



Patient Journey: Pathology Data Accelerating Empowerment Through Education

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OCTOBER 6 | 12:15–12:45 PM CT



COLLEGE of AMERICAN
PATHOLOGISTS

Laboratory Quality Solutions

CAP23 | CHICAGO

#PATHDATA

Patient Journey: Pathology Data Accelerating Empowerment Through Education

Future of Cancer Data Summit
College of American Pathologists
Hyatt Regency Chicago
Chicago, IL • October 6, 2023

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Translating Research Across Communities-TRAC

George Mason University –Center for Health and Risk Communication

Disclosures

- No disclosures



HOPE

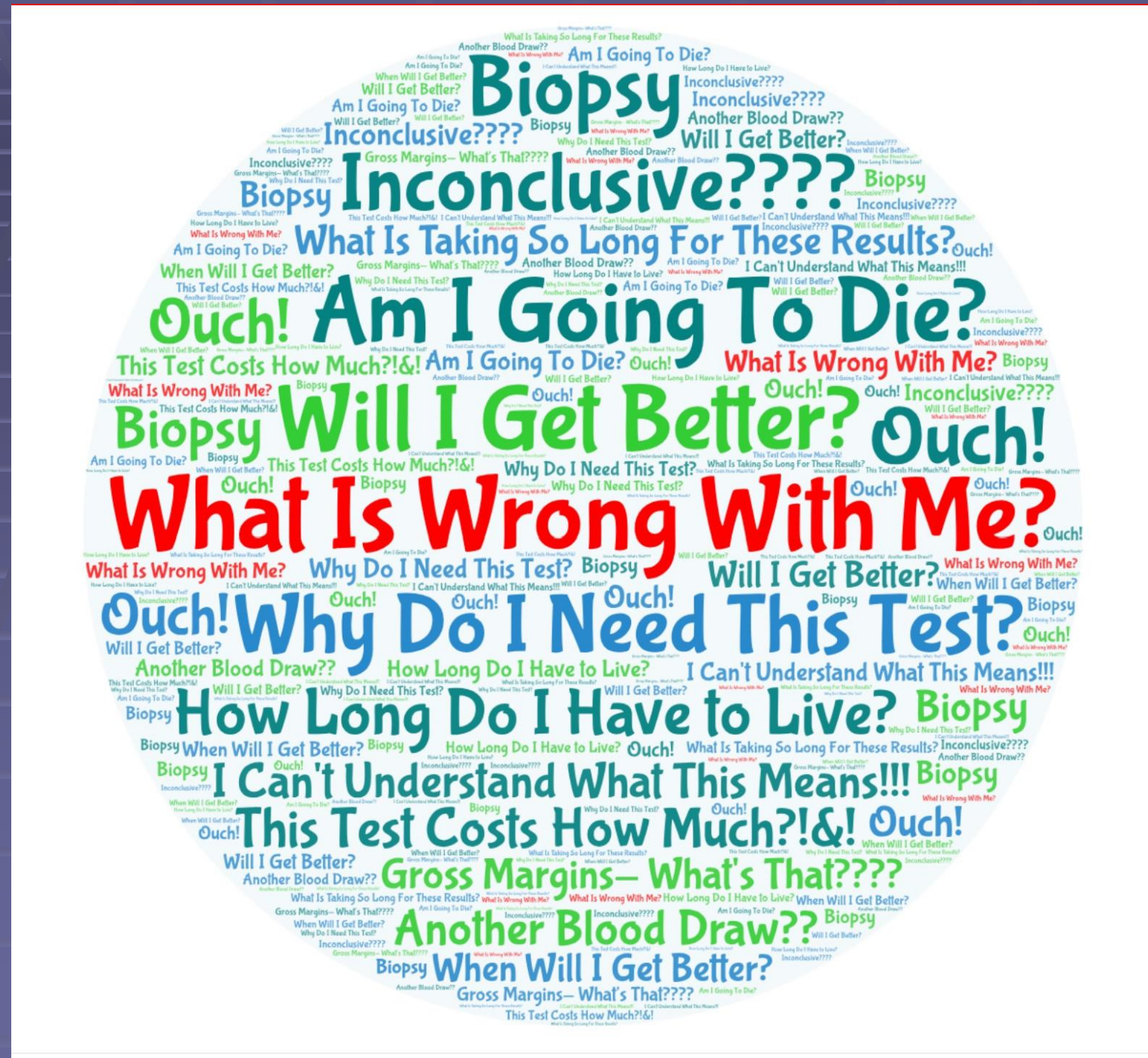
If there is any doubt that patient understanding of pathology data matters, then imagine you're the patient and try to understand what this says!!

“대부분의 사람들이 이해하지 못할 복잡한 과학 용어를 사용하는 대신 분명하고 간단한 방식으로 의학 지식을 전달하는 것이 중요하다. 질병의 원인과 치료법을 평범한 언어로 설명할 수 있는 의사가 기술만 아는 의사보다 환자와 사회에 더 더 도움이 된다.

Pathology Data: Not One Size Fits All



Patient Experience: Not One Size Fits All



Accelerate Empowerment Through Education?

- **Journey – With a Team**
- **Highway – Not a straight line**
- **Road Map -Information/Knowledge**
- **Compass – Empowerment**

~~Pathology~~ Who is in the Biospecimen Sandbox? ~~Patient~~

Advocacy

- ★ Patients
- ★ Caregivers
- ★ Public
- ★ Organizations

Research and Medical

- ★ Health Care Team
- ★ Researchers
- ★ Clinical Trial PI-Team
- ★ Community MDs
- ★ Academic Center MDs and PhDs
- ★ Pathologist

P&P Agencies and Industry

- ★ NCI
- ★ FDA
- ★ CMS
- ★ HRSA
- ★ AHRQ
- ★ NIH
- ★ 3rd Party Payers
- ★ Industry



Across The Scientific Spectrum



**CCH Cancer Summit Oct 2012
Nara, Japan**

- **Physical**
- **Behavioral**
- **Social**
- **Cultural**
- **Economic**
- **Political**
- **Spiritual**
- **Technological**

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Pancreatic Cancer Patient Dilemmas...

**Surgery? Whipple? Bypass? Stent?
Treatment? Radiation? PET Scan?
Cancer Center? Local? Clinical trial?
Eligible? Insurance? Who? What?**

**Invasive ? Non-invasive?
Academic Center ? Local ?
Informed Consent?
Clinical Trial?
Genetic Testing?
Eligible? Insurance?**

**Personalized medicine?
Targeted Therapies?
Chemo-resistant? Receptor?
Side effects?
Gene Mutations? Germline?
Sporadic? Overexpression?**



Understanding Choices In Order To Make Decisions: What Patients Want

Would any of following services provided by trained professional staff be of value when making decisions and understanding your choices:

- Understand the potential risk or benefit of the treatment 85.7% (96/112)**
- Understand what is involved with the treatment itself 85.8% (97/113)**

Treatment Decision Making: In Addition to Their Doctor.....Outside Sources of Info for Patients

Answer Options	GREATLY influences	SOMEWHAT influences	BARELY Influences	DOES NOT influence	NOT applicable
Information received from a patient NGO organization	15	63	19	7	11
Information read in the newspaper or mainstream magazine	5	37	35	27	10
Information heard on the TV or radio	1	20	41	41	11
Information retrieved on the internet	11	60	25	9	8

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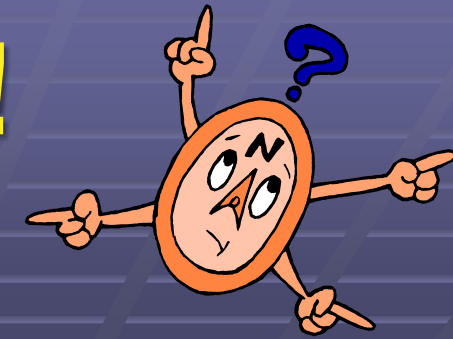


All About the Swabs DIY Pathology!!




Any Upsides??

Patients Need Help!



- **No coordinated data system to help patients understand and manage information**
- **Patients often have a fairly small timeframe to make important healthcare decisions**
- **Patients and caregivers often receive limited clinical trials and disease information & guidance**

Pathology **Data, Data, Data:** Barriers or Building Blocks??

- **Data** Technical jargon: Confusing to patients?
- Report **data** clinical implications? Clarity or not?
- Tissue sequencing **data**: Mutational Burden 
- Patient access to **data** before clinician:
- Patient understanding of **data**: Room to improve?
- Expectations of **data** are all over the place!!
- How can **data** translate into better patient care?

Consequences of Poor Quality- 📉

- **False + and False -**
- **Inaccuracy; non-reproducibility**
- **Erodes public confidence**
- **Wastes time & money**
- **Impedes clinical benefit**
- **Takes another 100+++ Years**

Strengthening Data Use and Understanding for Patients

- 👍 **New frontier requires new attitudes**
- 👍 **Improve X- Sector Capabilities**
- 👍 **Patient-Clinician-Pathologist-Researcher**
- 👍 **Expectations are all over the place**
- 👍 **Translate into better care for patients**
- 👍 **Spend the time and money and do it right**
- 👍 **Financial and operational issues**
- 👍 **Have to stand tall- Do good by doing right**



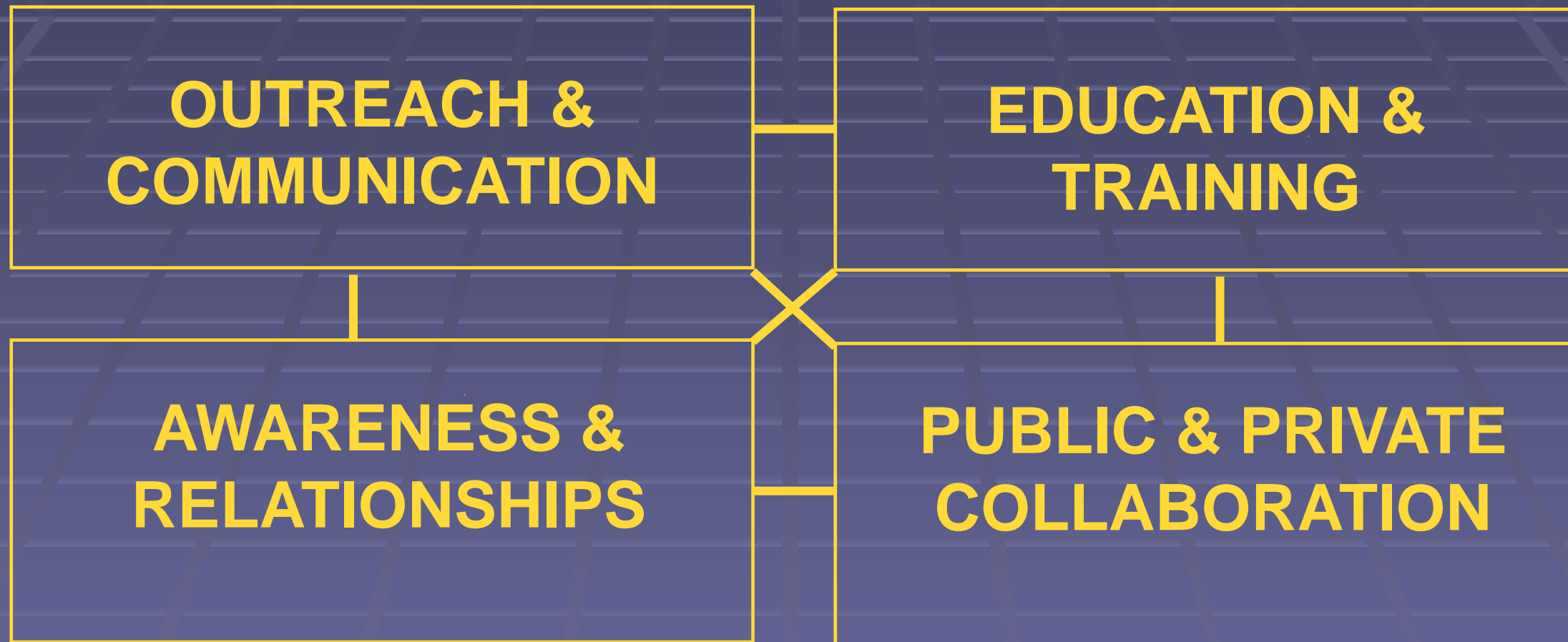
Accelerate Empowerment Through Education!!!

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HOPE: Help Our Patient's Empowerment

- ✓ **Every patient is unique**
- ✓ **Information Is Not Knowledge**
- ✓ **Make Informed Decisions**
- ✓ **Build Your “Team”**
 - ✓ **Healthcare Team and Support Team**
- ✓ **Establish Team “Game Plan”**
- ✓ **Communication Is Vital**
- ✓ **Clear Expectations**

GALA Training and Education Initiative for Strategies and Programs Across Sectors



**Patients; Public; Policy Makers; Researchers;
Clinicians; Industry; Agencies; Payers**

Confidence, Public Trust, Quality

Confidence in you and your team

Confidence in the reason

Confidence in the test

Confidence in the system

Confidence in the procedure

Confidence in the test results

Confidence in the diagnosis

Confidence in the recommendation

Confidence in the outcome

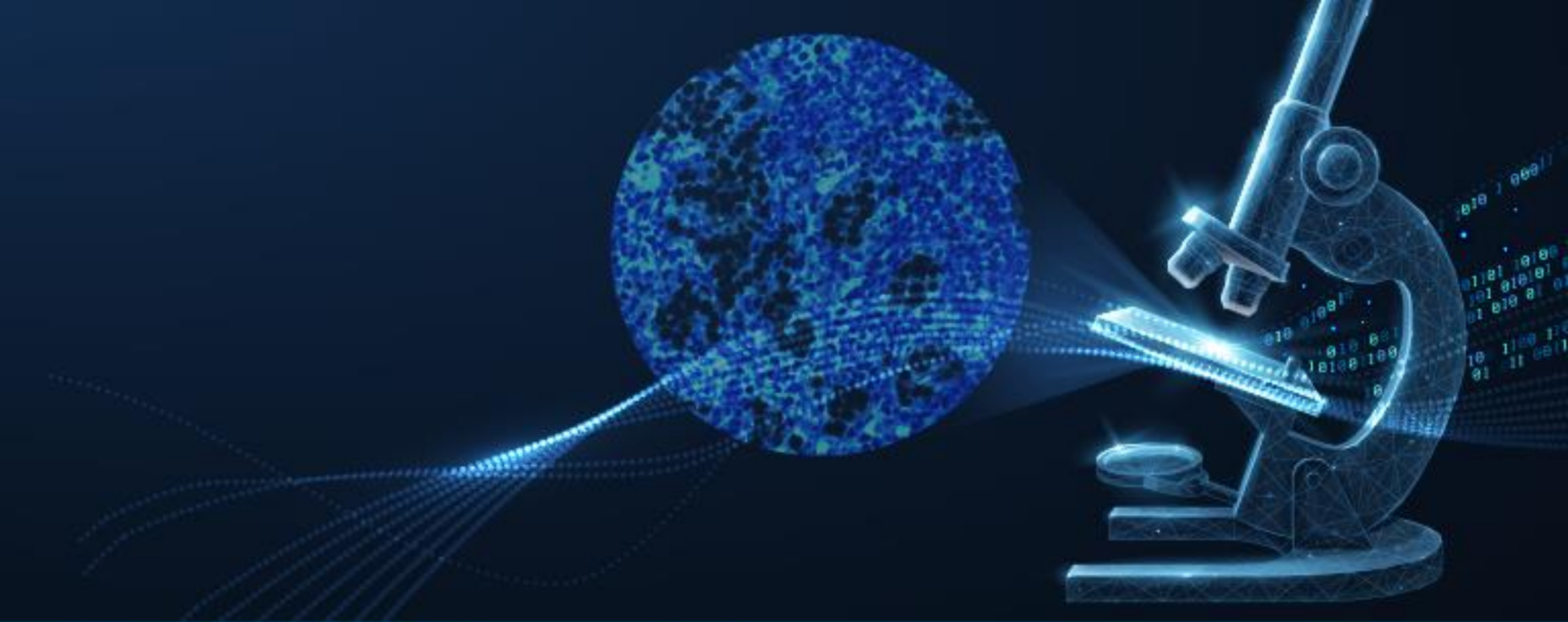
Confidence...period



Why We Must Get This Right...

“ We must harness the scientific, industrial, and social will to accelerate discoveries into accessible and meaningful clinical applications. Patients, families, friends, and loved one are counting on us...Because in the end, it’s not about you, or me, or the science, it’s about the patient.”

Paula Kim - Research & Patient Advocate



**The Future of Cancer Data:
Unlocking Insights With Pathology Reporting Summit**
October 6, 2023