Harnessing the power of big data in prostate cancer research – Data access and sources in the PIONEER project

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About PIONEER

Prostate Cancer D**I**agn**O**sis and Treatme**N**t **E**nhancement through the Power of Big Data in E**uR**ope

The European Network of Excellence for Big Data in Prostate Cancer

- An IMI2 funded pan-European public private partnership consisting of 32 stakeholders from across 9 countries.

- Launched in May 2018 PIONEER brings together all relevant stakeholders in the field of prostate cancer research as well as clinical and social care.

- Five year (2018-2023) 12 M€ program.

PIONEER's goal & Key Aspects

To ensure the optimal care for all European men diagnosed with prostate cancer by unlocking the potential of big data and big data analytics.
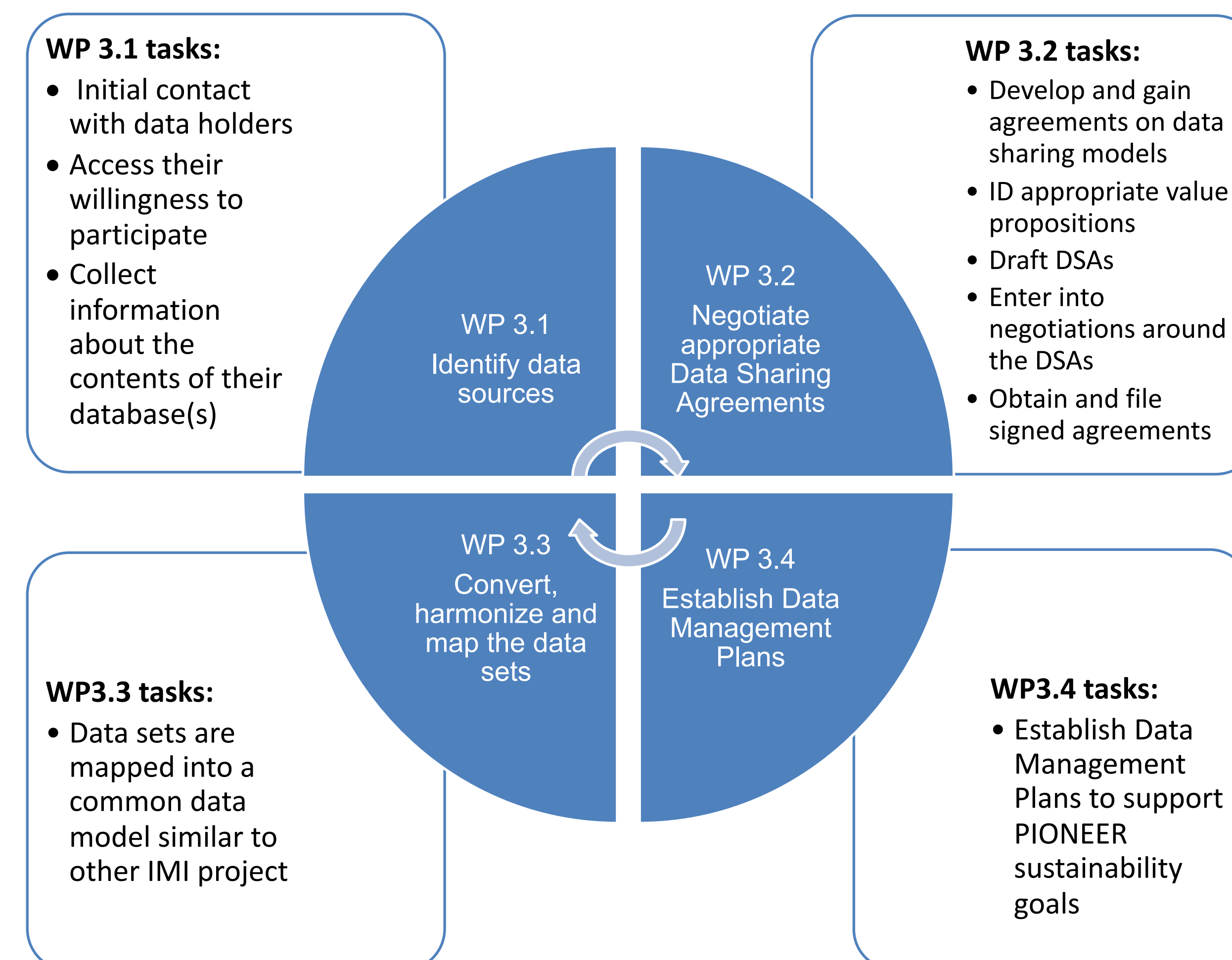
- ambitious
- transformative
- collaborative
- disease-specific
- patient-centric

Work Package 3

Data Access and sources

Identify, approach and negotiate appropriate data sharing agreements with a variety of holders of high-quality, real-life prostate cancer-based datasets across European and non-European patient populations.

Methods and Materials

To effectively tackle WP3 work plan, subgroups were formed:

WP 3.1 tasks:
- Initial contact with data holders
- Access their willingness to participate
- Collect information about the contents of their database(s)

WP 3.2 tasks:
- Develop and gain agreements on data sharing models
- ID appropriate value propositions
- Draft DSAs
- Enter into negotiations around the DSAs
- Obtain and file signed agreements

WP 3.1 Identify data sources

WP 3.2 Negotiate appropriate Data Sharing Agreements

WP 3.3 Convert, harmonize and map the data sets

WP 3.4 Establish Data Management Plans

WP3.3 tasks:
- Data sets are mapped into a common data model similar to other IMI project

WP3.4 tasks:
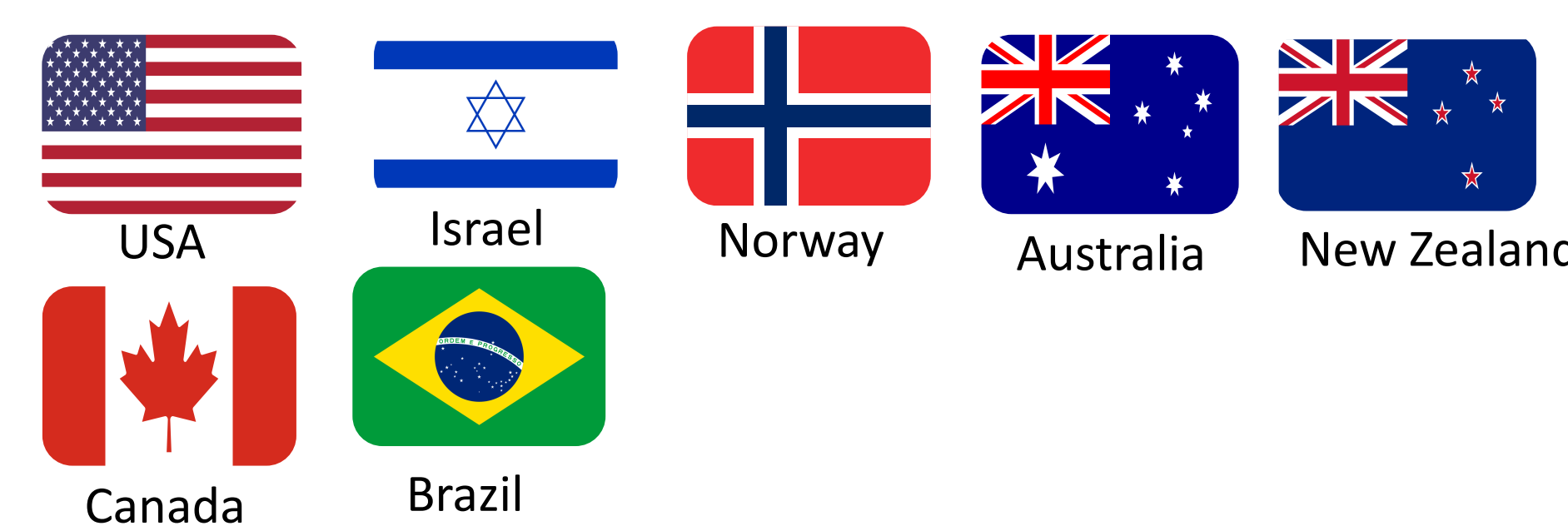- Establish Data Management Plans to support PIONEER sustainability goals

Data sources

Type of data contributors that my be approached by PIONEER for participation: Academics, Large clinical practices and medical centres, Life sciences industry, Data aggregators, Payers/governments
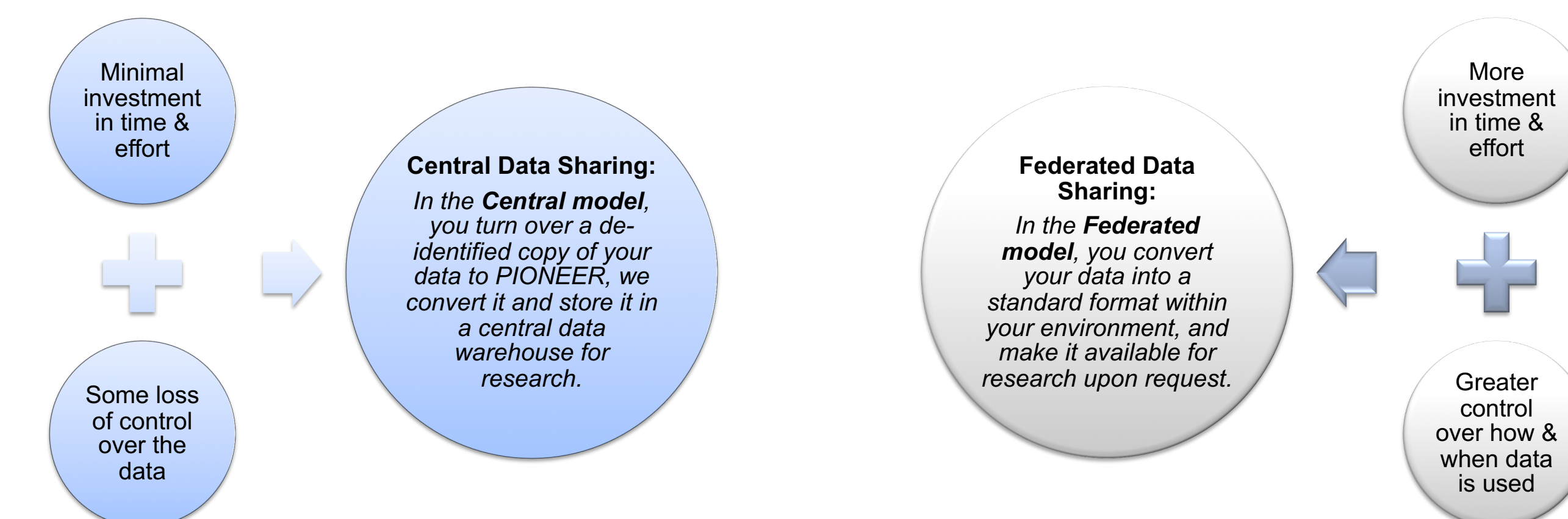
EU-based data sources from:

EU | Sweden | Netherlands | Finland | UK | Germany

Denmark | Italy | Ireland | Belgium | Spain/Catalonia

Non-EU data sources from:

USA | Israel | Norway | Australia | New Zealand

Canada | Brazil

Individual databases are built on: Retrospective and Prospective single institute, Prospective multi-institute, Population-based cohorts, Randomised control trial cohorts, Retrospective and prospective multi-institutional

Data sharing models

- PIONEER will utilise the Federated (remote data) and Central (imported data) data sharing models
- The data sharer can determine which model is best for them

Minimal investment in time & effort

Some loss of control over the data

Central Data Sharing: In the **Central model**, you turn over a de-identified copy of your data to PIONEER, we convert it and store it in a central data warehouse for research.

Federated Data Sharing: In the **Federated** model, you convert your data into a standard format within your environment, and make it available for research upon request.

More investment in time & effort

Greater control over how & when data is used

Results

PIONEER has over 60 EU and non-EU potential data sources identified

WP3 and WP8 (legal, ethics and governance) have established two standardised DSA (Data sharing agreement) templates to be used with data contributors.

As of September 2019 datasets:
- **ERSPC Rotterdam and PRIAS (Europe)** datasets are in the process of being mapped to OMOP (Federated sharing model)

- **Malmö Diet and Cancer/Malmö Preventative Medicine** (Sweden) has chosen to use the Central sharing model.

- Access to clinical trial datasets from industry partners, in most cases, will be provided through **Project DataSphere**.

- Negotiations are underway for access to databases from Australia/New Zealand, Germany, Finland, the UK, the Netherlands, Denmark, Norway and the USA.

Conclusion

PIONEER has infinite potential thanks to its size and content.

By applying big data analytics and developing a data platform of unparalleled scale, quality and diversity, PIONEER will be able to answer questions about prostate cancer in a new way that will empower meaningful improvement in clinical practice, prostate cancer disease-related outcomes and health economic outcomes across the European healthcare landscape.

How to contribute

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