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Rare Disease Cures Accelerator- Data and Analytics Platform Virtual Workshop 2020

Up Next: *Data ingestion and data governance*



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C-Path



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RDCA-DAP: Data ingestion and data governance

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Why share data?

Patients/Patient Groups

- **Faster drug development**
- Understand disease course/variance
- Visibility to industry
- Drive collaboration



Industry

- **Design more effective trials**
- Understand disease course/variance
- Understand / develop biomarkers/endpoints



Academics

- **Improves their research**
- Understand disease course/variance
- Understand / develop biomarkers/endpoints
- Visibility of data and research, collaboration
- Publish more/better papers



Patients are willing to share data – with conditions

[N Engl J Med](#). Author manuscript; available in PMC 2018 Dec 7.

Published in final edited form as:

[N Engl J Med](#). 2018 Jun 7; 378(23): 2202–2211.

doi: [10.1056/NEJMsa1713258](#)

PMCID: PMC6057615

NIHMSID: NIHMS980034

PMID: [29874542](#)

Clinical Trial Part

[Michelle M. Mello](#), J.D., Ph.D.

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, Ghisk

[Orphanet J Rare Dis](#). 2019 Jun 12; doi: [10.1186/s13023-019-1123-4](#)

Published online 2019 Jun 12; doi: [10.1186/s13023-019-1123-4](#)

Share and protect our health data: an evidence based approach to rare disease patients' perspectives on data sharing and data protection - quantitative survey and recommendations

[Sandra Courbier](#)¹, [Rebecca Dimond](#)² and [Virginie Bros-Facer](#)¹

► Author information ► Article notes ► Copyright and License information [Disclaimer](#)

► [Am J Hum Genet](#). 2020 Sep 14;S0002-9297(20)30292-5. doi: [10.1016/j.ajhg.2020.08.023](#).

Online ahead of print.

Global Public Perceptions of Genomic Data Sharing: Attitudes toward DNA and

Anwer⁴, Jerome Atutornu⁵,
Christine Critchley⁹, Josepine
Gry Houeland¹⁰, Heidi C
Lera L Izhevskaya¹⁷, Aleksandra
Brandi Leach²², Keying Liu²³,
Col²⁷, Emilia
Lauren
ith³,
Thorogood
am¹, Xiaoqian

► [AMIA Annu Symp Proc](#). 2014 Nov 14;2014:1699-708. eCollection 2014.

Sharing my health data: a survey of data sharing preferences of healthy individuals

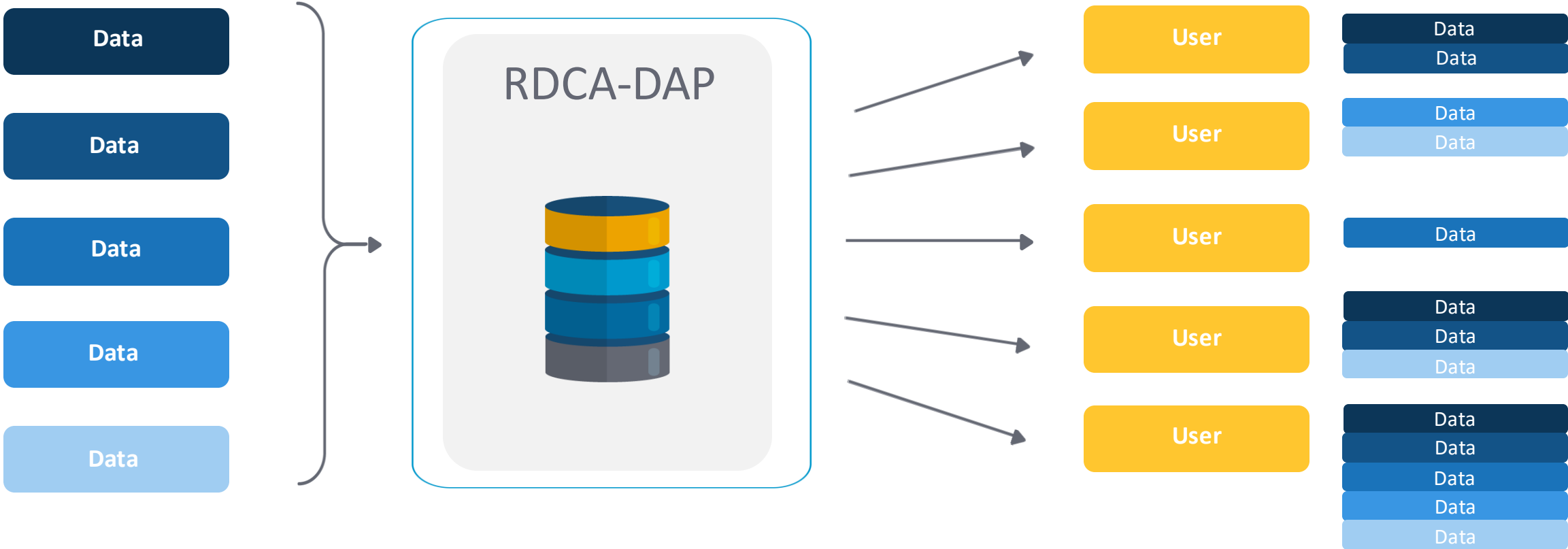
[Elizabeth A Bell](#)¹, [Lucila Ohno-Machado](#)², [M Adela Grando](#)³

Affiliations + expand

PMID: 25954442 PMCID: [PMC4419941](#)

[Free PMC article](#)

Optimizing data ingestion and usability:

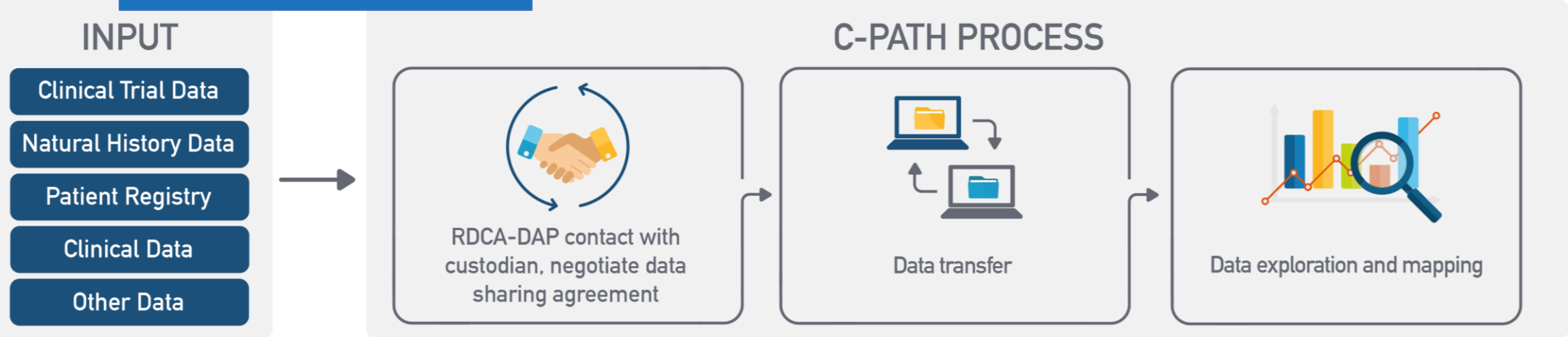


*Permissions and conditions
for sharing data*

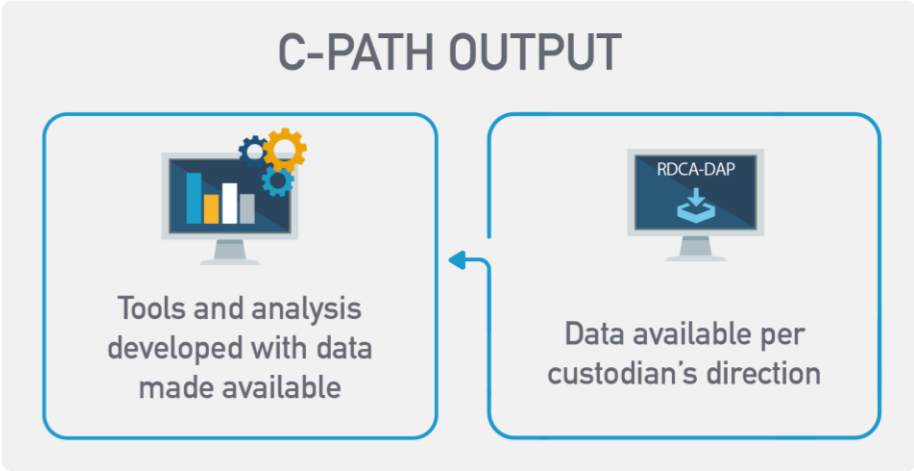
*Permissions and conditions
for using data*

Data Flow in RDCA-DAP

*Permissions and conditions
for sharing data*



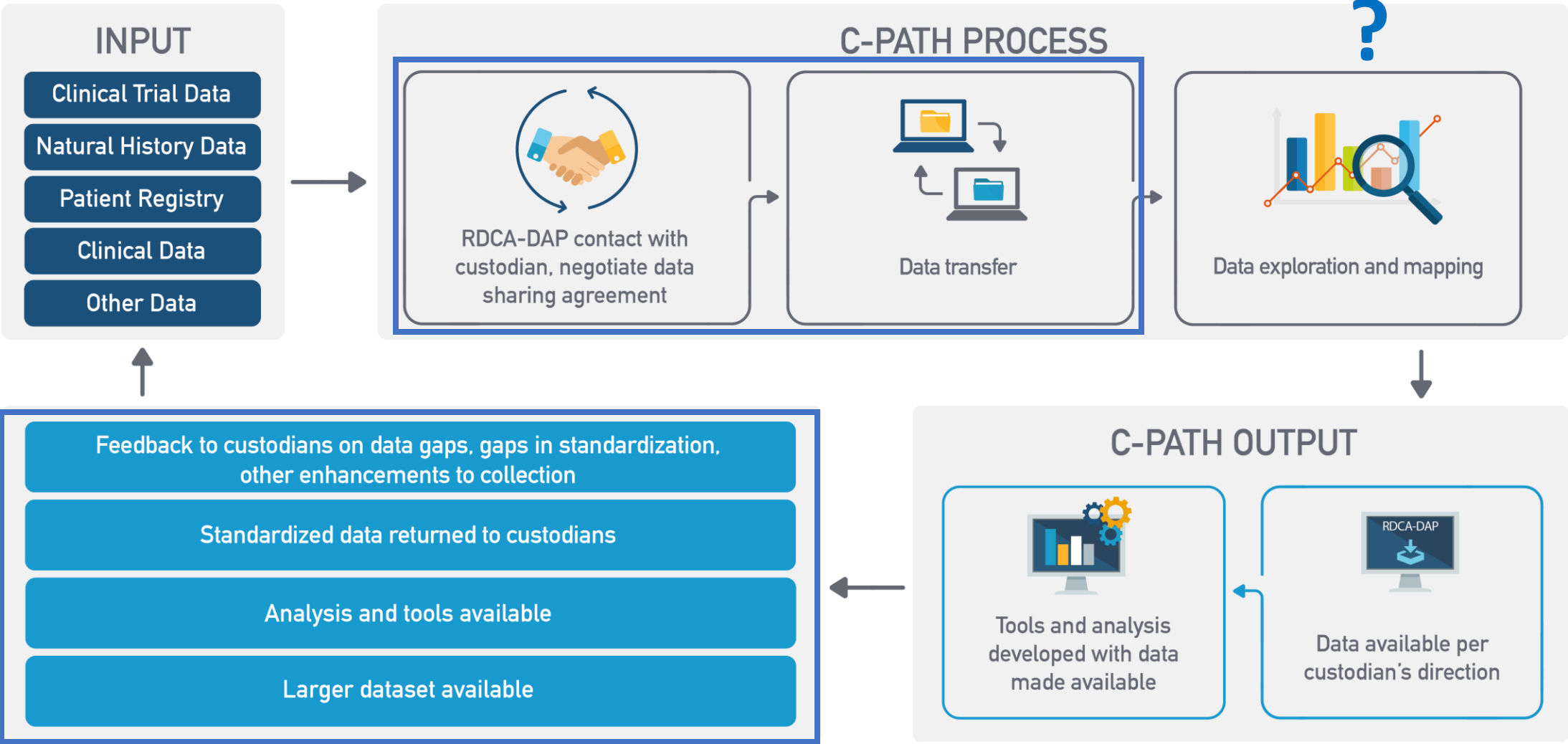
*Permissions and conditions for
using data*

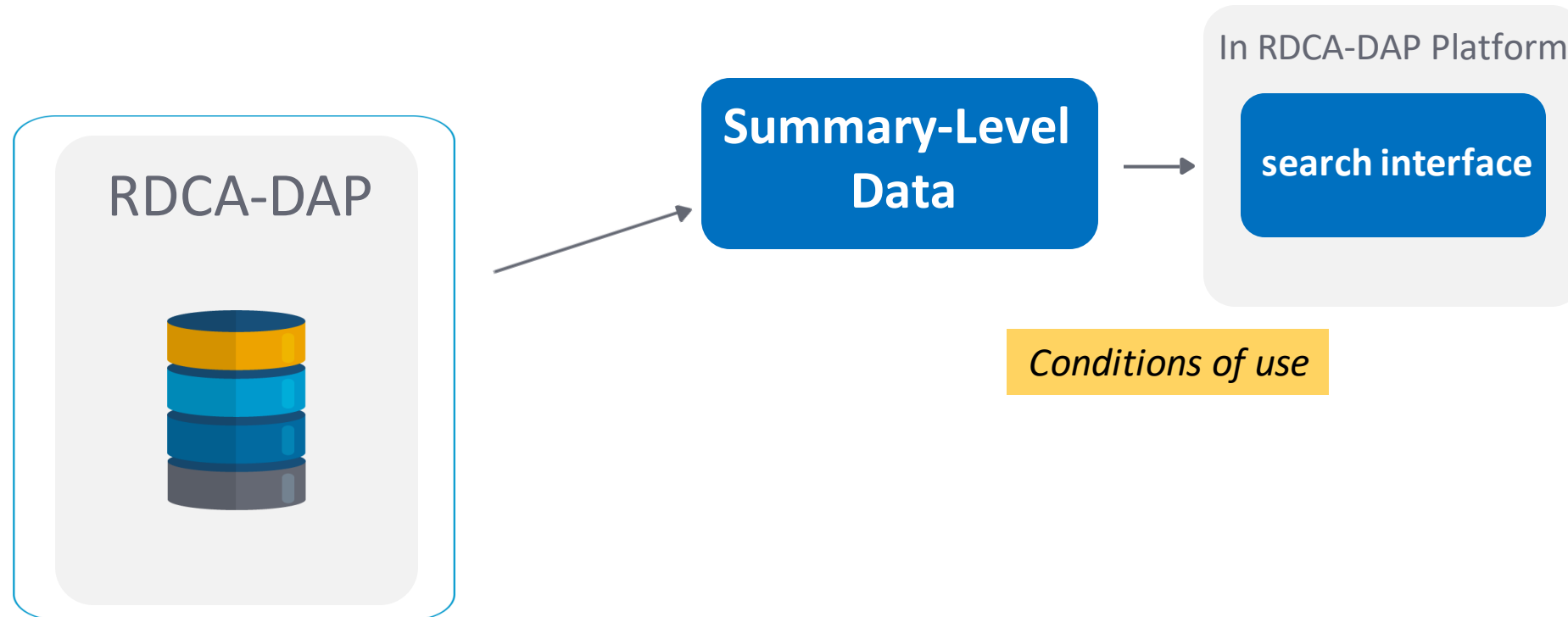


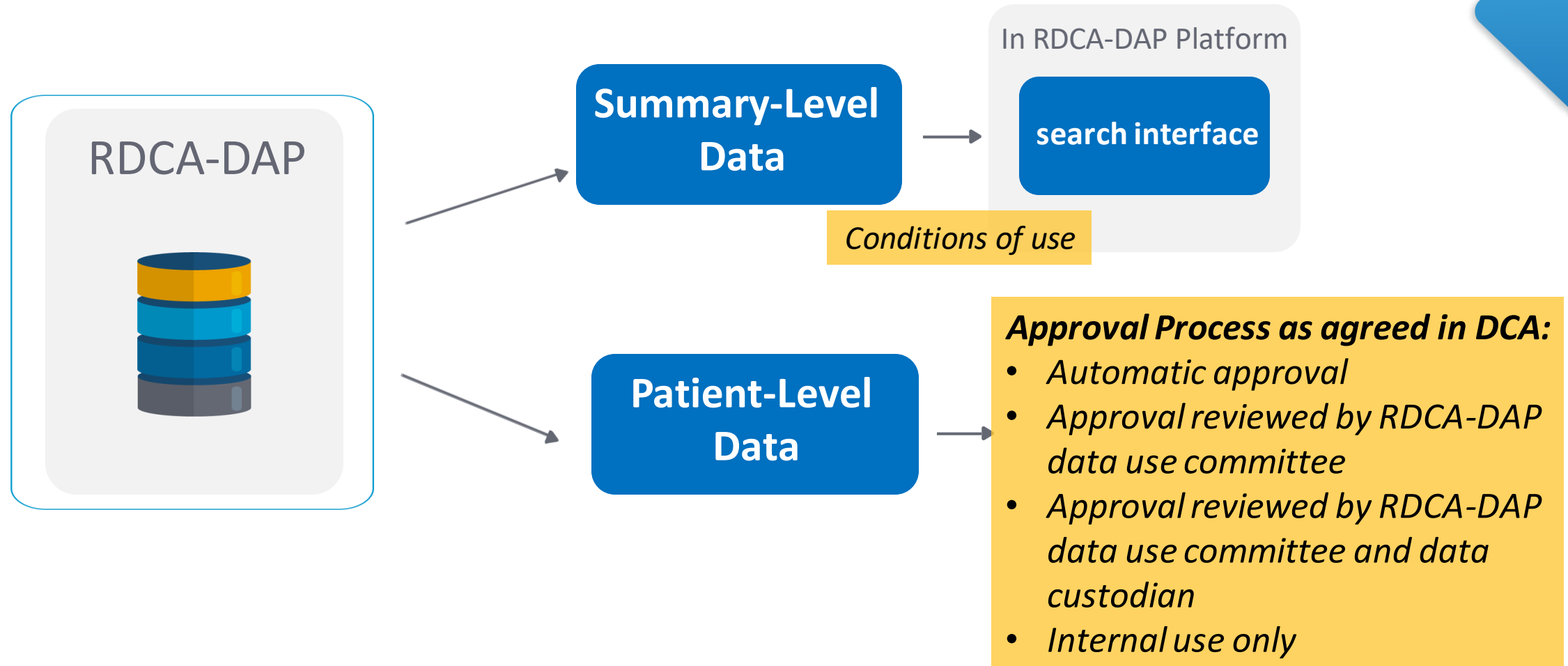
Legal document between RDCA-DAP and the custodian that dictates how RDCA-DAP can use a dataset.

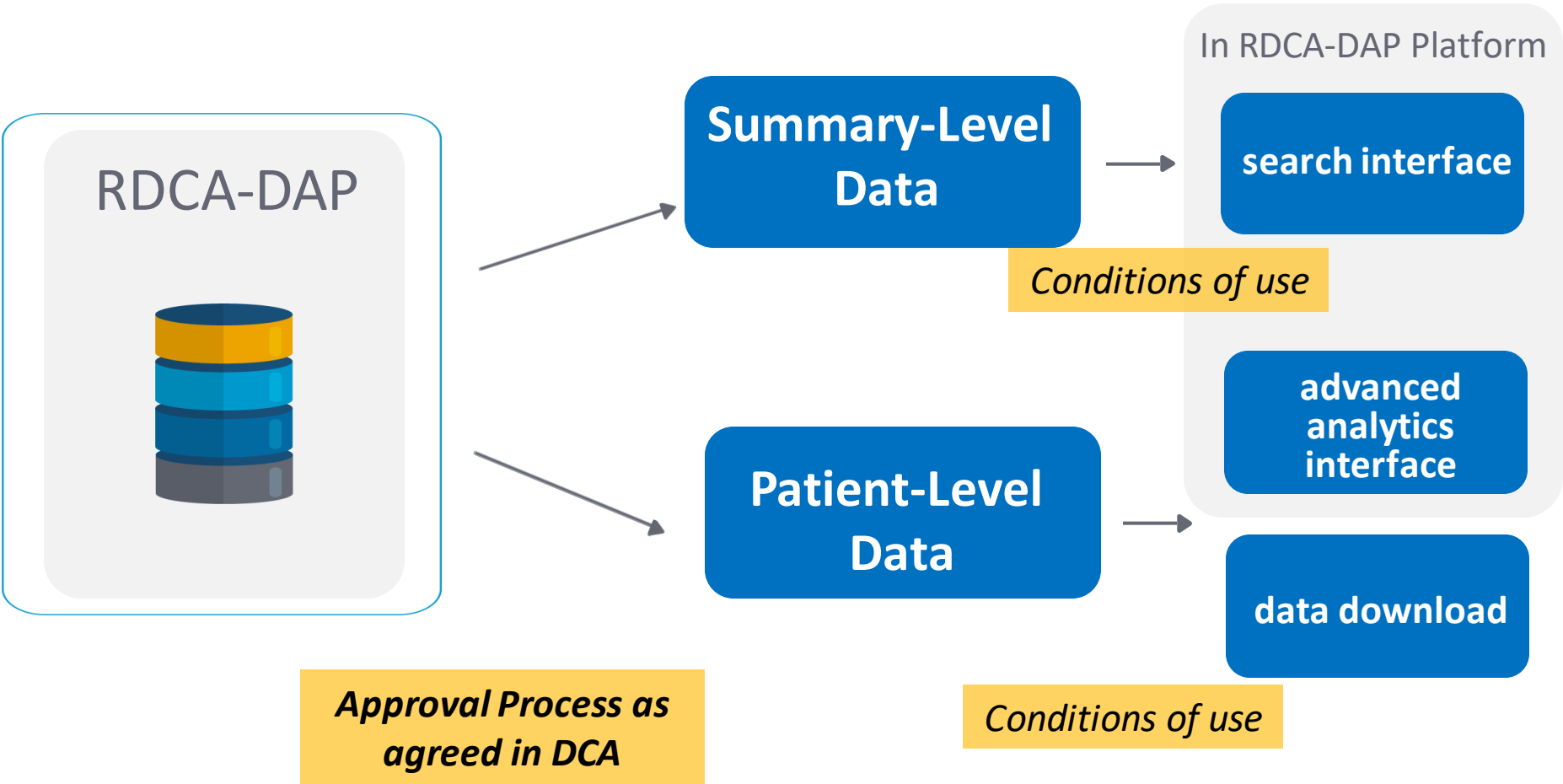
- Tells us that the data was collected ethically, the patient consent allows sharing of the data, and that the custodian is able to share the data, and that it will be de-identified
- Tells us what we are allowed to do with the data – share with anyone, share after approval, or only share metadata or summary data
- Assures the data custodian of data protection/ data privacy
- Details any other feedback agreed to by both parties (e.g. publication notifications, credit to the custodian)
- Provides details of the dataset and associated documents to help us interpret the data

Interactions with the custodian









Legal document between RDCA-DAP and the data users that dictates what the user can do with the data

- Ensures secure data storage, data privacy (limitations of use to approved researchers and subcontractors)
- Ensures that use is limited to the approved research
- Requires acknowledgement of data source in public disclosures
- Ensures ethical use of data
- Ensures data is not sold or shared on to other users, data cannot be patented etc.
- Encouragement of public disclosure of results, sharing results with data custodian

Who should share data?

Patients/Patient Groups



Industry

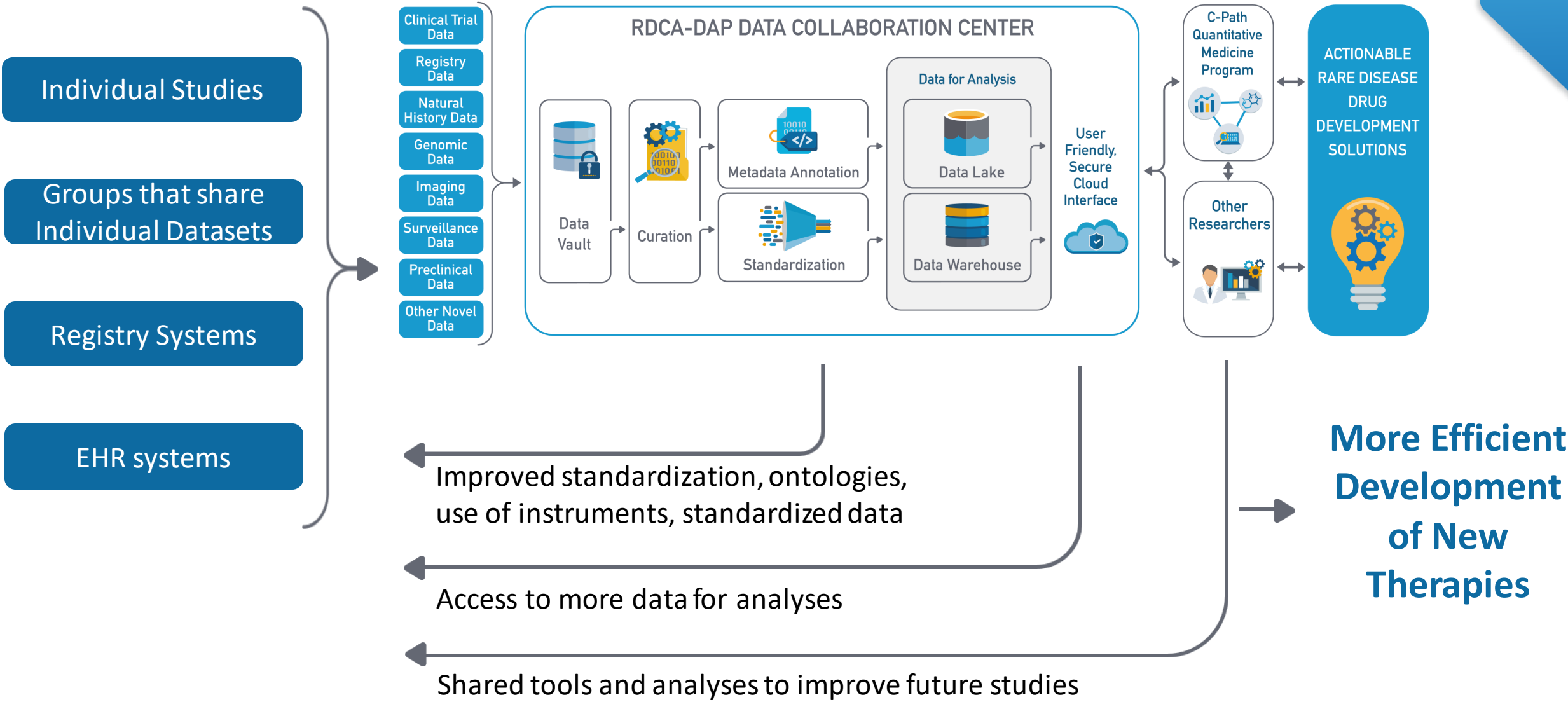


Academia



**By working together and sharing data together we can
accelerate therapy development for Rare Diseases.**

RDCA-DAP in the Ecosystem of Rare Disease Data





THANK YOU!

Don't forget to answer survey questions.

For more information, email rdcadap@c-path.org

#RDCADAP