

# Portal to support patient engagement projects

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*For the Cancer Data Ecosystem and Network for Direct Patient Engagement Teams*

# Overview:

## Direct Patient Engagement for Discovery Science Research Program

### June 2018 BSA Presentations

FUNDAMENTAL RESEARCH



*Research to Develop Evidence-Based Approaches to Patient Engagement*

DEMONSTRATION PROJECTS



*Patient Engagement for Priority Cancer Sequencing (PE4PC-Seq)*

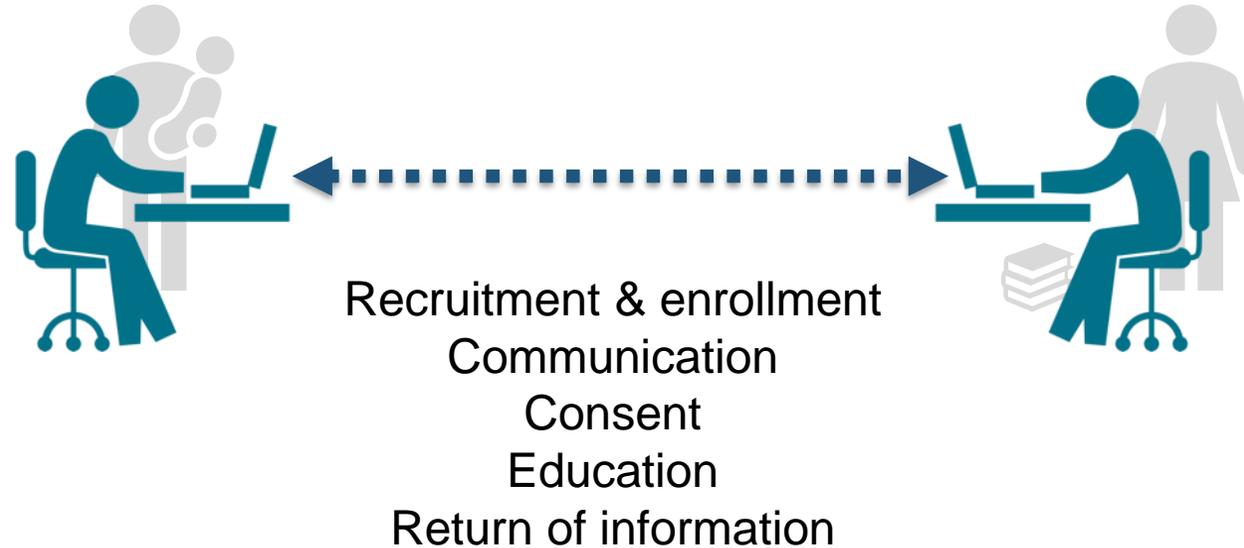
PATIENT PORTAL



## The Blue Ribbon Panel recommended a portal to support patient engagement, twice.

- Enhanced Data Sharing Working group:
  - portal to enable individuals to contribute data for scientific research as part of National Cancer Data Ecosystem
- Recommendation for Network for Direct Patient Engagement:
  - a place for patients to consent to share their health data in order to enhance knowledge around personalized medicine

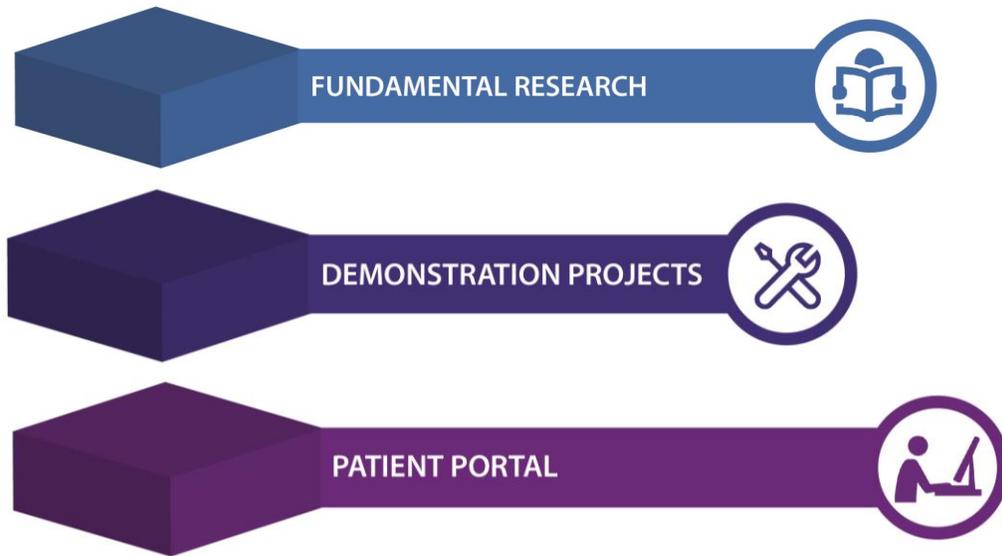
Participants & project team interact directly via a portal to collaboratively advance cancer research.



Terms:

- *Portal*: Web-site to enable ongoing interaction to collaboratively advance cancer research.
- *NCI Cancer.gov Network for Direct Patient Engagement (NDPE) Portal*: Project to support NCI efforts that require a portal as one piece of an engagement strategy.

# NCI projects may utilize portals as one element of engagement approach.



## Existing engagement projects

- Cancer Moonshot<sup>SM</sup> Biobank (FY17)
  - Longitudinal biospecimen collection from diverse cohort
  - Portal to support ongoing interactions
- Center for Cancer Research Rare Tumor Patient Engagement Network (FY18)
  - Advance research and provide personalized care
  - Portal for data self-reporting & trial recommendations

## Future engagement projects

- Research to Develop Evidence-Based Approaches to Patient Engagement (Winn)
- Patient Engagement for Priority Cancer Sequencing (PE4PC-Seq) (Mechanic)

## *Cancer.gov NDPE Portal* will support existing & future engagement efforts.

- Reduce development time and costs for NCI engagement projects, building on current digital properties
  - Avoid duplication of efforts
  - Leverage digital presence of cancer.gov
- Support an integrated experience for individual participants
  - Find relevant projects for participation
  - Avoid need to re-enter demographic information
  - Return information about contribution to research

## *Cancer.gov NDPE Portal includes Patient Gateway & Modular Components.*

- Patient Gateway on cancer.gov
  - Single point of entry (e.g., web site) to all NCI patient engagement efforts
  - Uses direct engagement approaches to enable individuals to participate in cancer research studies
- Modular Components
  - Re-usable & customizable components that support launch of study-specific portals

# *Patient Gateway* will amplify communication of engagement efforts.

*Patient Gateway*: a single point of entry on cancer.gov, NCI's website featuring information for patients & health professionals

Cancer  
Moonshot<sup>SM</sup>  
Biobank

Adult  
Rare Tumor  
Patient Engagement  
Network

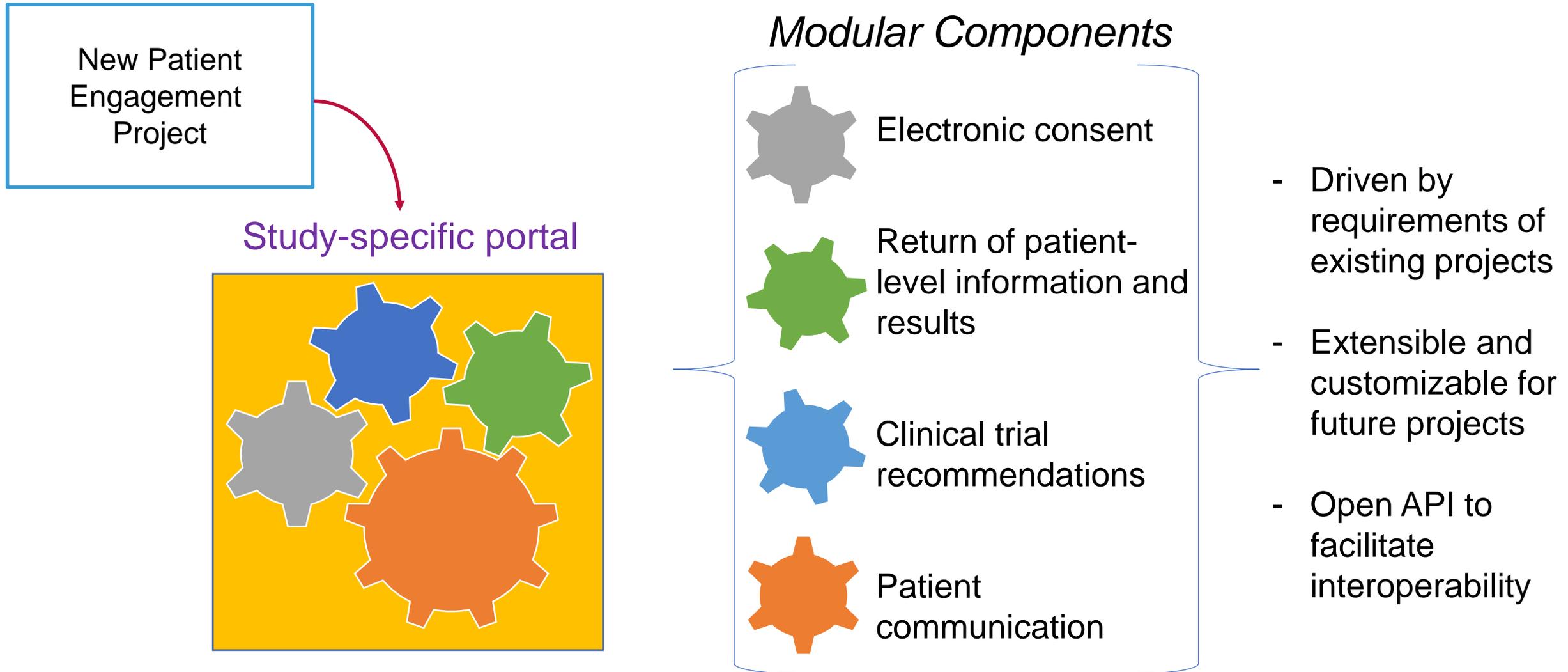
Pediatric  
Rare Tumor  
Patient Engagement  
Network

Future NCI Patient  
Engagement  
Projects

Global services support multiple engagement studies.

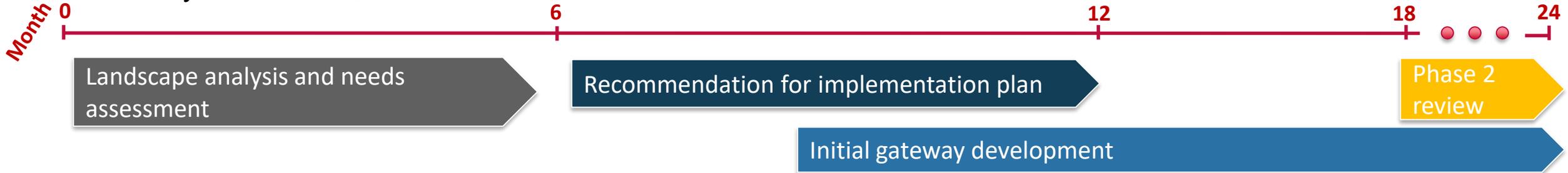
- Search & filter across projects
- Secure account registration & log-in
- Lay summaries of studies
- Links to education & resources, including cancer.gov & NCI contact center

# Re-usable *Modular Components* will support study-specific portals.



# Phase 1: Generate recommendations for *Modular Components* & launch *Patient Gateway*.

Multi-year contract, issued in FY19



- Establish internal advisory team
- Survey NCI needs & requirements
- Identify needs & preferences of individual participants
- Identify existing resources

- Recommendation for each module
- Plan to integrate materials developed by early adopters
- Plan to incorporate best practices for engagement

- Develop *Patient Gateway* integrated with cancer.gov
- Integrate Moonshot Biobank and RTPEN portals into *Patient Gateway*

*All activities in collaboration with  
NCI Office of Communications and Public Liaison (OCPL)* 10

## Phase 2: Develop *Modular Components*.

- Deploy recommendations for *Modular Components*
- Extend *Patient Gateway* for newly identified needs
- Continued, iterative development based on user needs and feedback
- Develop mechanism for third-party component contribution
- Plan for sustainability, dissemination & outreach

# Cancer.gov NDPE Portal will leverage existing resources & expertise.



Office of Communications  
and Public Liaison



Moonshot Biobank

Center to Reduce Cancer  
Health Disparities



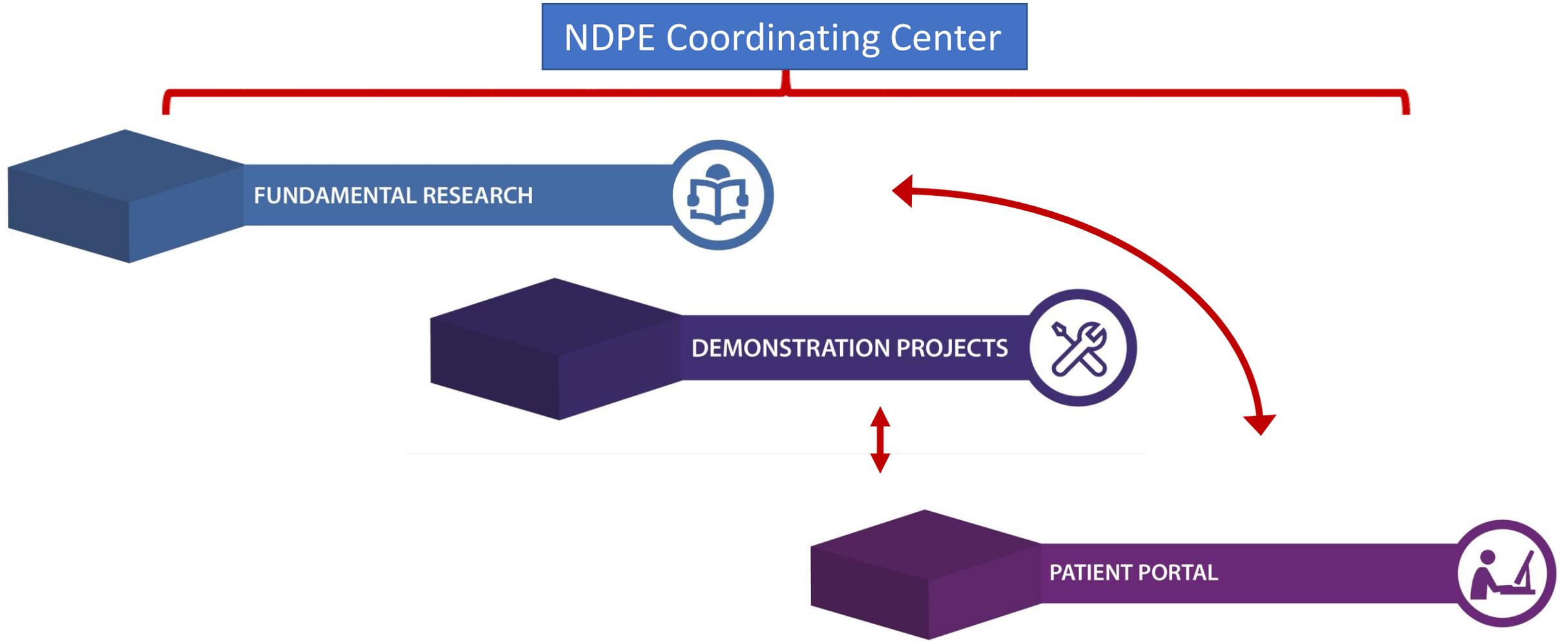
Rare Tumor Patient  
Engagement Network  
(Center for Cancer Research)

Office of Advocacy  
Relations



Coordinating Center for  
Clinical Trials

# Integration: Direct Patient Engagement for Discovery Science Research Program





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CANCER  
INSTITUTE**

[www.cancer.gov](http://www.cancer.gov)

[www.cancer.gov/espanol](http://www.cancer.gov/espanol)