Vivli

CENTER FOR GLOBAL CLINICAL RESEARCH DATA

Vivli Clinical Research Data Sharing: Share. Discover. Innovate.

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NASEM

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Introducing Vivli

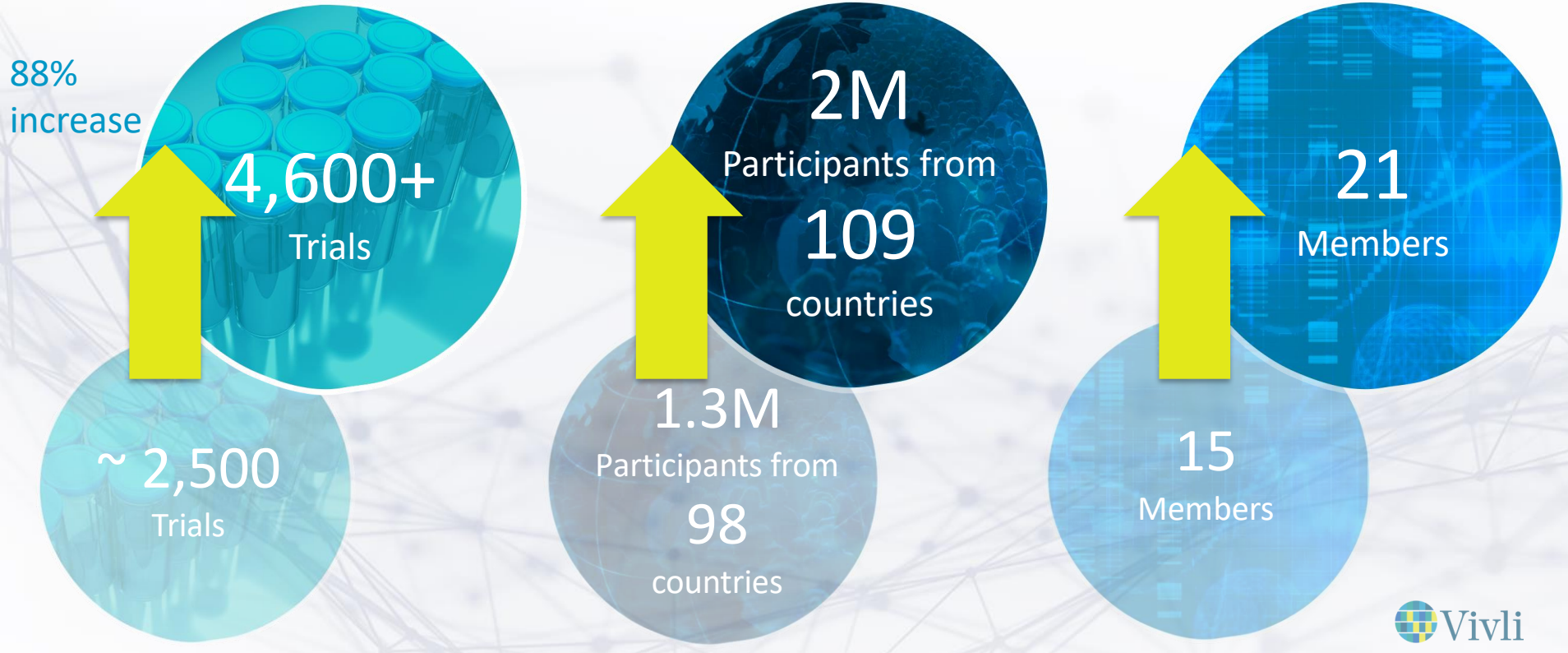
THE ENTITY

- Non-profit organization
- Convening function
  - Biomedical industry (pharma, bio, device)
  - Academia
  - Non-profit funders and foundations
  - Government (funders and regulators)
  - Patient/patient advocates
- Governance and policy
  - Harmonizing language & agreements
  - Move culture of data sharing
- Advocacy
  - Lowering barriers
  - Promoting incentives
- Oversight of Implementation

THE PLATFORM

- A user-friendly, secure, state-of-the art data sharing and computing platform
- Serving the international community, including trials from any disease, country, sponsor, funder, or investigator
  - Open search
  - Robust security
  - Modern tools and technologies

Vivli by the numbers from our launch July 2018 to today…



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Vivli Diverse Membership

Interesting Facts and Figures From our First year

- Enthusiasm in Vivli has remained strong since our launch
- Data from 12 members has been requested
- 81 submitted proposals
- Data from over 80 trials have been accessed involving ~65,000 participants
- In 2020 we will have reached financial sustainability

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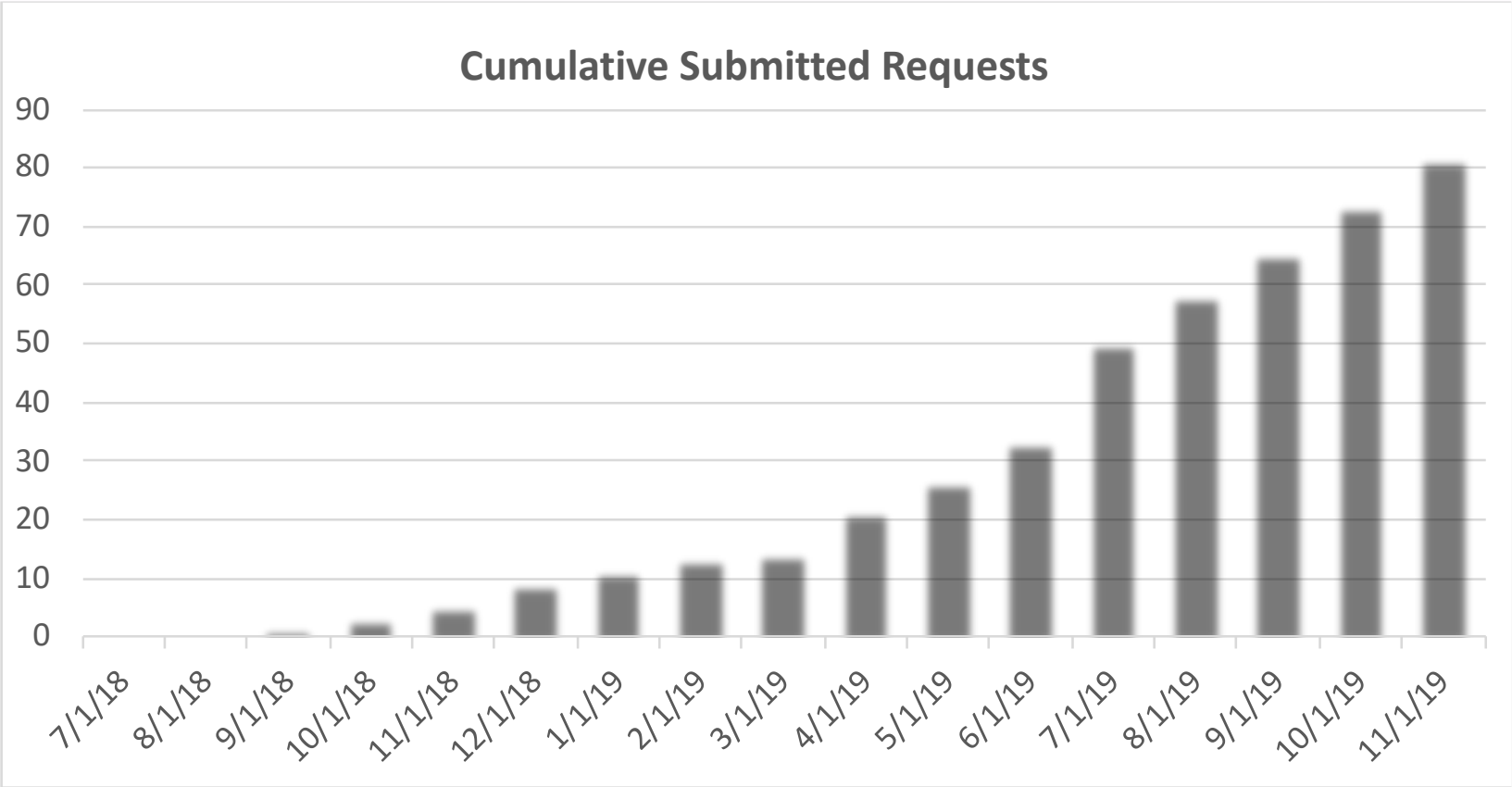
Steady increase in submitted proposals to Vivli



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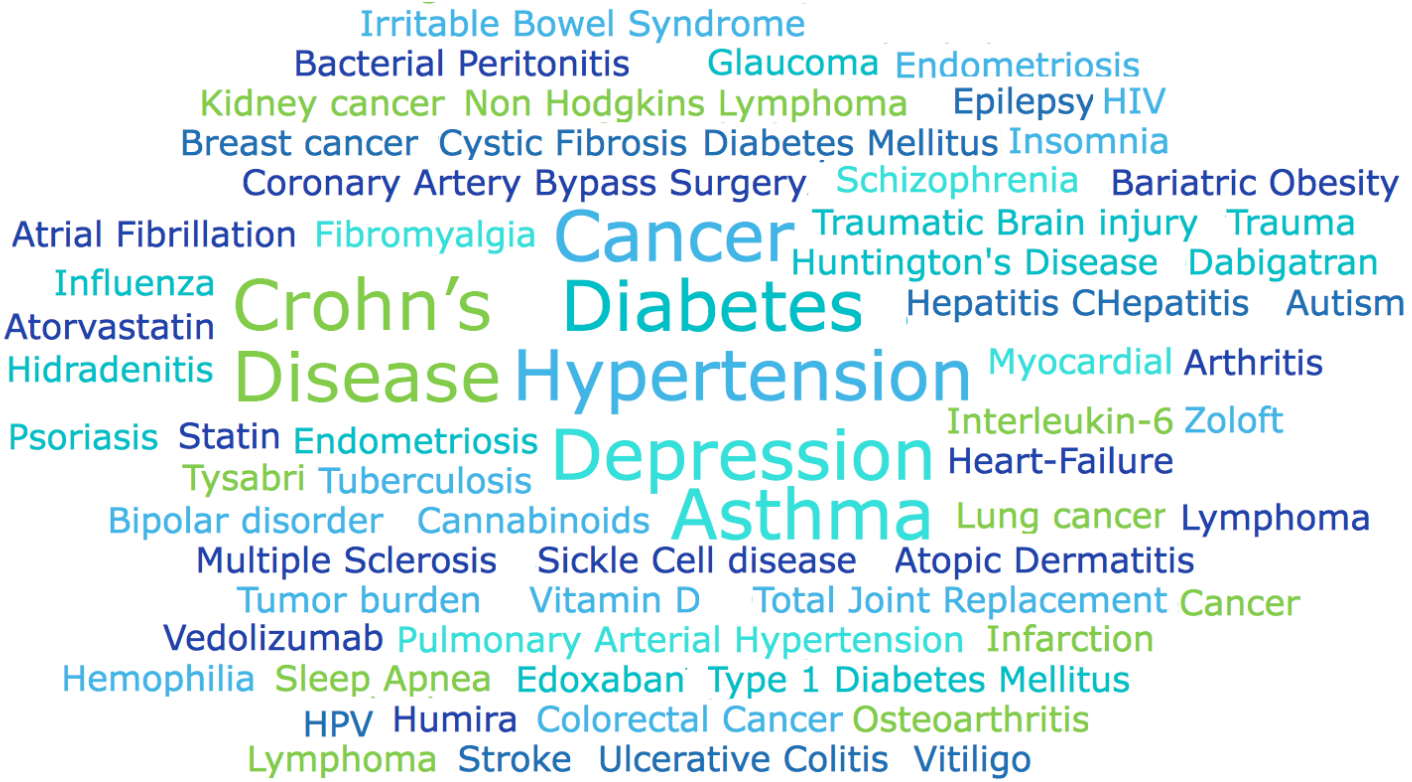
Vivli is a Global Data Platform – Agnostic to Disease, Funder or Data Contributor



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Sharing clinical trial data

- Upholding general principles– *conducting the sharing of trial data in a fair manner*
- IRP – that includes members of the public
- Employ a DUA that is harmonized
- When and what to share
- Sustainability: “Those who benefit from sharing should pay fair share.”
- Technology: “At present, data sharing platforms are not consistently discoverable, searchable, or interoperable”

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Challenges – Contributors and Requesters

- Data contributors
  - Sharing of rare disease datasets
  - Anonymization of datasets
  - Sharing of imaging data/large datasets
- Data Users
  - Silo-ing of data sources limits analysis
  - Data formats are heterogeneous
  - Imbalance in supply/demand curve

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Lessons learned #1

We need to be *flexible* to meet our users where they are (review process, data types, tools) and *harmonize* where it is critical for the user experience (DUA)

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Lessons learned #2

- Sharing IPD is a complex endeavor presenting many challenges both technical and governance in nature.
- These can only be effectively addressed by enlisting the efforts of a variety of stakeholders.

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Lessons learned #3

As a non-profit organization that manages a platform, we do not have major influence over incentives to share data but can only enable this aspect (DOIs, training, resources etc.).

The broader research ecosystem of funders, academia and publishers hold the levers to reward investigators for sharing data for the public good.

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