

# CHECKLIST FOR REVIEW

## 1 Preparatory work at the planning stage

<p>1.1 The arguments justifying the need for the registry are presented (clinical relevance and public health relevance).</p>	
<p>1.2 The purpose, mission and benefits of the registry are explicitly specified:</p> <ul style="list-style-type: none"><li>a) for patients</li><li>b) for all other stakeholders</li></ul>	
<p>1.3 The legal framework is clarified.</p>	
<p>1.4 Integration of the registry at the national/international level is clarified.</p>	
<p>1.5 The funding body and any competing interests are transparently disclosed.</p>	
<p>1.6 Development and longer-term funding are assured, a financial plan is available.</p>	
<p>1.7 Aims and functions are clearly defined.</p>	
<p>1.8 The organisation of the registry is clearly described in a plan/regulations.</p>	

## 2 Expertise required for registry management

2.1 The managers' expertise matches the aims of the registry.	
2.2 Scientific expertise is assured (methodology, clinical expertise in the relevant area).	
2.3 Technical expertise is available (registry development, processes, logistics, database quality and security).	

## 3 Data protection and data ownership

3.1 A data protection concept sets out all necessary measures to comply with the requirements of (national and cantonal) data protection legislation. This includes data protection regulations that cover the following points:	
a) Protection of privacy: description of data anonymization/coding processes and informed consent, as well as the right to inspect data, management of revocation of consent and data retention.	
b) Technical data security	
c) Data access/data ownership/inspection and access rights/further use of data by third parties.	

## 4 Data collection

4.1 The data variables to be collected are clearly defined and adapted to the aims.

4.2 Technical structures are adequate and capable of development.

4.3 Linkage to administrative/official data or integration into hospital information systems (interoperability) is assured.

4.4 A data flow diagram is available, clearly describing data collection, transmission and processing.

## 5 Quality assurance

5.1 A validation plan is available, including periodic review procedures, to ensure data quality.

5.2 For standardised reports (e.g. hospital comparisons), an assessment and publication plan is available, precisely describing data analysis, the main indicators and the presentation of results.

5.3 Comparative analyses are supported.

## 6 Data use

6.1 There is regular public reporting of results.

6.2 Further use of data is made possible, e.g. for quality-related, research and public health purposes.

## 7 Change of purpose and dissolution

7.1 The appropriateness of the registry's aims and functions is periodically evaluated.

7.2 Processes for a change of purpose are defined.

7.3 Processes for dissolution of the registry are defined.

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ISSUED BY:

