

UroEvidenceHub: Harnessing the OMOP CDM and OHDSI analytic tools to advance urological evidence generation

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Background

The generation of robust, reproducible evidence in urology has long been constrained by fragmented, siloed datasets that vary in structure, terminology, and quality across institutions and national boundaries. Retrospective analyses are frequently limited to single-centre data, and multi-site studies face substantial barriers in data harmonization. The UroEvidenceHub (UEH¹) was conceived to address these challenges directly: a collaborative, federated research infrastructure dedicated to enabling large-scale, real-world evidence generation across the urological specialties — encompassing uro-oncology, functional urology, urolithiasis, and benign prostatic disease, among others.

Central to the UEH's technical architecture is the adoption of the OMOP CDM and the suite of open-science analytic tools developed by the OHDSI collaborative. This submission describes how the Hub leverages these standards to enable reproducible, transparent, and scalable urological research.

Methods

The UEH provides both the primary infrastructure for initiating new urology registries like ProReg and the long-term sustainability platform for existing data collection projects such as PIONEER+, PRAISE-U and PRAISE-U+, each retaining full governance and custodianship of its data under a GDPR-compliant hybrid data sharing model. PIONEER+ is the sustainability phase of the IHI public-private partnership project PIONEER, that established the basis of the UEH by gathering and exploiting a large network of both centralized and federated data sites mapped to the OMOP CDM with standardized data analytics².

ProReg is a prospective registry of clinical data, outcomes and PROMs, currently enrolling patients across Europe with an ambition to become the premier prostate cancer data resource. We have built ProReg to address the limitations we encountered during PIONEER, such as missingness, incompleteness, variation in coding practices or poor quality control. ProReg captures data one patient at a time or via bulk upload for existing datasets. We are establishing a complete ETL and analytics environment that will let us harmonize all the UEH data assets to the latest OMOP CDM and allow for coordinated analyses.

The UEH aims to expand by providing RWE for personalized clinical care, and by tackling other urological diseases in the near future.

See figure 1 for an overview of the UEH and figure 2 for an overview of the UEH analytics platform.

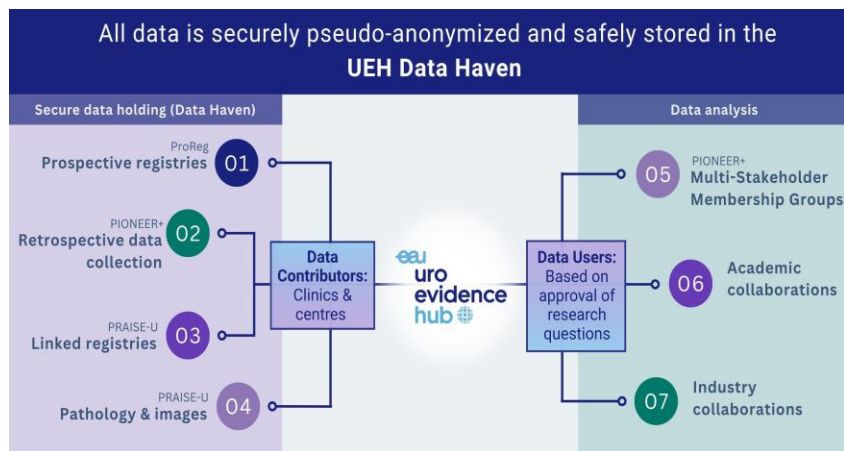


Figure 1: Overview of the UEH data haven and analysis setup.

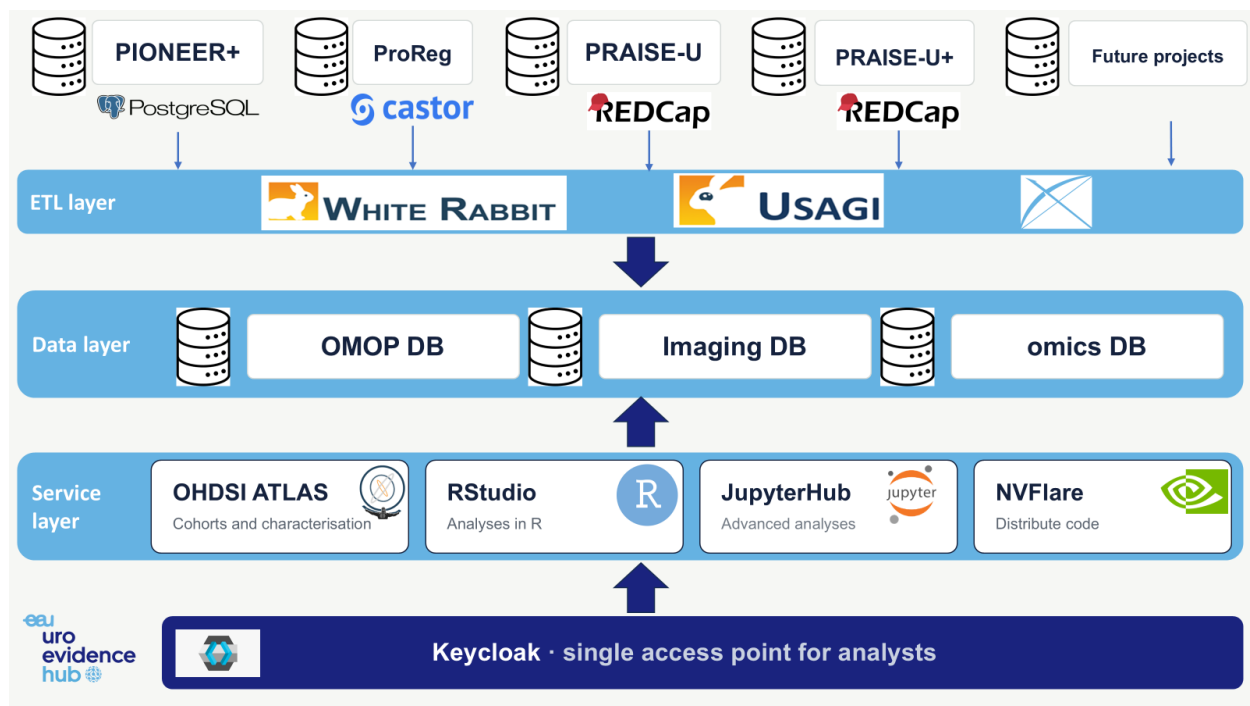


Figure 2: Overview of the UEH analytics platform.

Results

The UEH has supported RWE-generation in prostate cancer by answering prioritized research questions. Recent publications have utilized cohort characterization, incidence rates calculations, time-to-event analysis and treatment trajectories analyses³⁻⁶. PIONEER+ continues to grow with more than 65 members involved from 21 countries, see figure 3.

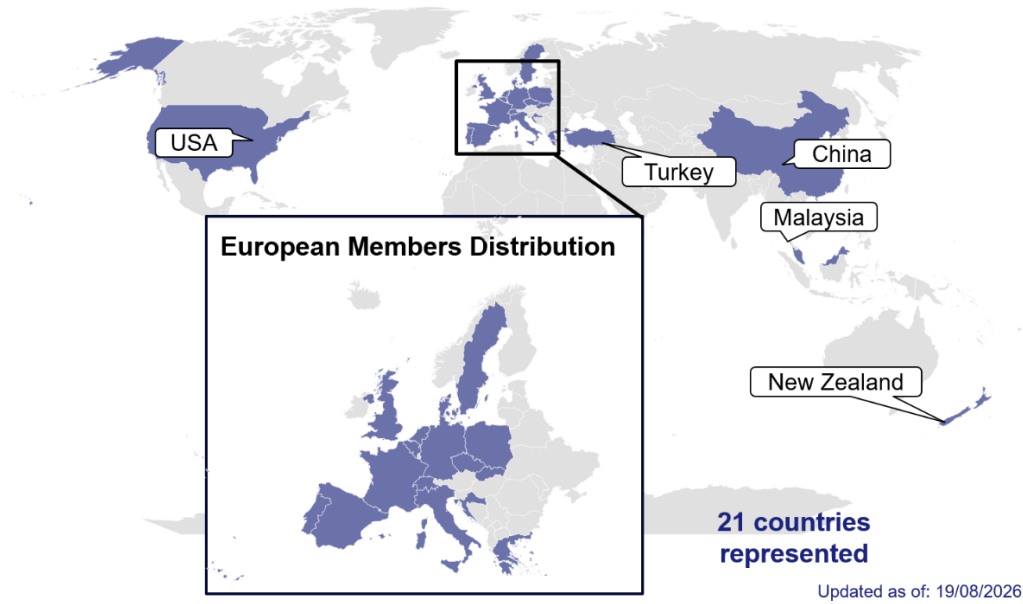


Figure 3: Distribution of PIONEER+ members.

To date, ProReg has captured data for more than 6600 prostate cancer patients from 10 data sites, with a mean follow-up time of 7.5 years, across the whole disease progression. We will continue to gather data on existing patients follow-up and PROMs for the foreseeable future and are in contact with more than 50 additional sites at different stages of onboarding. Figure 4 shows an overview of the current status of ProReg.

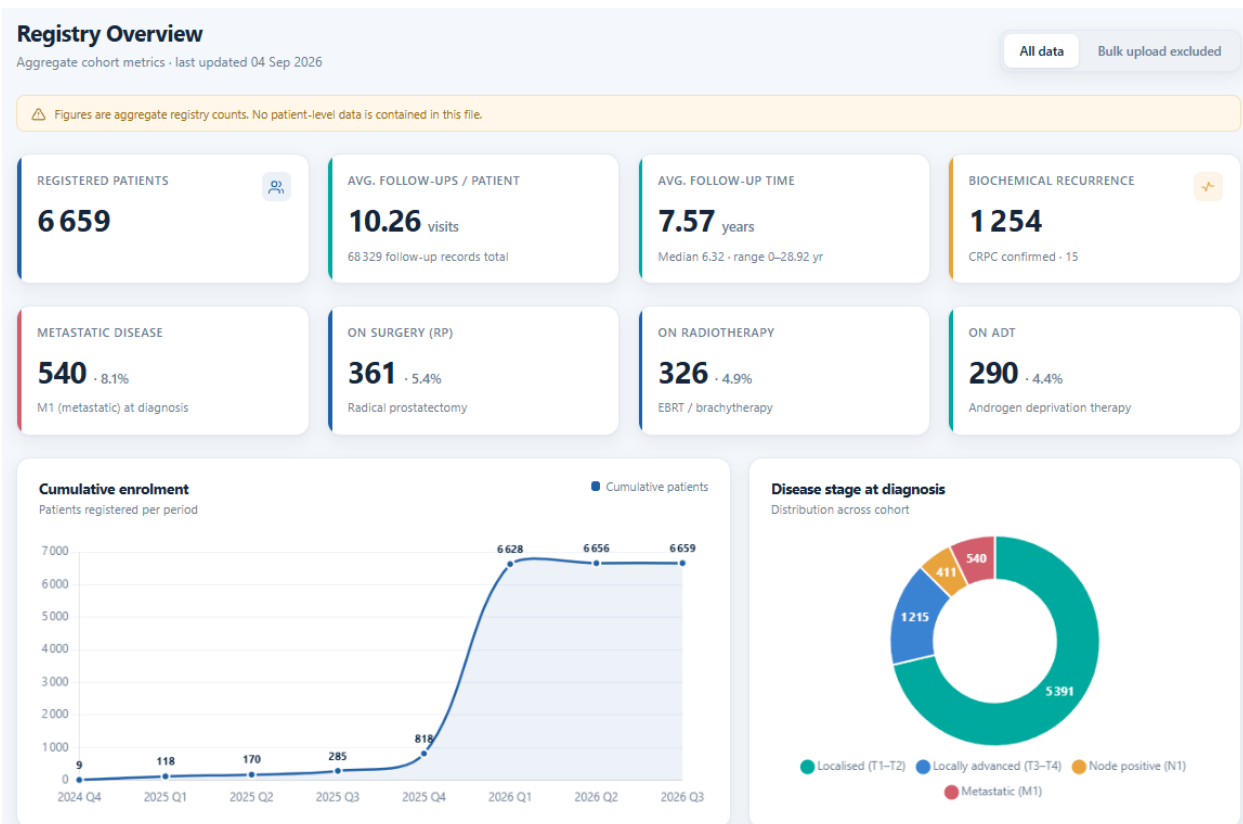


Figure 4: Dashboard of the data currently included in ProReg.

Conclusion

We present here the UEH, a continuously growing, high quality data source for prostate cancer using the OMOP-CDM connected with a state-of-the-art analytics platform. Our data assets and analytics infrastructure are open to the wider OHDSI/broader research community via membership in our research projects, provided by committing active time, patient data or funding. We also open membership into our Life science Advisory Board to industry partners.

The UEH demonstrates that a federated, OMOP-standardized, OHDSI-powered research network is both feasible and scientifically productive in urology. By adopting community-validated standards and open-source tools, the UEH enables reproducible, multisite evidence generation that would be impossible through conventional data-sharing models. As the network expands and study output grows, UEH aspires to become a primary infrastructure for generating the real-world evidence that urological practice increasingly demands.

References

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