Save Sight Registries

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Data source | Human | Disease registry | Other

Administrative details

Administrative details

Data source ID

105438

Data source acronym

SSR

Data holder

University of Sydney

Data source type

Disease registry

Other

Data source type, other

Patient outcomes registry

Main financial support

Funding from industry or contract research

Care setting

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

Yes

Description of the qualification

Custom qualification by steering committee subject matter experts

Data source website

https://savesightregistries.org/

Contact details

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Main

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Data source regions and languages

Data source countries

Australia

Austria

Belgium

Bosnia and Herzegovina

Canada

Egypt

Fiji

France

Germany

India

Indonesia

Ireland

Italy

Japan

Jordan

Lebanon

Mexico

Nepal

Netherlands

New Zealand

Nigeria

Portugal

Serbia

Singapore

Slovakia

Slovenia

South Africa

Spain

Switzerland

Taiwan

United Arab Emirates

United Kingdom

Data source languages

English

Data source establishment

Data source established

15/06/2007

Data source time span

First collection: 14/05/1989

The date when data started to be collected or extracted.

Publications

Data source publications

Preclinical and clinical studies of photobiomodulation therapy for macular oedema

Dexamethasone Implant for Diabetic Macular Oedema: 1-Year Treatment Outcomes from the Fight Retinal Blindness! Registry

Characterization of Poor Visual Outcomes of Diabetic Macular Edema: The Fight Retinal Blindness! Project

THREE-YEAR TREATMENT OUTCOMES OF AFLIBERCEPT VERSUS RANIBIZUMAB FOR DIABETIC MACULAR EDEMA

Subretinal fluid may protect against macular atrophy in neovascular age-related macular degeneration: 5 years of follow-up from Fight Retinal Blindness registry

Brolucizumab clinical and safety outcomes in a neovascular age-related macular degeneration national database: Fight Retinal Blindness Spain (FRB Spain)

Adherence to Anti-VEGF Treatment in Patients with Neovascular Age-Related Macular Degeneration: A Real-World Study

THE FIGHT INHERITED RETINAL BLINDNESS! PROJECT: A New Treatment Outcome and Natural History Registry for Inherited Retinal Disease

Fight Retinal Blindness SPAIN. Report 3: clinical outcomes of vascular endothelial growth factor inhibitors in low vision eyes with neovascular age-related macular degeneration. A national database study

Outliers of Treatment Frequency in Retinal Vein Occlusion: 24-Month Comparative Analysis of Fight Retinal Blindness! Practitioners

Impact of cataract surgery on patients receiving intravitreal therapy for retinal vein occlusion

Three-Year Outcomes of VEGF Inhibitors in Naive Branch Retinal Vein Occlusion: Fight Retinal Blindness!

Treat-and-Extend Versus Pro re nata Regimens of Ranibizumab and Aflibercept in Neovascular Age-Related Macular Degeneration: A Comparative Study from Routine Clinical Practice

One-Year Anti-VEGF Therapy Outcomes in Diabetic Macular Edema Based on Treatment Intensity: Data from the Fight Retinal Blindness! Registry

European Unmet Needs in the Management of Neovascular Age-Related Macular Degeneration in Daily Practice: Data from the Fight Retinal Blindness! Registry

https://doi.org/10.1136/bjo-2023-323915

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

Yes

Disease details (other)

Macular Degeneration, Choroidal neovascularisation, Retinal Vein Occlusion, Diabetic Retinopathy, Glaucoma, Keratoconus, Optometry, Dry Eye, Ocular Melanoma, Uveitis, Retinopathy of Prematurity, Inherited Retinal Diseases

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Prescriptions vocabulary, other

Custom made list

Dispensing of medicines

Not Captured

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

Yes

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Captured

Indication vocabulary

Other

Indication vocabulary, other

Custom made list

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

Yes

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

Custom made list

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

Custom made list

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Captured

Biomarker data vocabulary

HPO

Other

Biomarker vocabulary, other

Custom made list

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

Yes

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

Yes

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

Custom made list

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Route of administration

Strength

Medicinal product vocabulary

Other

If 'other,' what vocabulary is used?

Custom made dictionary

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

IVI, KORQ, GAL-9, OSDI, PHQ4

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Ethnicity

Gender

Other

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Adolescents (12 to < 18 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

Estimated percentage of the population covered by the data source in the catchment area

Information not available

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

Information not available

Population

Population size

40039

Active population size

13032

Population by age group

Age group	Population size	Active population size
Paediatric Population (< 18 years)	383	60
Infants and toddlers (28 days – 23 months)	2	
Children (2 to < 12 years)	17	2
Adolescents (12 to < 18 years)	364	58
Adults (18 to < 46 years)	4195	748
Adults (46 to < 65 years)	4552	1614
Elderly (≥ 65 years)	30909	10610
Adults (65 to < 75 years)	7543	2716
Adults (75 to < 85 years)	12288	4496
Adults (85 years and over)	11078	3398

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

2.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

3.00

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

SaveSightRegistries_Terms of Use_11May2020

English (702.88 KB - PDF) View document

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Description of data collection

Data is collected in real time as doctor sees the patient. Bespoke web browser based data collection system. Patient questionnaires include IVI, KORQ, GAL-9,

OSDI, PHQ4. More details in attached documentation.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

Event triggering de-registration of a person in the data source

Death

End of treatment

Event triggering creation of a record in the data source

For most modules (diseases within SSR Registry), trigger is patient receiving treatment for disease as first/baseline visit record.

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Informed consent for use of data for research

Other

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Informed consent, other

Some modules for registry is OPT-OUT consent in some countries e.g. Australia, however most have OPT-IN consent where patient consent is sought before being entered in the registry. Further to this, if data is to be used for a publication, a publication committee evaluates these requests for data access/analyses.

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

No