



Patients and Health Care Payers: How Should They Communicate With Each Other When Novel Therapies Are Approved?

December 1, 2021

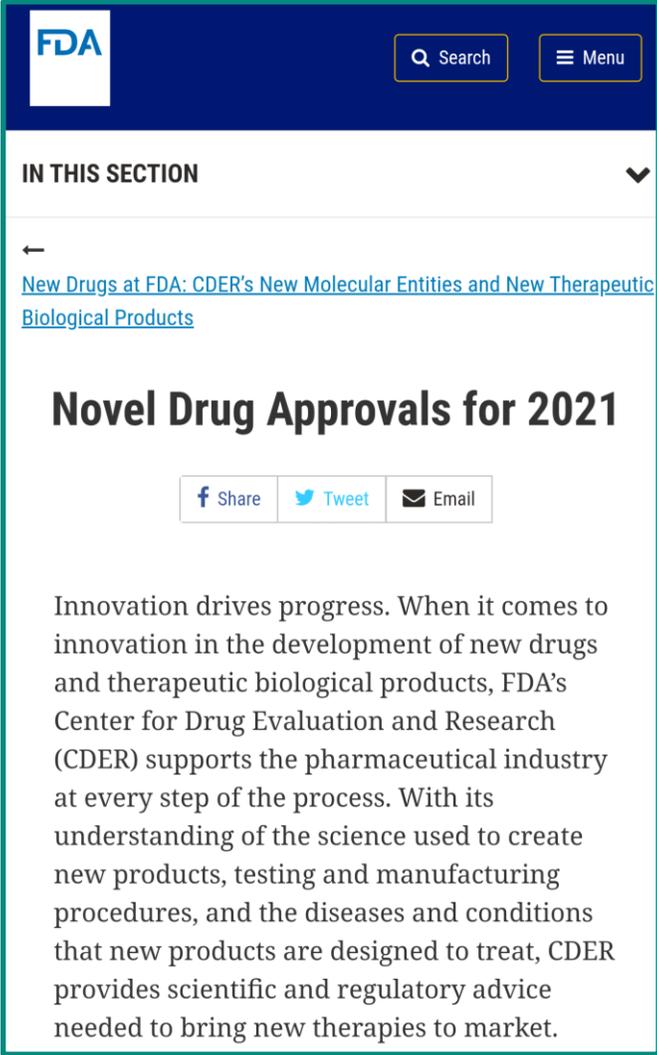
*Project supported by the Patient
Centered Outcomes Research
Institute, Eugene Washington Patient
Engagement Program
Project EAIN-19981*

Principles of Trustworthy Communication

Among Patient Communities and
Health Care Payers Regarding Novel Therapies

Findings from the NEHI Conference on Novel Therapies
and Patient-Payer Communication

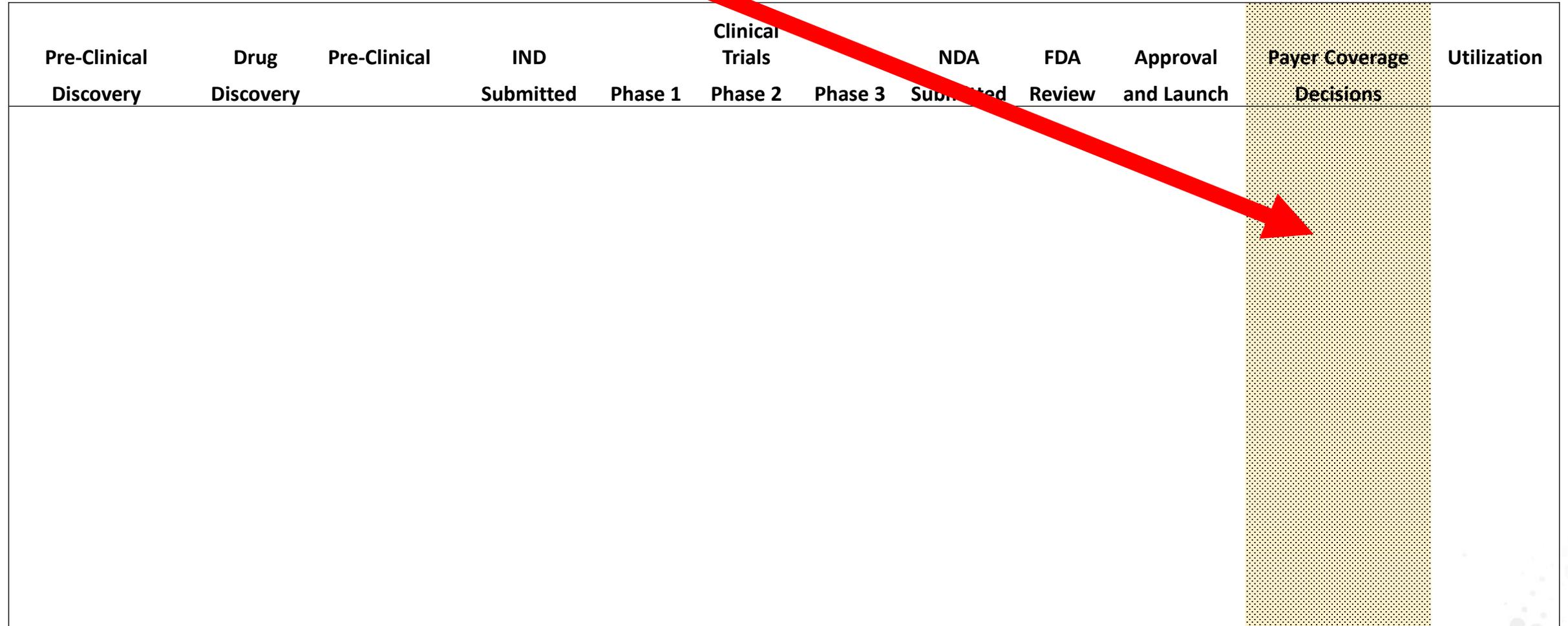
Focus of the Project: Novel Drug Therapies



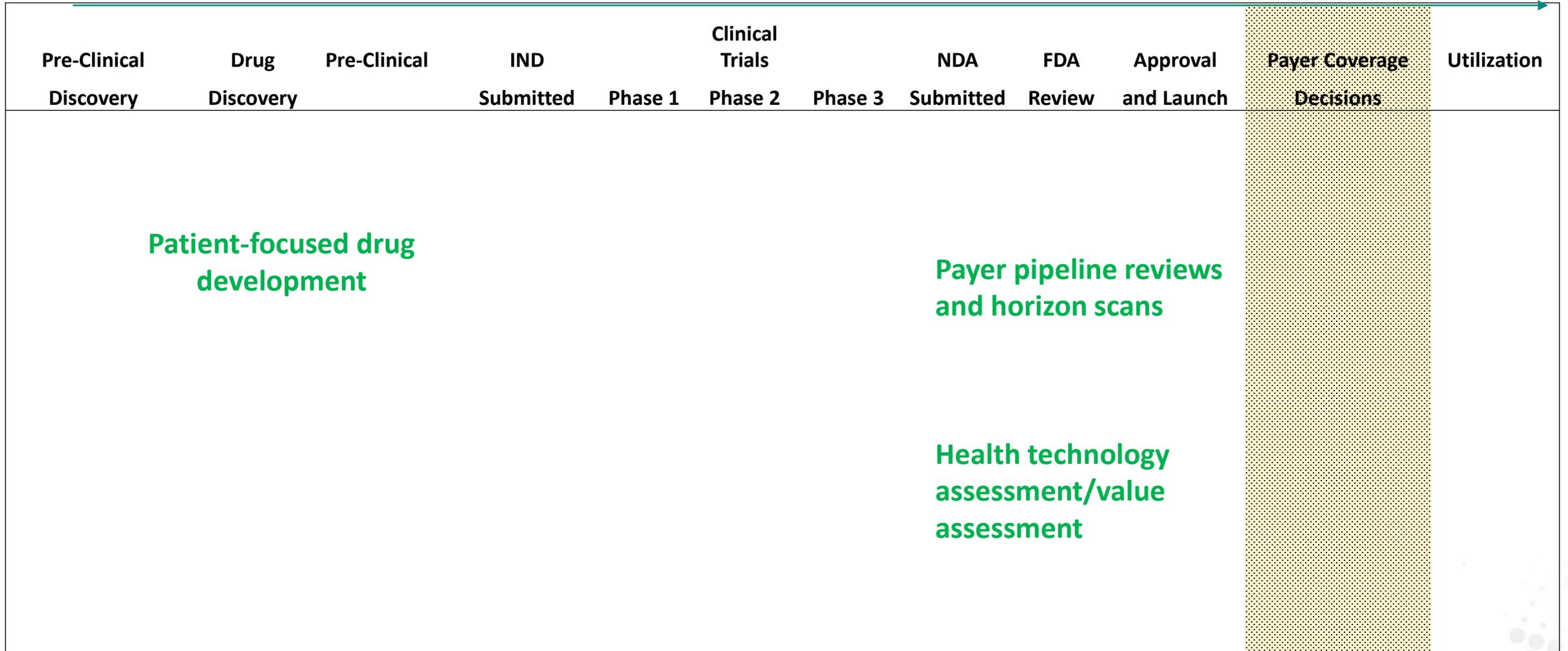
The screenshot shows the FDA website interface. At the top left is the FDA logo. To its right are search and menu buttons. Below the header is a section titled "IN THIS SECTION" with a dropdown arrow. A back arrow is visible. The main heading is "Novel Drug Approvals for 2021". Below the heading are social sharing buttons for Facebook (Share), Twitter (Tweet), and Email. The main text reads: "Innovation drives progress. When it comes to innovation in the development of new drugs and therapeutic biological products, FDA's Center for Drug Evaluation and Research (CDER) supports the pharmaceutical industry at every step of the process. With its understanding of the science used to create new products, testing and manufacturing procedures, and the diseases and conditions that new products are designed to treat, CDER provides scientific and regulatory advice needed to bring new therapies to market."

[FDA/CDER Novel Drug Approval Web Site](#)

TIME →



TIME



What drives the need to communicate?

Key Concerns for Payers

- Cost of novel therapies
- Strength of evidence supporting adoption of novel therapies

Key Concerns for Patients

- Access
 - Prompt coverage decisions
 - Minimal time-to-therapy
- Affordability
- Communicating patient experience
 - Example: patient experience as reported through patient-focused outcome endpoints, endpoints often incompletely or under-reported in clinical evidence
- Communicating patient community **expertise**
 - Learned experience with treatment and management of the disease

An emerging need for communication

“(I)ncluding the patient voice in formulary decisions should be a key objective moving forward.”

AMCP Partnership Forum: Principles for Sound Pharmacy and Therapeutics (P&T) Committee Practices: What's Next?

Journal of Managed Care & Specialty Pharmacy
January 2020

The Challenge

- Little systematic communication now underway from patient communities and health care payers, and vice versa
- Organized engagement is evolving and will likely continue to evolve, (example: patient engagement with health technology assessment)
- Principles of trustworthy communication can guide this evolution

Patient Engagement in Research

- Reciprocal relationships
- Co-learning
- Partnerships
- Transparency, honesty, trust

[PCORI Best Practices in Engaging Stakeholders](#)

Equity and Inclusion Principles (March 2021)

- Inclusion
- Equitable partnerships
- Trust and trustworthiness
- Accountability and actionability

[Equity and Inclusion Guiding Engagement Principles](#)

Code of Conduct: Ethical Values and Principles for Patient Engagement in the Life Cycle of a Medicine

Relevance
Fairness
Equity
Capacity-building
Respect
Integrity
Trust
Clarity of purpose
Beneficence
Non-maleficence
Equality
Transparency
Independence

[Code of Conduct for all stakeholders involved in patient engagement activities within medicines development](#) ,

Innovative Medicines Initiative (European Union, European Patients Forum, European Federation of Pharmaceutical Industries)

Five Principles for Trustworthy Communication

Shared Principles of Good Communication

Trust, empathy, and transparency

Representativeness

**Shared focus on evidence and a
commitment to collaboration**

Timeliness

**Shared focus on total
costs of patient care**

The Five Principles in Detail

Trust, empathy and transparency

- **Patient groups – adopt standards of transparency**
- **Payers- adopt principles of transparency in decision-making**
- **Patients and payers adopt best practices in patient engagement**

Representativeness

- Authenticity of patient representation
- Patients represent heterogeneity and diversity of real-world patient population

Shared focus on evidence and a commitment to collaboration

- Patients share expertise from patient-focused drug development and from the patient journey
- Patients share expertise in identifying expert, front-line clinicians
- Patients and payers share collaboration on development of Real World Evidence

Shared focus on total costs of patient care

- Patients share expertise on managing the physical and cost burden of disease
- Collaboration on development of Real World Evidence
- Appropriate patient engagement with utilization management decision-making
- Patient engagement with value-based arrangements (VBAs)

Timeliness

- Aspire to timely communication that respects payer decision-making cycles

Four Challenges

- **“De-mystifying” payer decision-making**
 - Better understanding in patient communities of the rapidly evolving landscape of services that support payer decision-making
- **Patient engagement in decision-making**
 - Patient engagement in the standard decision-making processes, such as P&T committees and utilization management decisions
- **Systematizing communication**
 - Finding “common points of entry” for patient groups to address larger payer audiences
- **Timeliness**
 - Assuring timely patient engagement with payer decision schedules

Today's Panel



Jennifer Graff, PharmD
Academy of Managed
Care Pharmacy



Annie Kennedy
EveryLife Foundation for
Rare Diseases



Donna Messner, PhD

- On a scale of 1-5, how applicable are our principles of communication to your current work?
- On a scale of 1-5, how applicable will these principles of communication be to your work over the next 3-5 years?
- Which of the 5 principles is the most important to your goals or mission?
 - Trust, empathy, transparency
 - Representativeness
 - Shared focus on evidence and a commitment to collaboration
 - Timeliness
 - Shared focus on total costs of patient care

Upcoming NEHI Briefing



Prior Authorization: Can we all be happier?

In this briefing, hosted by NEHI President and CEO Wendy Warring, we will report on the recommendations from our 9-month project on prior authorization. The project's goal was to develop consensus for feasible reforms among members of a Steering Committee that included providers, payers, and representatives of employer and consumer organizations.

Most of the discussion, however, will be devoted to hearing the perspectives on these and other suggested reforms from five individuals who have studied prior authorization and worked to improve it. Our experts come from different areas of the health care system, and we anticipate a lively, informative, and interesting discussion with the opportunity for audience members to pose tough questions.

Wednesday, Dec. 15, 1 – 2 p.m.

[Register Now](https://nehi-us.org/events) | nehi-us.org/events

Thank You



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