

# Data Repository Project

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- **SAC review 2010 → recommendations**
- **SAC review 2014 → results**

- **Data Preservation and Sharing Policy**
- **Standard Protocol Template**
- **Data Repository**
- **Minimum dataset form**

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- **Data Preservation and Sharing Policy**
  - **available on the QLG website**
  - **addition in progress**

- **Data Preservation and Sharing Policy**
- **Standard Protocol Template**
- **Data Repository**
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- **Standard Protocol Template**
  - **already in use**
  - **feedback?**

- **Data Preservation and Sharing Policy**
- **Standard Protocol Template**
- **Data Repository**
- **Minimum dataset form**



- **Data Repository**

- **13 studies, 6000 patients, 33 countries, different cancer sites**
- **regularly updated (3 more studies to be added in the next months)**
- **data available for secondary research (see policy)**

- **Data Preservation and Sharing Policy**
- **Standard Protocol Template**
- **Data Repository**
- **Minimum dataset form**

- **Minimum dataset form (1)**
  - **Patient identification data**
    - Patient identification number
    - Date the patient entered the study

- **Minimum dataset form (2)**

- **Socio-demographic data**

- Gender
- Age
- Country
- Education
- Employment (+ sick leave)
- Marital status
- Cohabitants

- **Minimum dataset form (3)**

- **Clinical data**

- Performance status
- Cancer site
- Date of diagnosis
- Stage of disease
- Comorbidities
- Treatment(s) received
- Currently under treatment

- **Minimum dataset form (4)**
  - **Quality of life data**
    - Date of assessment
    - Progressive number of assessment

# Thank you for your attention

## Questions?

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