

Our Goals

Map oncology data across 123 OECI Cancer Centers.

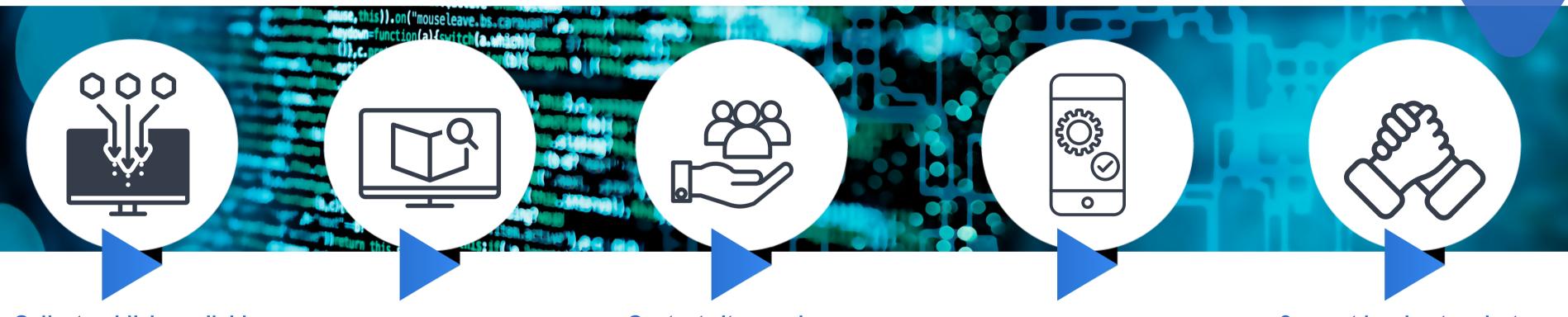
Stakeholders and data elements:

- Researchers EMR, trials, administrative, registries;
- Providers second opinions;
- Policymakers clinical practice guidelines, latest initiatives;
- Patients trials, novel therapies and diagnostic methods.

Automated updates whenever possible, e.g., trials.

Automated machine translations to all EU official languages, which can be refined by the sites and other contributors.

Execution summary



Collect publicly available information about existing data

Place information on a Wiki

Contact sites, make a presentation (if they want), and ask for modifications on the data

Use information from the Wiki to create a decision support application with personalized interfaces for each stakeholder

Support local networks to attract research funding

Potential connections ions to DIGICORE

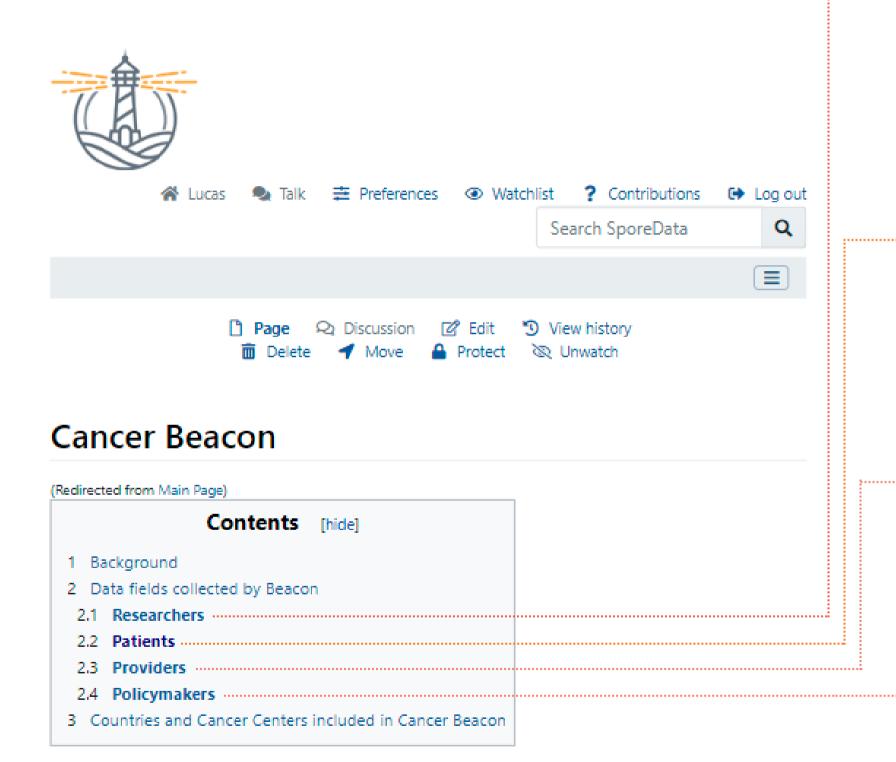
Mapping claims and administrative data - clinical outcomes

Mapping cancer registries - rich cancer epidemiological data

Stepwise instructions on how to directly access data.

European Alliance for Personalized Medicine (EAPM) for policy making.

WIKI TEMPLATE



Researchers [edit]

- Electronic health information: general characteristics including overall field categories, times
 since the system has been in place, and the overall setting as defined in the STROBE reporting
 guideline checklist. Publications previously using these databases are also published so that
 the authors can be contacted.
- Trials and cohort studies: this information is automatically gathered from the EU Clinical Trials Register and clinicaltrials.gov, along with the respective trial page description where contact information for trial coordinators and other points of contact can be found.
- Cancer registries at the regional or national level: field categories, overall registry goals and setting, previous publications along with contact information for researchers with access to the data.
- Research publications: link to publications from researchers from each Oncology Center, specifying publications with contact information on researchers.

Patients [edit]

- Trials available at hospitals close to their residence: the information is provided along links to
 pages with contact information on trial coordinators as well as information on how to enroll in
 a given study. All information is translated to all official country languages using automated
 translation tools, and provided in lay rather than technical language.
- Novel therapies and diagnostic methods: this information is provided along with links to
 pages from the Oncology Center providing more information as well as clinical points of
 contact. All information is also provided in all official country languages, using lay language.
- Patient associations: advocacy groups focused on cancer that can provide patients with information on multiple aspects related to screening, treatment, palliative care, well-being and quality of life, among other topics.

Providers [edit]

- Experts: pages linking to contacts with clinical experts within each Oncologic Center, so that
 other providers can reach out to them in search of a second opinion regarding difficult cases.
- Open educational meetings: links are provided to open educational meetings where clinicians from other centers can participate through video conferences. These meetings include Grand Rounds, journal clubs, among other Cancer Center-specific resources not sharing private patient information.

Policymakers [edit]

- Clinical practice guidelines: links to public drafts of clinical practice guidelines published by national or transnational organizations, along with links to the main panel participants contributing toward those guidelines.
- Policy reports: links to any policy reports addressing issues such as access to care and equity, public health, global health, healthcare services and quality, health insurance, pharmaceuticals, the impact of COVID-19, telehealth, medical and humanitarian aid, among others. Links to contact information for those contributing to these reports are also provided.











