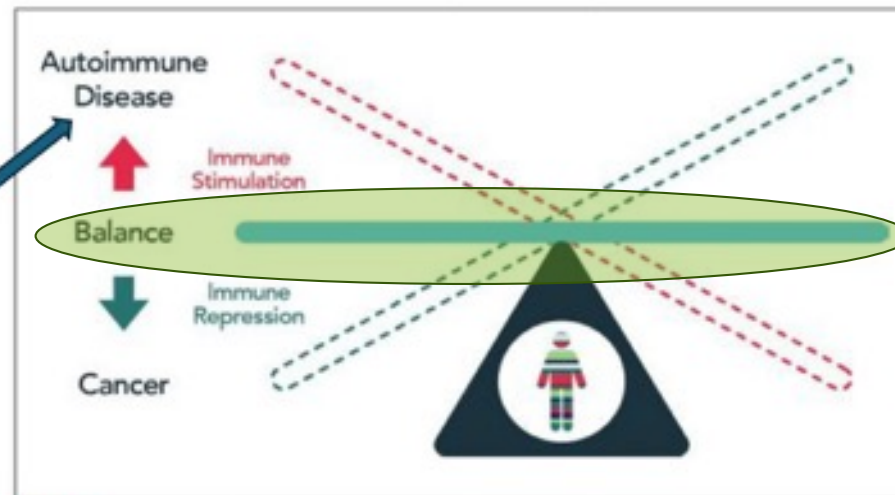


Figure 1 Stimulating the immune system to fight cancer involves monitoring the careful balance between immune repression and stimulation to detect side-effects such as the formation of autoimmune diseases

Martins et al. 2019. Nat Rev Clin Onc
Brahmer et al. 2010. JCO ; Raschi et al. 2020. Target Oncol.
<https://www.dow-online.com/monitoring-the-balance-between-immune-repression-and-stimulation-in-cancer-immunotherapy-1375-201704>

U WEXNER MEDICAL CENTER

- **Balance** is the sweet spot!
- Better answers than steroids
- Consult with other specialty **colleagues** (rheumatology, etc.)

Courtesy of Dr.
Alexa Meara &
<https://autoimmunecancer.org>

AI can **help** if...

Ethical principles are applied

- Respect human dignity, rights & values
 - E.g., equity, fairness, accountability

Chatbots can handle **nonmedical** info

- Can make human conversation more productive

Prompts include **participant needs**

- Ask each cohort population

Master protocol factors are considered

AI can **hurt** if...

Usage is not transparent

- Explain why/how it is being used
- Chatbot creates mistrust when not disclosed
- Some people don't use or want technology

Standards are not applied

- Lack of harmonization + coordination + training

Info dehumanizes sensitive situations

- e.g., rare disease, children
- Redundant questions frustrate

“The bottom line is that AI-created output **isn't yet reliable enough** to be distributed to patients without review and correction.

Industry is working to make it better, and it will improve over time, but I don't know when distributing it **without human review** will be feasible, if ever.”

PAIR group discussion, February 2024

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Help people use genAI better



“Don’t make up things”

- Limits hallucinations & confabulations



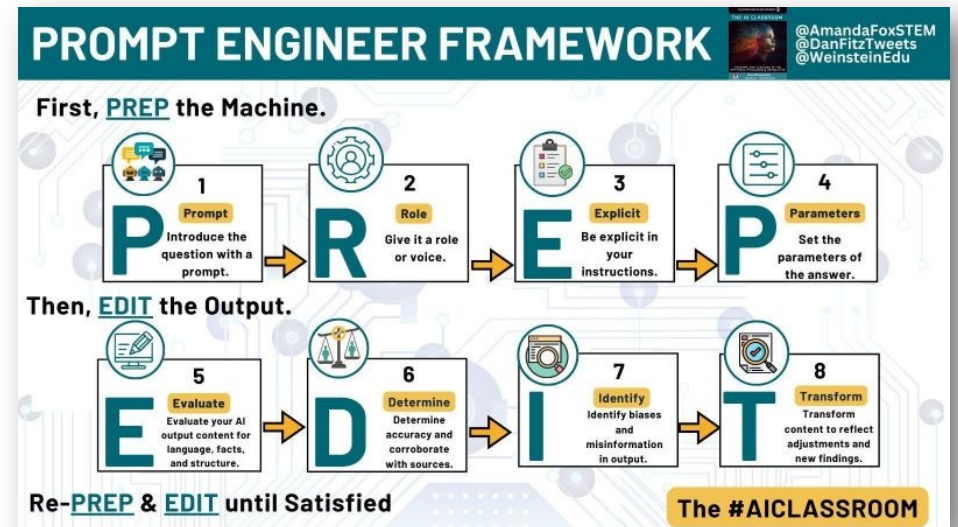
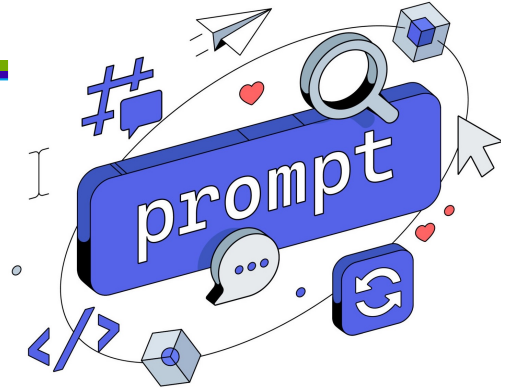
“List limitations & all sources”

- Sources with links
- Separate general vs. specific info



K.I.S.S.

- Don’t say “prompt engineering”
– help them learn how
- Explain like I’m 10-14 years old



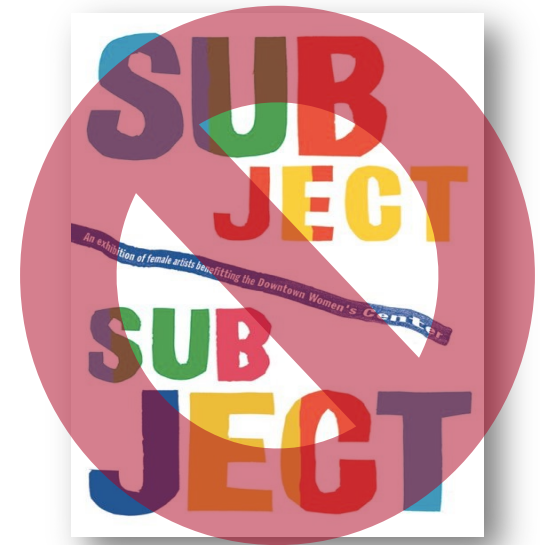
Please help! Stop blaming patients



Patients don't 'fail'
treatment.

TREATMENTS fail patients.

PATIENTS also **respond**
...their disease may not



Let's work together on **accurate** language
+ better clinical trials & care