Partnering in the AI Era: Navigating AI's Impact and Opportunities with Patient Advocacy Groups

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From advocacy to algorithms: Patient organizations are beginning to embrace artificial intelligence.

HOW GENERATIVE ARTIFICIAL INTELLIGENCE IS CHANGING PATIENT ADVOCACY

NATIONAL HEALTH COUNCIL

New AI Tool Improves the Accuracy of a Breast Cancer Prognosis

American Cancer Society®

HealthTree Foundation Launches AI-Powered Personalized Clinical Trial Finder

HEALTHTREE FOUNDATION

Global Genes® + RAREX

A new grant will support the integration of AI to enhance data analytics...

CROHN'S & COLITIS FOUNDATION

Crohn's & Colitis Foundation's IBD Ventures Invests in Mobius Care to Advance AI-Powered Precision Medicine for IBD

DKI HEALTH

We wanted to understand how PAGs are using AI, and how pharma can partner on patient-centered solutions.

Secondary Research

- **42 PAGs** reviewed, with zebricks™

Primary Research

- **12 Advocacy Leaders:** 15-min written survey + 60-min Zoom interviews

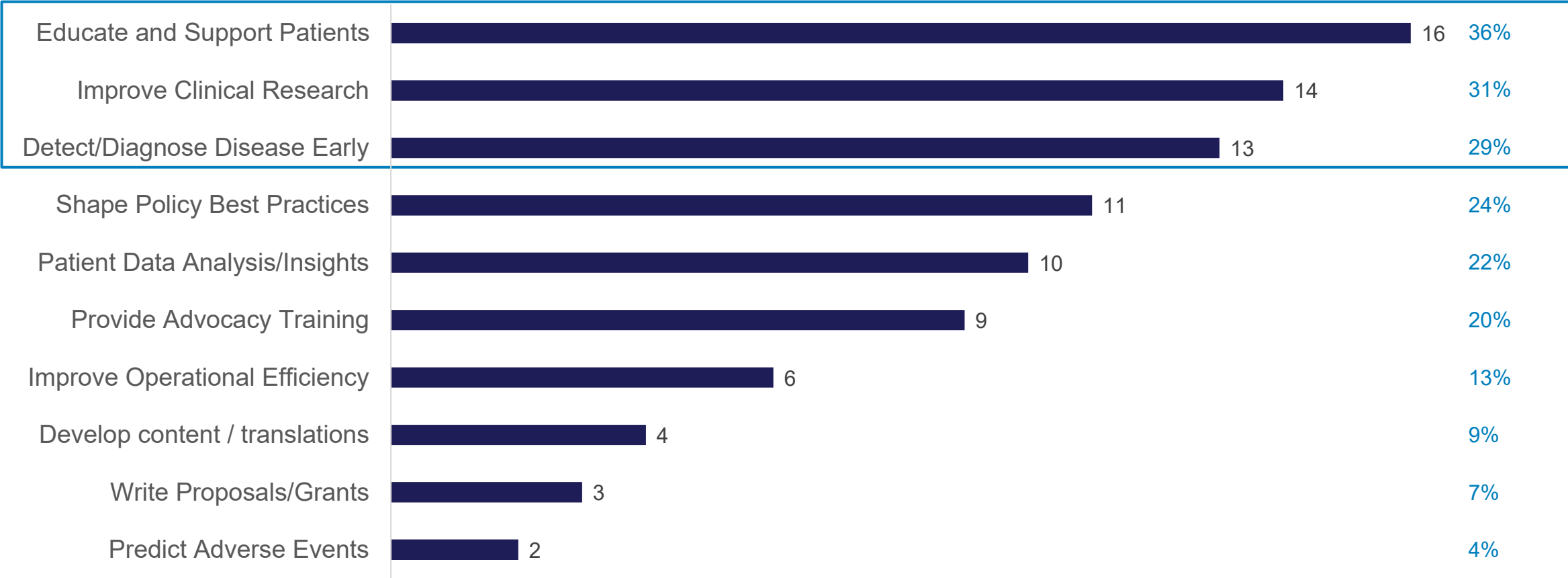- **3 Pharma Executives**: 30-60 min Zoom interviews

Our discussions focused on current use, potential opportunities, risk management, and pharma partnerships.

Key Questions

1. How are you using AI tools and technologies?

2. Where do you see the biggest opportunities?

3. What risks/concerns are important to address?

4. Which areas should avoid AI intervention in decision-making, if any?

5. How do you hope to work with pharma and biotech on utilizing AI?

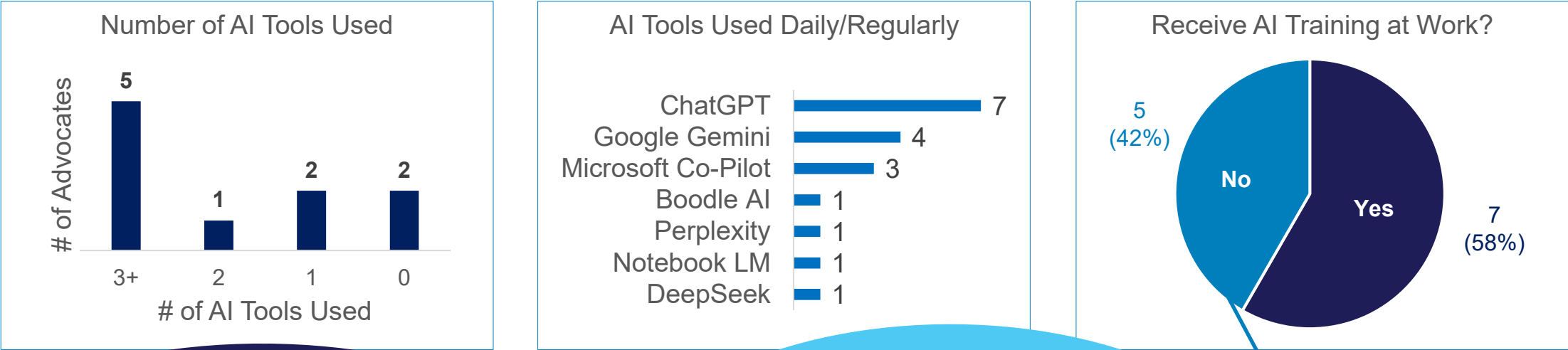# AI is most used by PAGs for patient education/support, clinical research, and early detection and diagnosis.

Number of Patient Organizations Reporting AI Use for Each Purpose (N=45)

Purpose	Number	Percent
Educate and Support Patients	16	36%
Improve Clinical Research	14	31%
Detect/Diagnose Disease Early	13	29%
Shape Policy Best Practices	11	24%
Patient Data Analysis/Insights	10	22%
Provide Advocacy Training	9	20%
Improve Operational Efficiency	6	13%
Develop content / translations	4	9%
Write Proposals/Grants	3	7%
Predict Adverse Events	2	4%

Note: This chart is based on DKI Health's analysis of the data reviewed and insights from interviews; some purposes may overlap and/or be categorized differently.

Several advocacy leaders report using various AI tools to enhance their daily work.

Daily Use of AI Tools by Advocacy Leaders (N=12)

Number of AI Tools Used

- 3+: 5
- 2: 1
- 1: 2
- 0: 2

(# of Advocates vs. # of AI Tools Used)

AI Tools Used Daily/Regularly

- ChatGPT: 7
- Google Gemini: 4
- Microsoft Co-Pilot: 3
- Boodle AI: 1
- Perplexity: 1
- Notebook LM: 1
- DeepSeek: 1

Receive AI Training at Work?

- No: 5 (42%)
- Yes: 7 (58%)

"80% of our staff use AI every day. We embed Boodle.AI into everything we do... there's not a single thing that I write from scratch anymore. We use it for a lot of content, analysis, program development and grant writing… we use it all the time."

Courtney Bugler
ZERO PROSTATE CANCER

"We're using AI for grant writing, developing objectives, simplifying medical language, translating materials, and personalizing content. We're also exploring a newsletter system that aggregates info to better tailor updates for our members"
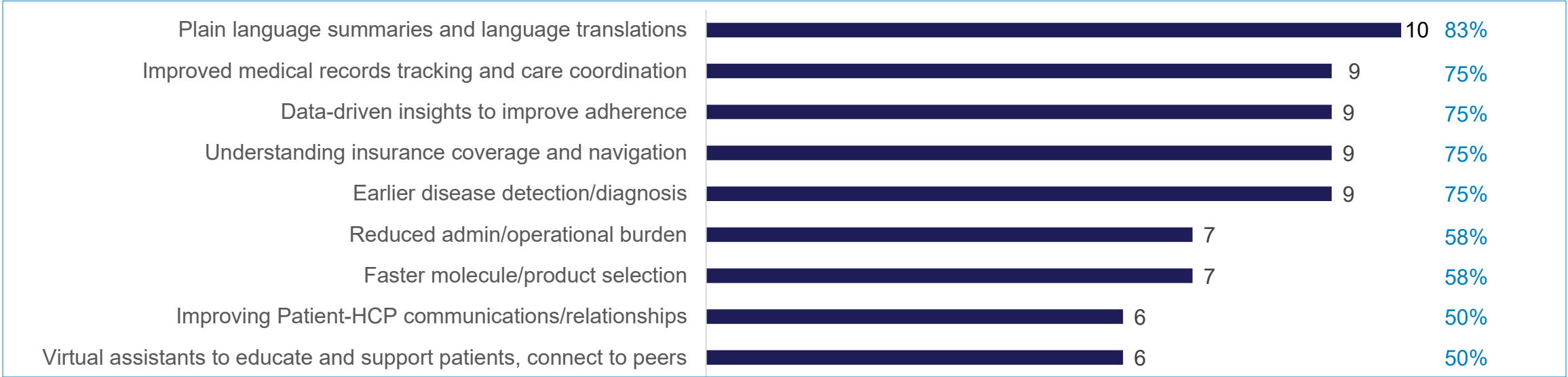
Sue Koob
PCNA

Reasons for not using AI?

"Not prioritized in my current work"

"Not necessary for our advocacy efforts"

They are excited about the potential of AI for patients.

Potential of AI Tools to Benefit Patients (N=12)

Category	Count	Percent
Plain language summaries and language translations	10	83%
Improved medical records tracking and care coordination	9	75%
Data-driven insights to improve adherence	9	75%
Understanding insurance coverage and navigation	9	75%
Earlier disease detection/diagnosis	9	75%
Reduced admin/operational burden	7	58%
Faster molecule/product selection	7	58%
Improving Patient-HCP communications/relationships	6	50%
Virtual assistants to educate and support patients, connect to peers	6	50%

"AI helps bridge the gap between patients and doctors. It helps patients express concerns clearly and allows doctors to better understand their experience, improving healthcare overall"

Alisha Lewis
SICKLE CELL ADVOCATE

"Our goal is not to save money for payers, but to improve the lives of cancer patients and their families. So that's how we want to see AI tools used…"

Jen Grand-Lejano
ACS CAN

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7

Key risks and concerns must be addressed.

Average Level of Concerns about AI for Patients (N=12)

(On a scale of 1-3, where 1= not concerned and 3=very concerned).

Most Concerned

2.9 **Bias and misinformation** in AI algorithms due to biased/inaccurate training data

2.8 **Lack of clear regulations and policies** protecting patient rights and interests

2.5 **Loss of human connection**/empathy/lived patient experience

2.5 **Data quality, privacy, and security** – affecting ability to provide informed consent

2.4 **Lack of patient trust** in AI-generated health information

2.3 **Lack of transparency** in AI decision-making, making it challenging to assess errors

1.8 **High energy consumption** – environmental impact of AI technologies

1.7 **Increase in health inequities**, based on limited access to AI tools (older, rural…)

Least Concerned

1.6 **Risk of HCPs losing influence** or credibility and impacting patient-HCP relationship

"AI is not a doctor, and it's not always reliable—especially in rare disease. If it's getting this much wrong for SMA, which is well-known, it's likely even worse for other rare diseases"

Arya Singh
SMA PATIENT/ADVOCATE

"We do see a challenge in AI not getting it right... trust is an issue, so we have to go slow. We'll follow some of the bigger organizations that are going to move forward with this"

Phil Gattone
NBDF

Governance is necessary – and several organizations are driving development of patient-centered principles for AI.
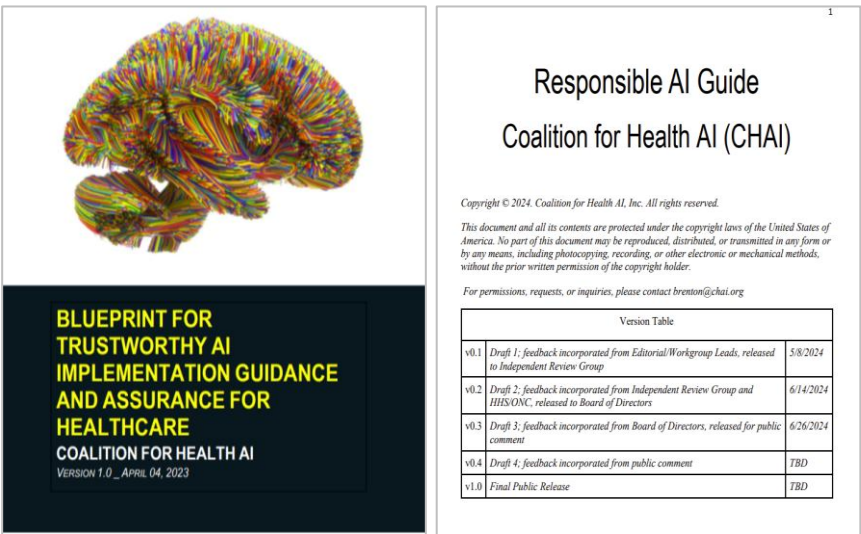
National Academy of Medicine	The Light Collective	Coalition for Health AI (CHAI)

National Academy of Medicine
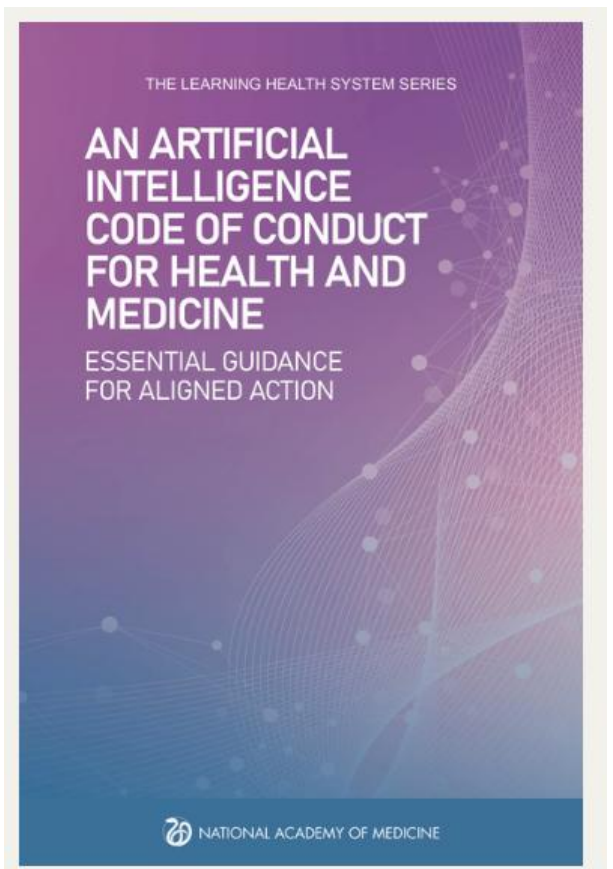
The Light Collective
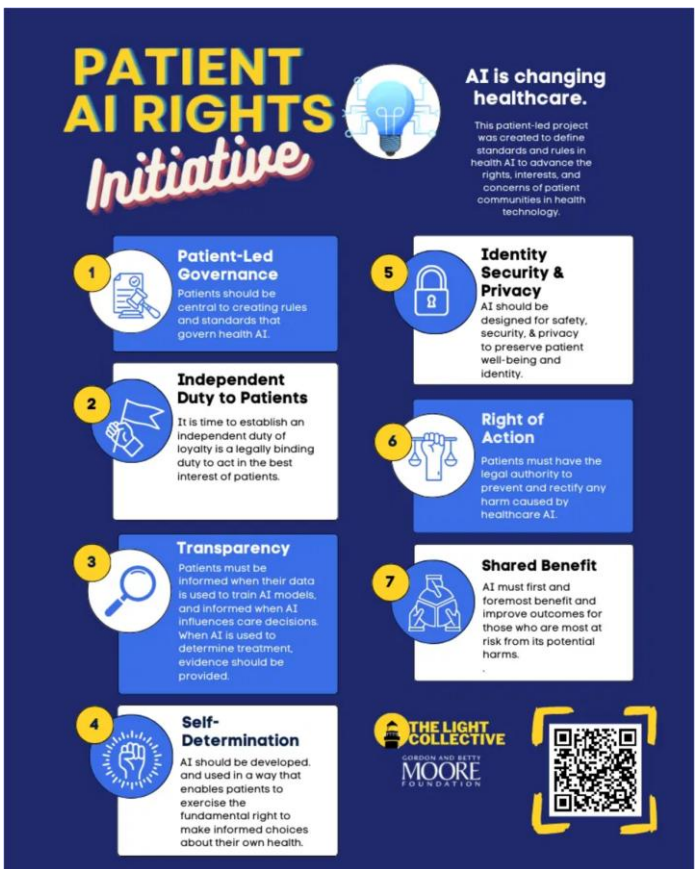
Coalition for Health AI (CHAI)

+ 4 Industry Leaders
+ 19 Health Systems

Pharma-PAG collaborations on AI are in early stages...

PEGGY LILLIS FOUNDATION FOR C. DIFF EDUCATION & ADVOCACY + **RECURSION** pharmaceuticals

IAPO International Alliance of Patients' Organizations + **VIATRIS**

ZERO PROSTATE CANCER + **NOVARTIS**

Partnered in the **ALDER trial** to evaluate a potential therapy for recurrent *C. difficile* infections (REC-3964)

"There are all these molecules but no one knows what they can do or which diseases they'd be effective in, so Recursion was using AI to identify potential treatments for C.diff"

Christian John Lillis
PEGGY LILLIS FOUNDATION

Collaborated on the development of **EczemaLess,** an app that leverages AI to track and manage Atopic Dermatitis

eczemaLess
Track and Manage Atopic Dermatitis with an Artificial Intelligence based EczemaLess App

DOWNLOAD NOW

VIATRIS

Zero is developing an AI-enabled prostate cancer patient support and navigation tool for patients, care partners, and at-risk communities using SMS texting as part of its **"Blitz the Barriers"** initiative

"Novartis is leaning in, doubling down in investing in a lot of cool things, including supporting our use and expansion of AI tools"

Courtney Bugler
ZERO PROSTATE CANCER

But companies are investing heavily, as AI is expected to accelerate drug development and enhance productivity.

> *"GenAI may drive **$60 to $110 billion annually** for pharmaceutical and medical-product industries"*
> McKinsey

Index* of AI Readiness of Top Pharma (2023)

Company	Index
Roche	77.5
Bayer	70.2
Johnson & Johnson	67.4
Novartis	61.4
Sanofi	59.1
AstraZeneca	58.1
Pfizer	57.7
GSK	52.1
Moderna	51.8
Bristol Myers Squibb	49.7
Eli Lilly	48
Merck & Co.	46.8
Novo Nordisk	39.6
AbbVie	36.5
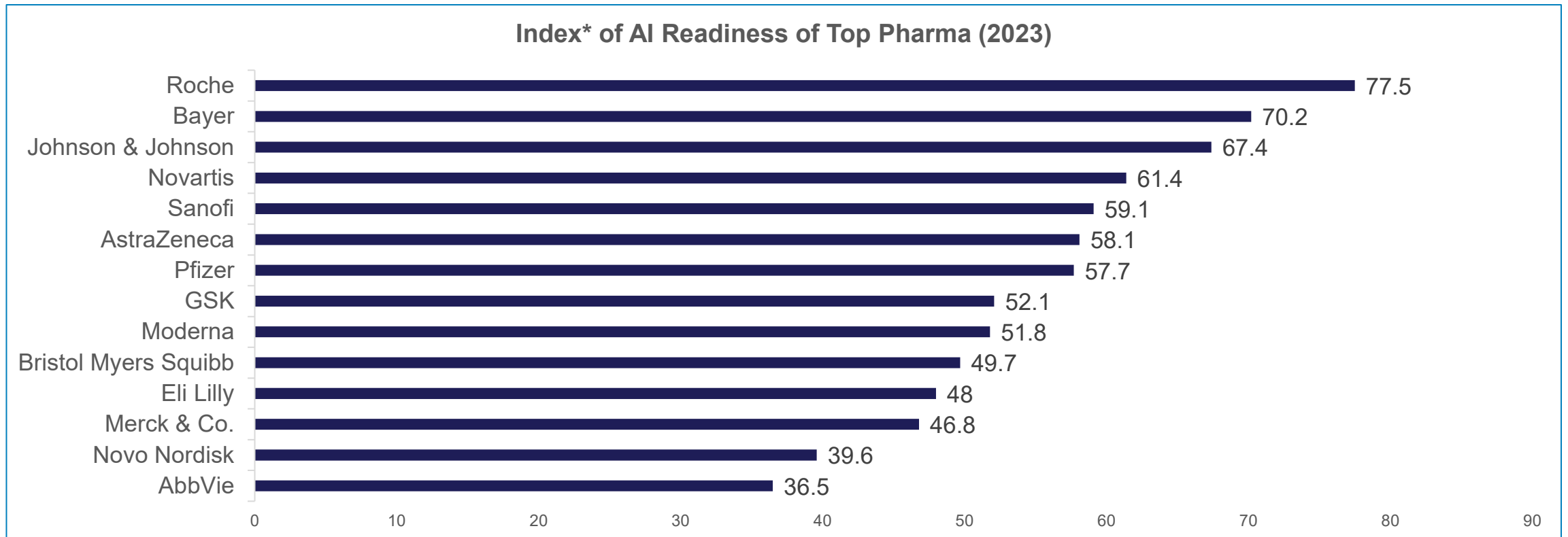
*Index calculated based on talent, innovation and execution of AI by Statista

Many of the AI technologies impact patient care, from drug discovery to patient engagement and reach.

Purpose	Select AI Tools	Adoption by Pharma [A Snapshot]
1 Drug Discovery & Development	TEMPUS, CytoReason, Benevolent[AI]	Pfizer, AstraZeneca, Boehringer Ingelheim, MERCK
2 Clinical Trial Optimization	CytoReason, Trials 360 Better Living Through Clinical Research	Merck KGaA Darmstadt, Germany, ThermoFisher SCIENTIFIC
3 Manufacturing & Supply Chain	Aera TECHNOLOGY	janssen
4 Early Disease Detection	iz.ai	NOVARTIS, Bristol Myers Squibb, sanofi
5 Patient Care & Engagement	happify health, IBM Watson Assistant	Biogen, Johnson&Johnson
6 Patient Data Analytics	TEMPUS, Benevolent[AI]	GSK
7 Content Creation & Marketing	Veeva AI Partner, sendspark, [PERSADO]	Multiple pharma companies

Key takeaways and recommendations for pharma

Unlock Shared AI Opportunities
Identify and scale shared AI use cases through strategic partnerships with PAGs.

Integrate Patient Input Into AI Across Functions
Embed patient and advocacy insights in AI technology adoption across all functions, from R&D and Commercial through Manufacturing and Access.

Adopt Best Practices for AI Governance
Integrate policies and guidance from leading health technology, medical, and patient organizations to incorporate best practices in AI development and deployment.

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