



Patient Participation in Research

Wendy Adams, Research Grant Director

NASEM July 11, 2024



Bay Area Lyme
FOUNDATION

Introduction

- My story
- Bay Area Lyme Foundation



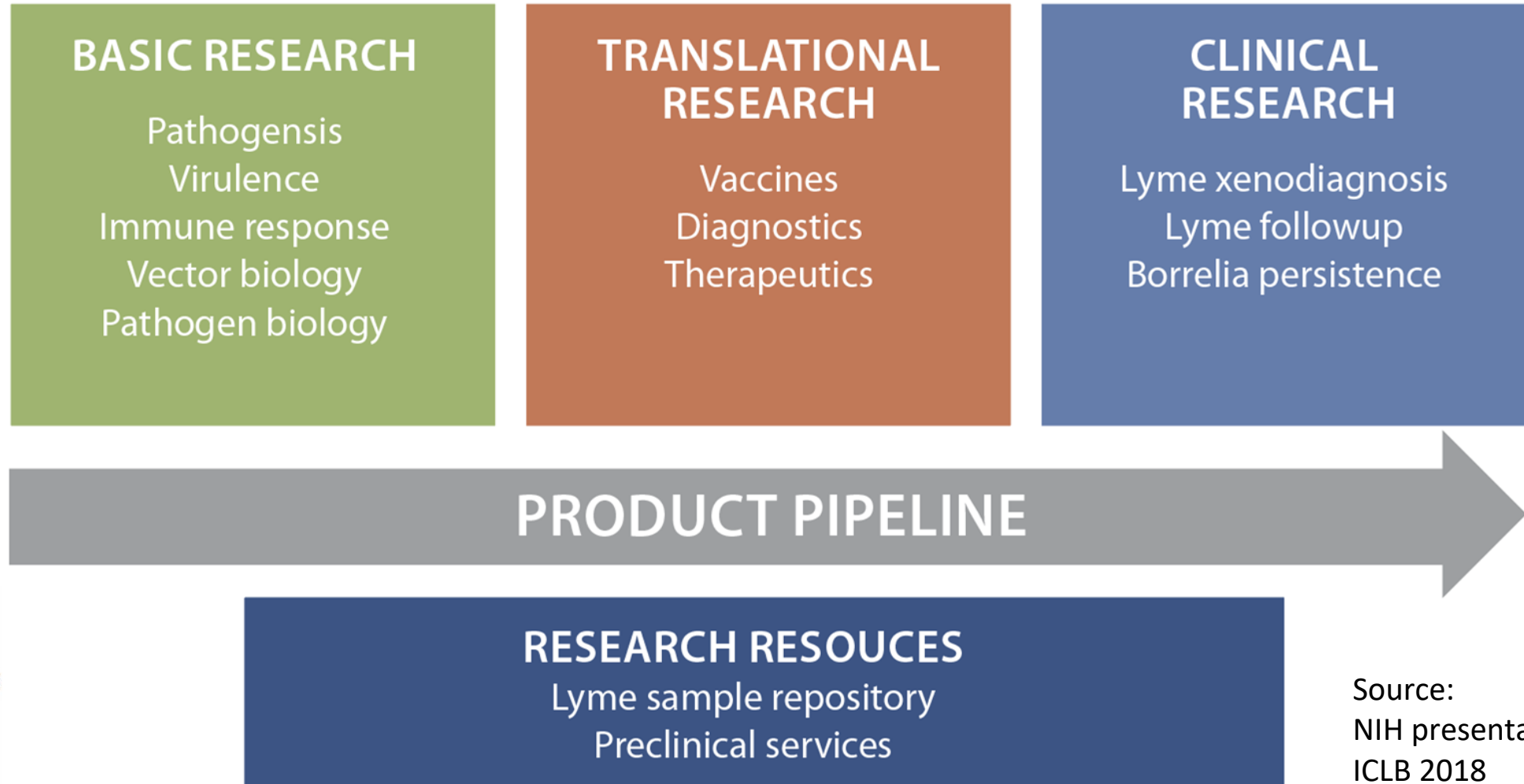
Patient research priorities - AAAS 2015

Top Ten Lyme Disease Research Questions

- | | | | |
|---|--|----|--|
| 1 | What DIAGNOSTICS would be both highly sensitive and specific for the disease and co-infections? | 6 | What NEUROLOGICAL DISEASE rehal disease? |
| 2 | What TREATMENTS treatment protocol to restore Lyme disease? | 7 | Why PERSISTENT DISEASE Lyme disease? |
| 3 | What DIAGNOSTICS diagnosis on the course? | 8 | What PERSISTENT DISEASE stage Lyme disease mission? |
| 4 | What TREATMENTS protocols are most effective? | 9 | How CO-INFECTIONS immune response patients with Lyme disease? |
| 5 | What NEUROLOGICAL DISEASE may be? | 10 | Are there TREATMENTS red for specific symptoms (e.g. neurologic)? |

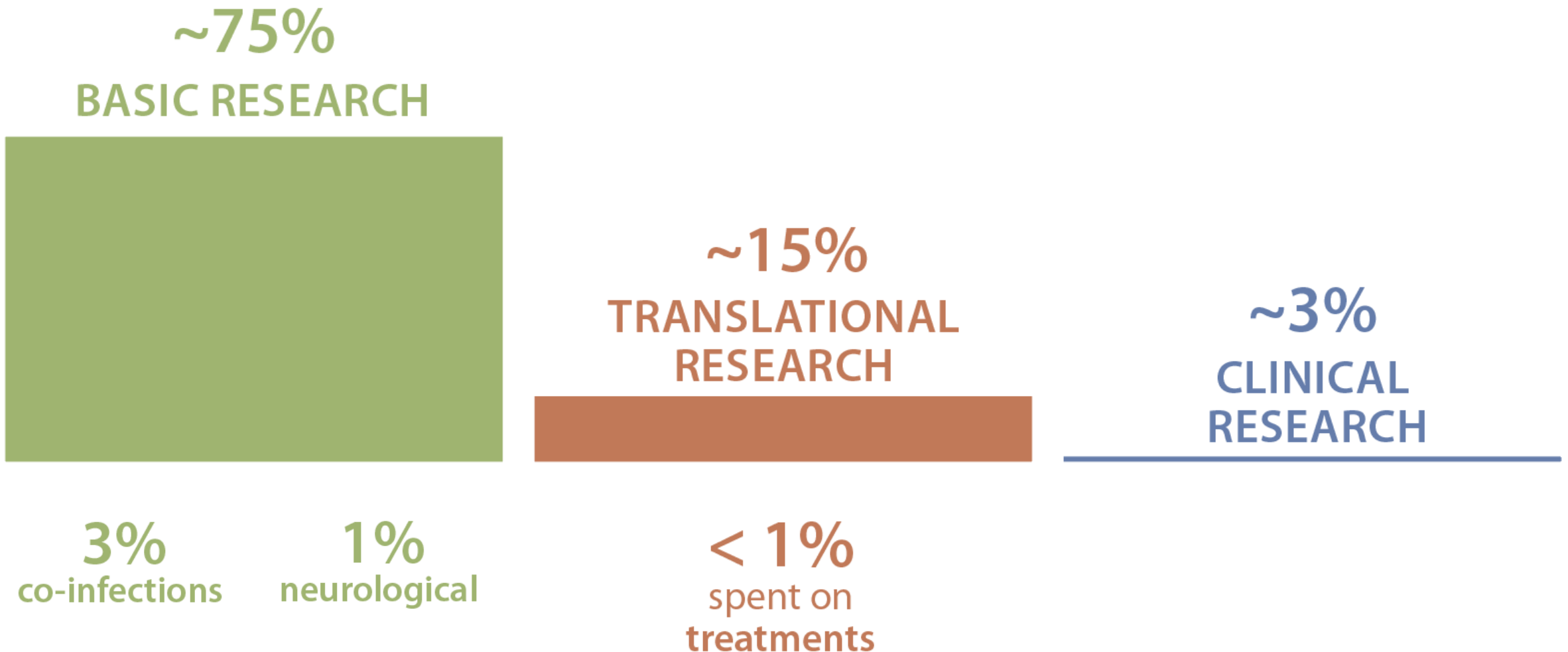


NIAID Extramural Tick-borne Disease Research



Source:
NIH presentation
ICLB 2018

NIAID Tick-borne Disease Funding 2013-2021



Source: NIH RePORTER

Patients help drive research engine in TBD

PATIENT INVOLVEMENT



INVESTIGATOR INITIATED



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PATIENT PARTNERED



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PATIENT LED or PATIENT FUNDED

Clinical Trials Network

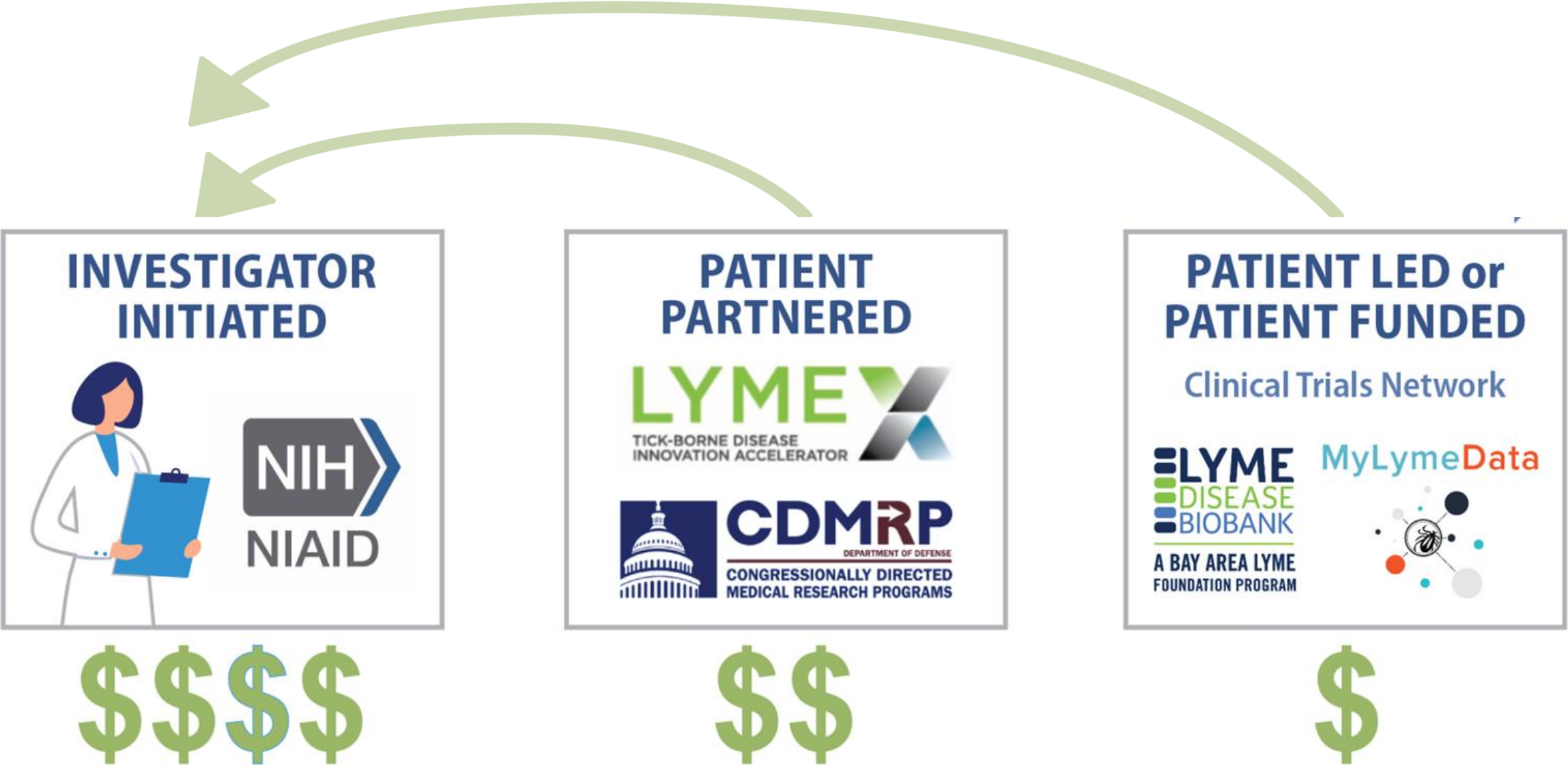


MyLymeData



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Patients help drive research engine in TBD



NIAID RFA for Persistent Disease Research

R01s funded through RFA AI-22-046

Contact PI	Title
John Aucott	Determinants of Post-Treatment Phenotypes in Lyme Disease
Linden Hu	Auto-antibodies as predictive markers for Post treatment Lyme Disease Syndrome
Brandon Jutras	The natural release of unusual peptidoglycan fragments drives persistent Lyme disease symptoms in susceptible hosts
Cherie Marvel	Neuroimaging and blood markers in post treatment Lyme disease with persistent neurologic symptoms
Michal Tal	Unlocking serology's secrets: harnessing novel immune biomarkers to predict Lyme disease progression and recovery
Rafal Tokarz	Genetic basis for persistence of <i>Borrelia burgdorferi</i>
Neal Woodbury	Discovery of early immunologic biomarkers for risk of PTLDS through machine learning-assisted broad temporal profiling of humoral immune response

Dr.
Bowden
NASEM,
4/22/24

Patient-led efforts fueling research engine in advance of NIAID funding

RESEARCHER	USED PATIENT-LED BIOBANK SAMPLES	PATIENT FUNDING	CDMRP FUNDING
John Aucott		✓	✓
Linden Hu	✓	✓	✓
Brandon Jutras	✓	✓	✓
Cherie Marvel		✓	✓
Michal Tal	✓	✓	
Rafal Tokarz	✓	✓	✓
Neal Woodbury	✓	✓	✓

MyLymeData - largest TBD patient registry

Table 3

Clinical and Diagnostic Characteristics of MyLyme Data Sample

Characteristic	All
Clinician diagnosed ^a	100%
PLD/CLD ^b	100%
Recollection of EM rash ^c	45%
With supportive lab tests ^d	82%
1 or more coinfection ^e	80%
Diagnostic Delays	
Diagnosed within 1 month ^f	8%
Diagnosed at late stage ^g	82%

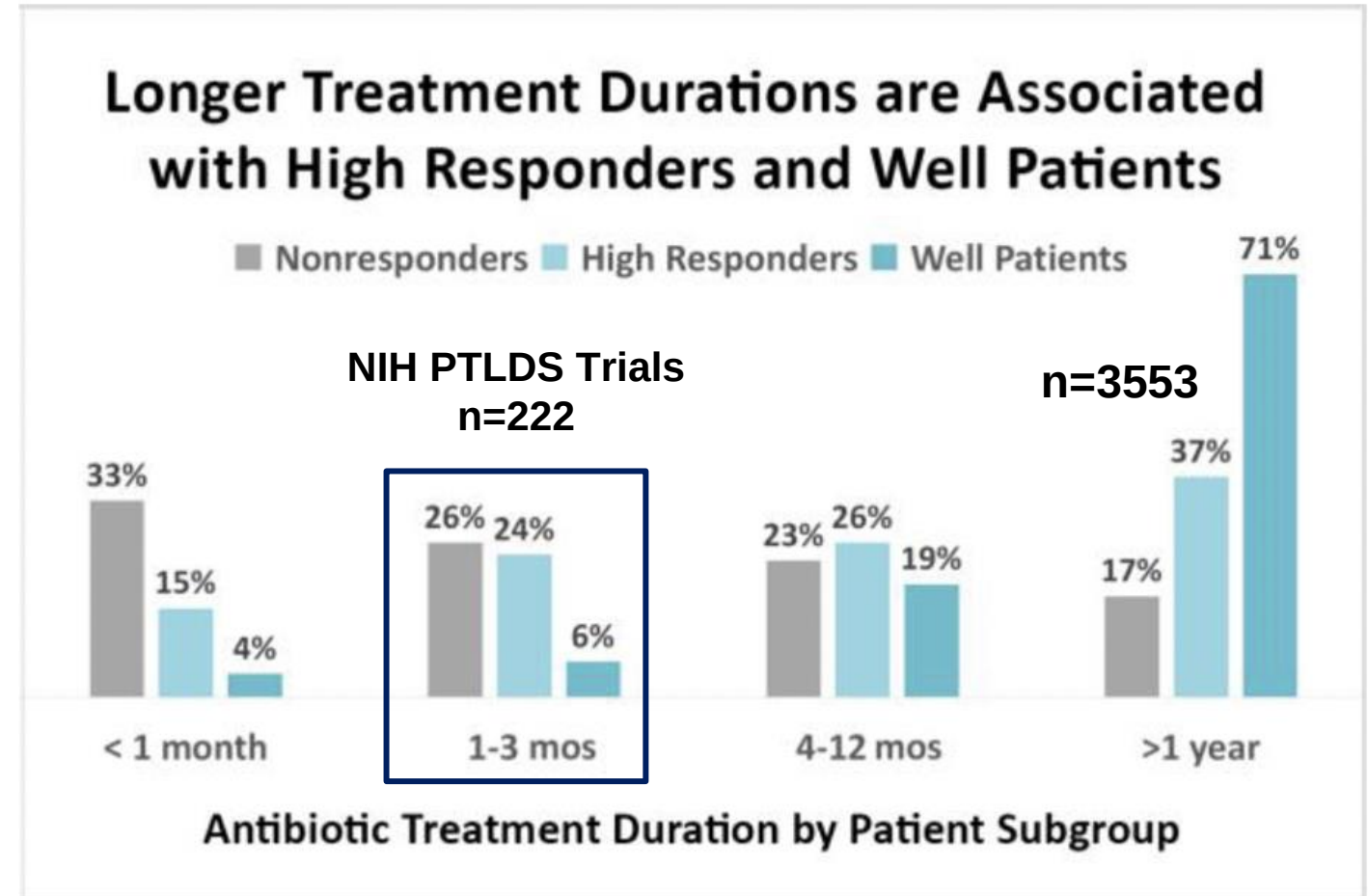
Int J Med “Does Biological Sex Matter in Lyme Disease?
The Need for Sex-Disaggregated Data in Persistent Illness”
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10284166/>

MyLymeData shows that patients do improve

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Healthcare “Antibiotic Treatment Response in Chronic Lyme Disease: Why Do Some Patients Improve While Others Do Not?”

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7712932/pdf/healthcare-08-00383.pdf>

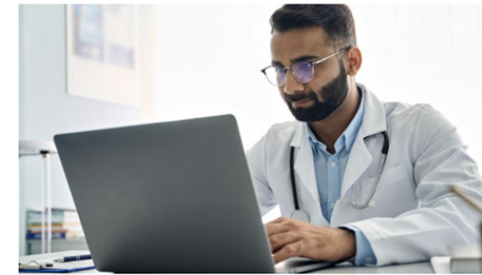
NIH has already embraced registries for IACI



National Heart, Lung,
and Blood Institute

NIH RECOVER makes long COVID data easier to access

April 25, 2024, 1:00 PM EDT



*Deidentified data from thousands of adults with long
COVID are now available to researchers*

WHAT: Secure data from more than 14,000 adults who
participate in National Institutes of Health [observational
research](#) on long COVID are now available to

CONTACT

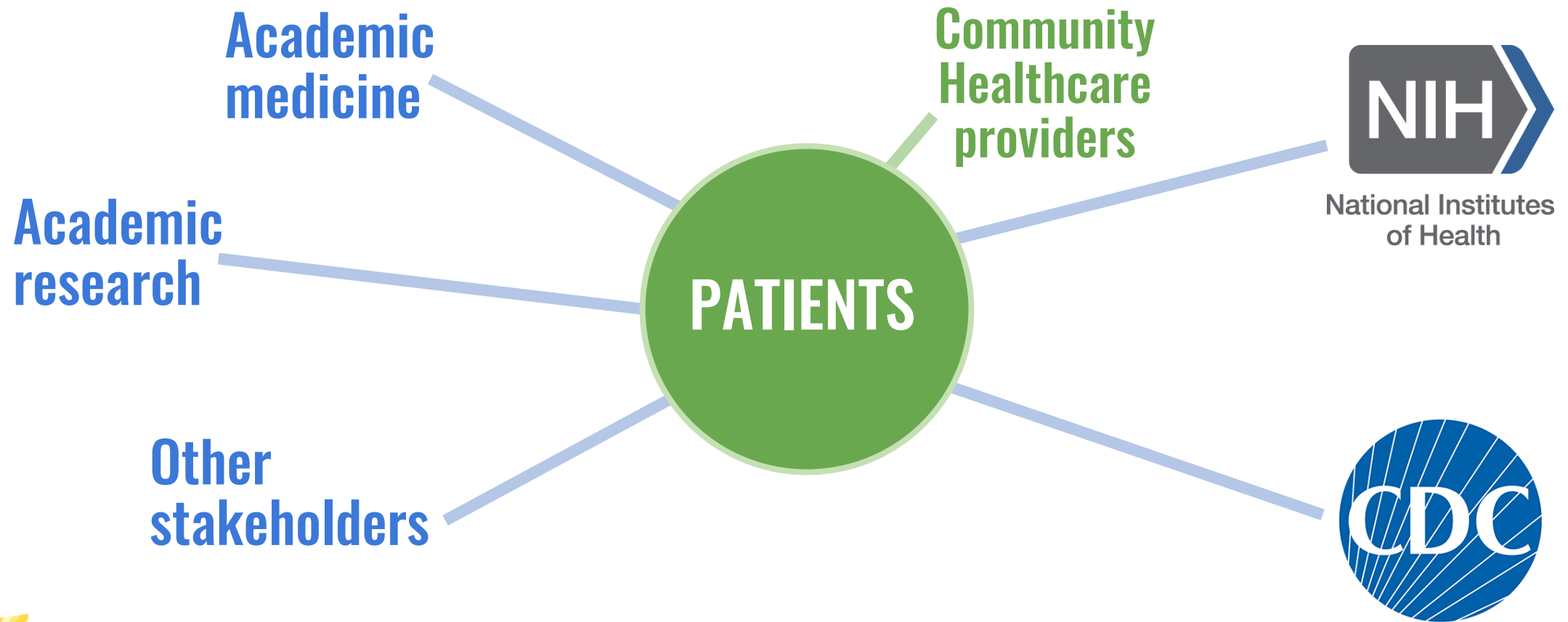


[nhlbi_news@
nhlbi.nih.gov](mailto:nhlbi_news@nhlbi.nih.gov)



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To change patient outcomes, traditional model must evolve





“If you don’t have the pathobiology figured out, **you try things.**

You don’t just slow, slow, slow, walk it,”

– Ezekiel Emanuel MD,
University of Pennsylvania,
Advisor, Obama & Biden