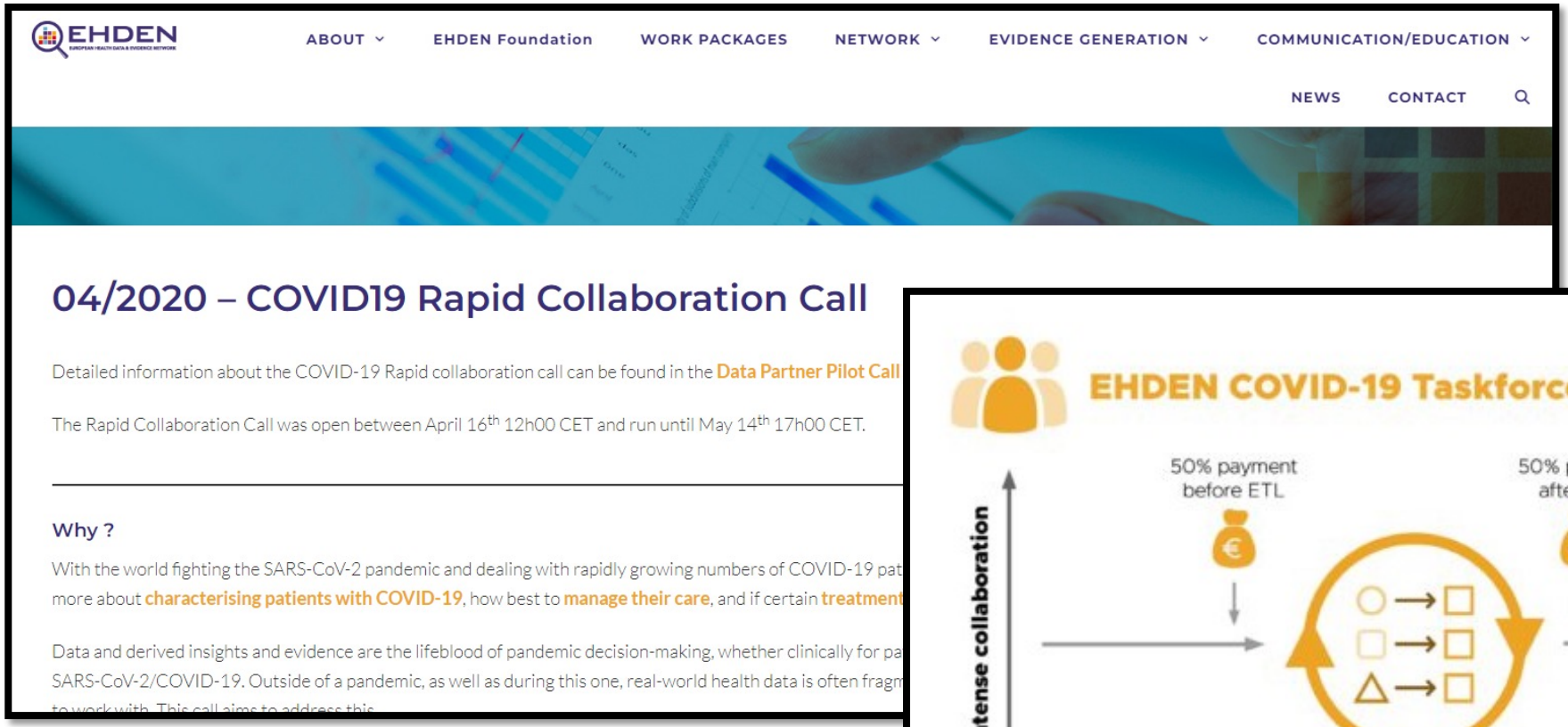
European Health Data & Evidence Network - learnings from building out a standardized international health data network

Recent OHDSI Publications
2023 DEC 05

Voss, E. A., Blacketer, C., van Sandijk, S., Moinat, M., Kallfelz, M., van Speybroeck, M., Prieto-Alhambra, D., Schuemie, M. J., & Rijnbeek, P. R. (2023). European Health Data & Evidence Network-learnings from building out a standardized international health data network. *Journal of the American Medical Informatics Association : JAMIA*, ocad214. Advance online publication. https://doi.org/10.1093/jamia/ocad214

Background


EHDEN
ABOUT
EHDEN Foundation
WORK PACKAGES
NETWORK
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NEWS
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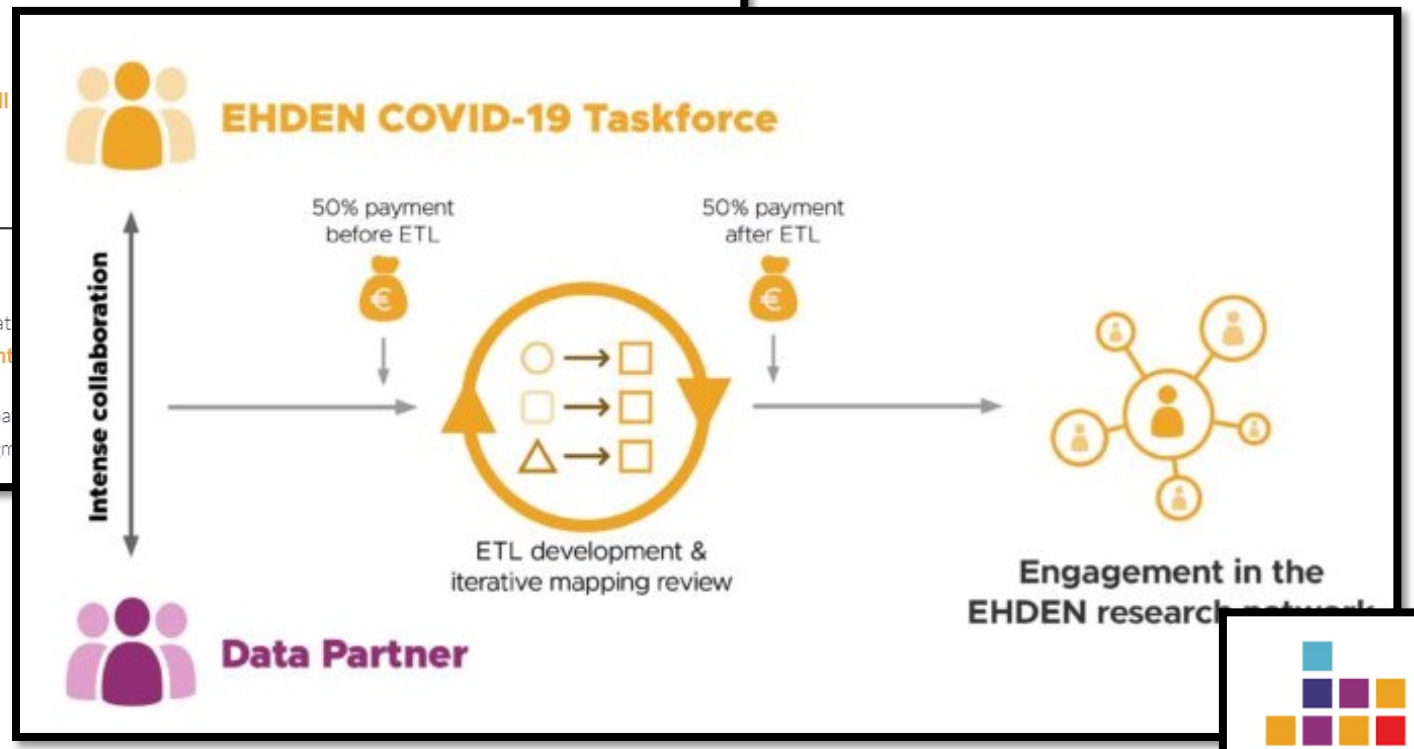
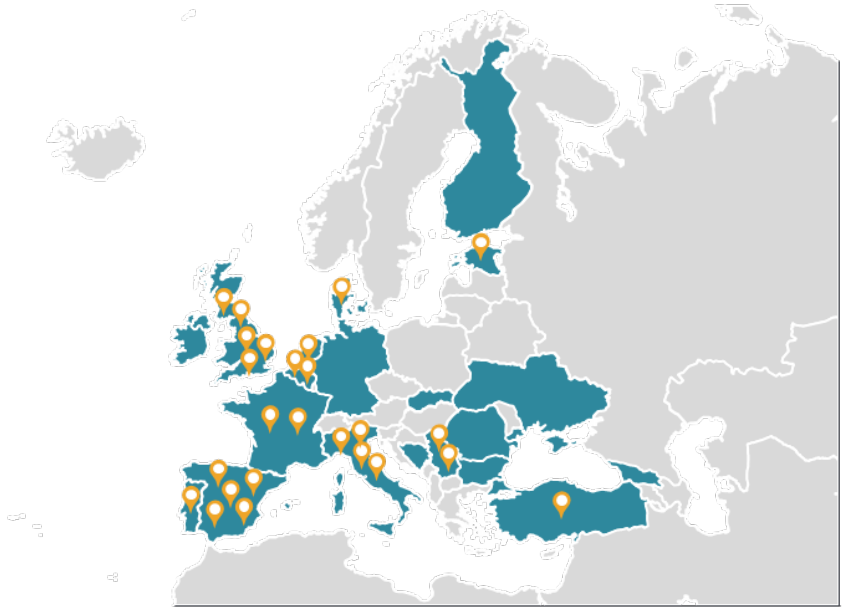
04/2020 – COVID19 Rapid Collaboration Call
Detailed information about the COVID-19 Rapid collaboration call can be found in the Data Partner Pilot Call
The Rapid Collaboration Call was open between April 16th 12h00 CET and run until May 14th 17h00 CET.
Why ?
With the world fighting the SARS-CoV-2 pandemic and dealing with rapidly growing numbers of COVID-19 pat
more about characterising patients with COVID-19, how best to manage their care, and if certain treatment
Data and derived insights and evidence are the lifeblood of pandemic decision-making, whether clinically for pa
SARS-CoV-2/COVID-19. Outside of a pandemic, as well as during this one, real-world health data is often fragm

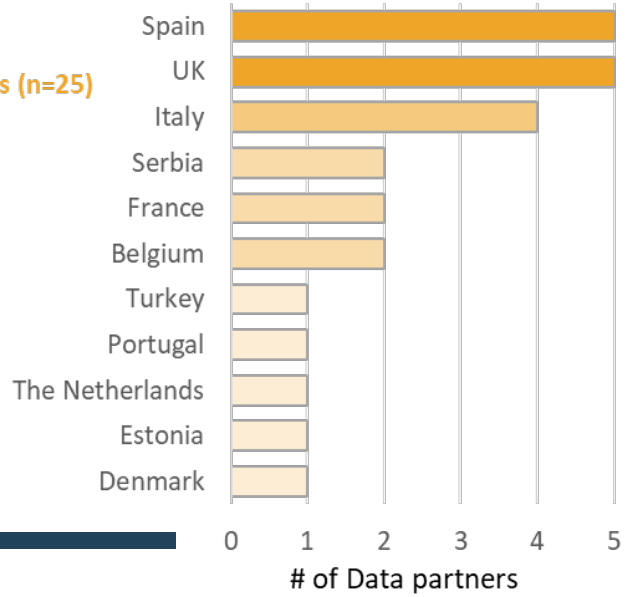

EHDEN COVID-19 Taskforce
50% payment before ETL
50% payment after ETL
Intense collaboration
ETL development & iterative mapping review
Engagement in the EHDEN research
Data Partner

Background



Awarded applications (n=25)

Applications (n=75)



1	Assistance Publique Hopitaux de Marseille
2	SIDIAP - The Information System for Reseach in Primary Care
3	Center for Surgical Science (CSS)
4	Fondazione IRCCS Istituto Neurologico Carlo Besta FINCB
5	Amsterdam UMC
6	Health Informatics Centre (HIC)
7	UCL (UK Biobank) [BigData@Heart]
8	Royal College of General Practitioners Research and Surveillance Centre
9	Servicio Cantabro de Salud and IDIVAL
10	University of Tartu
11	ULSM(Rosa Maria Príncipe)
12	Clinical Practice Research Datalink
13	Istanbul University Istanbul Faculty of Medicine
14	FIIBAP
15	Clinical Center of Serbia
16	Fondazione Poliambulanza Istituto Ospedaliero
17	LynxCare
18	Health Data Hub
19	Medaman
20	Azienda Policlinico Universitaria di Modena
21	Marco Massari (IRCSSE)
22	FIMIM/PSMAR
23	BIOCRUCES BIZKAIA HEALTH RESEARCH INSTITUTE
24	Clinical centre of Nis
25	DataLoch

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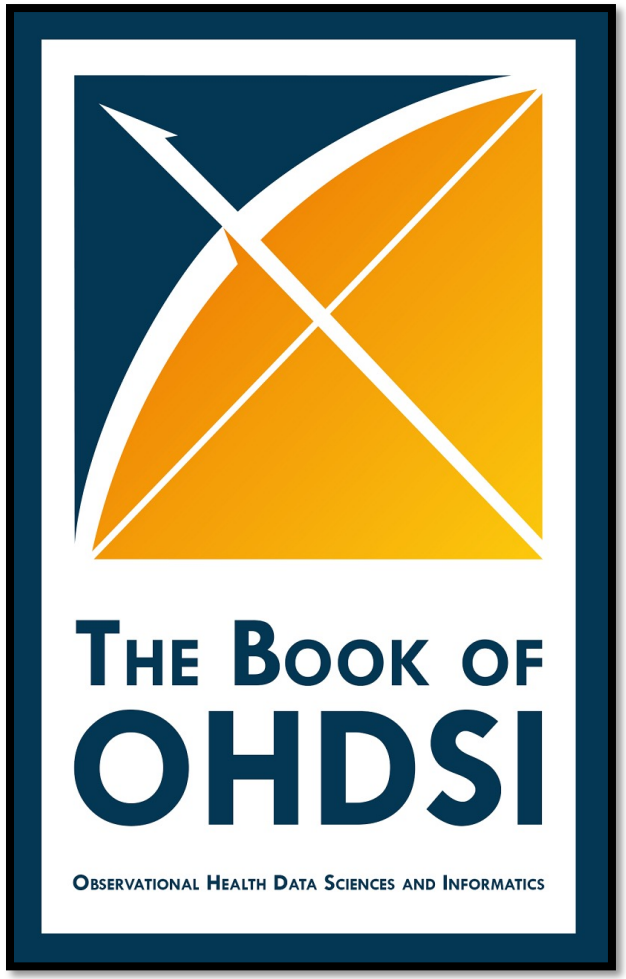
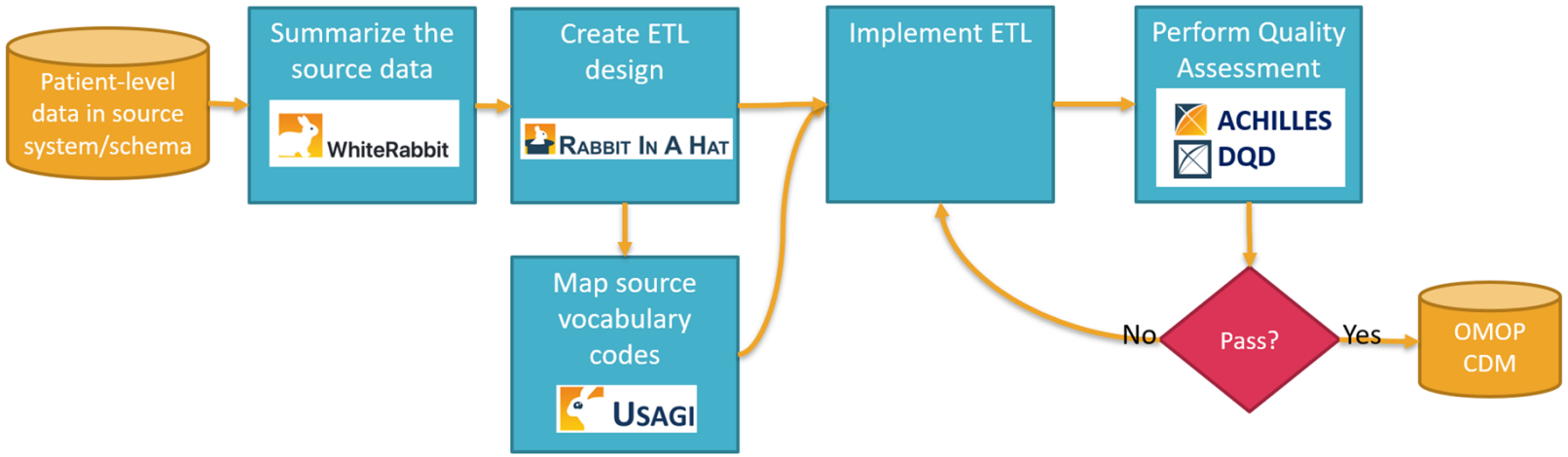
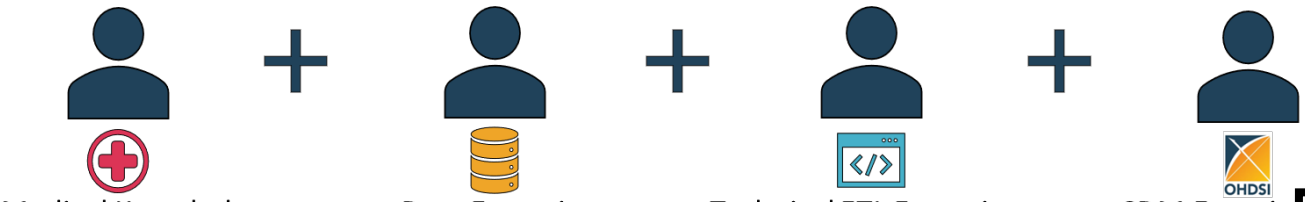
Background







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Approach

- Each Data Partner was expected to follow the current OMOP CDM ETL development process

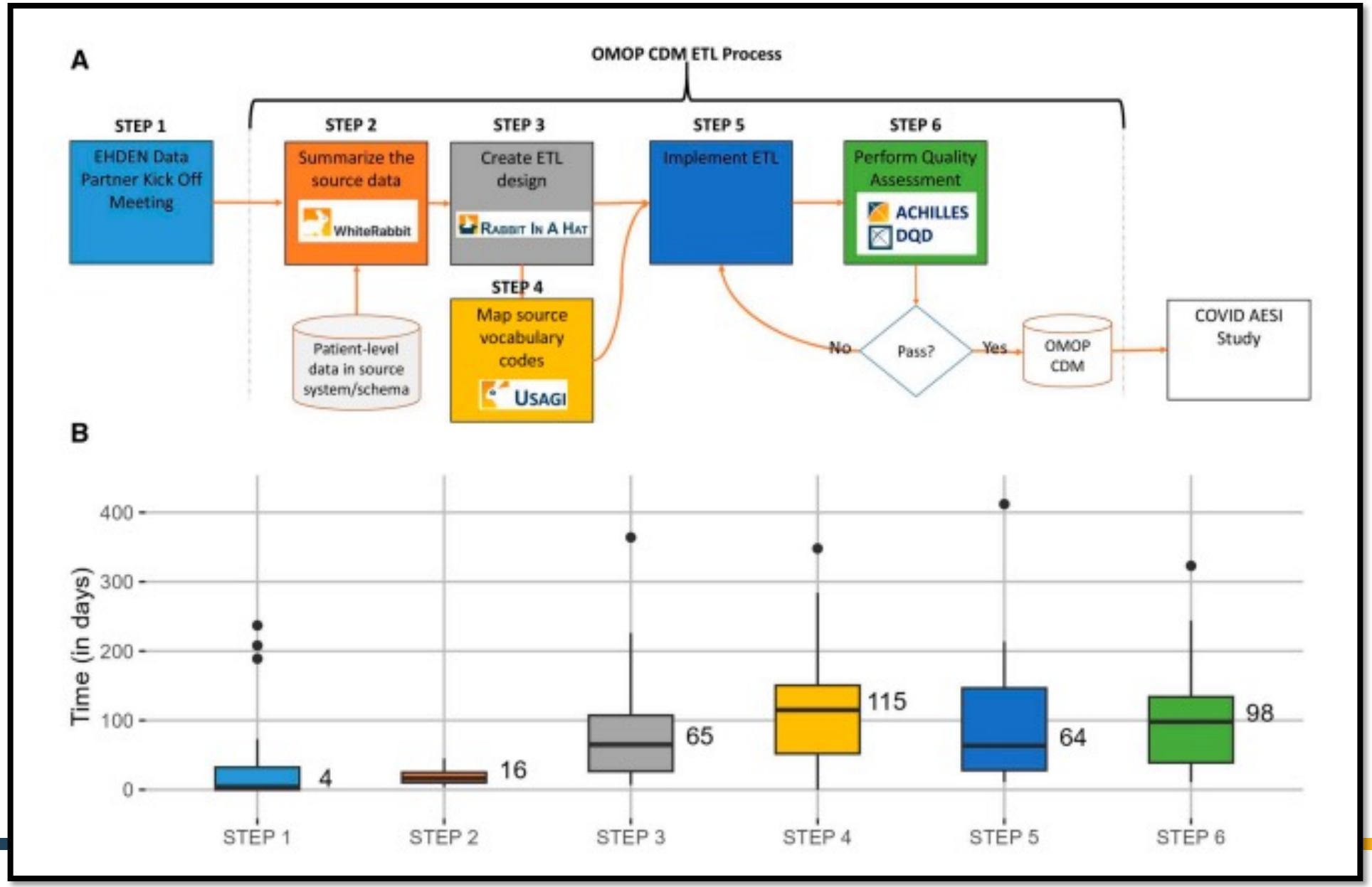
- The process was tracked in 3 ways
  - (1.) tracking data associated to ETL process
  - (2.) through surveys of DP
  - (3.) DataQualityDashboard results

- Success was measured as
  - total days to transform source data into the OMOP CDM (success: < 365 days)
  - if a DP participated successfully in network research (COVID-19 AESI study [1])

- 21 data partners were completed at the time of writing and the results reported for them

[1] Voss EA, Shoaibi A, Yin Hui Lai L, et al. Contextualising adverse events of special interest to characterise the baseline incidence rates in 24 million patients with COVID-19 across 26 databases: a multinational retrospective cohort study. *EClinicalMedicine*. 2023;58:101932. doi:10.1016/j.eclinm.2023.101932

Results - *tracking data associated to ETL process*



Results - *through surveys of DP*

- Through Surveys of DPs:

Survey question	Options	No. of data partners
What will be your primary role in this project? *(summarized as often as the role showed up, it is possible for multiple roles to be present on one team, however the role was only counted once per team)*	Informatician	20
	Computer scientist	17
	Project manager	16
	Data manager	8
	Clinical scientist	7
	Person in medicine	4
	Health policy individual	3
	Epidemiologist	3
	Statistician	2
	Something other than the above	5
	Preferred not to say	0

- Success Measures:
  - Of the 21 DPs, 52% had built their CDM in under 365 days, 43% participated in the COVID-19 AESI study [1], and 33% had both a timely ETL and participated in the COVID AESI study

[1] Voss EA, Shoaibi A, Yin Hui Lai L, et al. Contextualising adverse events of special interest to characterise the baseline incidence rates in 24 million patients with COVID-19 across 26 databases: a multinational retrospective cohort study. *EClinicalMedicine*. 2023;58:101932. doi:10.1016/j.eclinm.2023.101932

Main Conclusions

- Previously Identified:
  - Having the right composition of **team** provided important.
  - **Mapping source codes** to the OHDSI Standardized Vocabularies was frequently mentioned a challenging and took significant time.

- Novel Findings:
  - Uncovered the importance of establishing **governance rules** prior to the initiation of the work