

# DEFINITION AND ASSESSMENT OF QUALITY INDICATORS OF SARCOMA WORK-UP USING A TRANSDISCIPLINARY REAL-WORLD DIGITAL DATA PLATFORM

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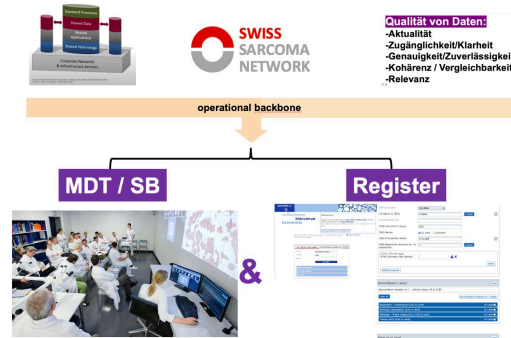
SWISS SARCOMA NETWORK; [www.swiss-sarcoma.net](http://www.swiss-sarcoma.net)

## Background

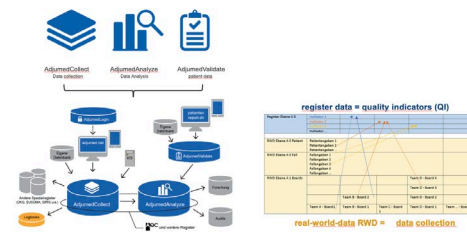
Sarcomas belong to the rare diseases and its management requires a transdisciplinary approach of several disciplines. Overall progress has been rather slow mainly because each single discipline assesses their own data. The French sarcoma network has shown the power of a registry to define new treatment approaches. Further, Switzerland will inaugurate a new law in 2021 on assessing the quality in medicine. However, to be able to report on quality, the capacity of assessing real-world data is a prerequisite, as well as to have a common source of definition on the quality indicators of sarcoma work-up (QI).

## Methods

The Swiss Sarcoma Network (SSN) created a real-world data platform ([www.adjumed.net](http://www.adjumed.net)) by combining the management of the weekly sarcomaboard with the sarcoma registry. This platform allows the collection of patient data, the analysis of each parameter in every possible combination, as well as the validation through patient reported outcomes. The SSN has inaugurated an international advisory board of world renowned sarcoma experts, among others to define 18 QI's. These 18 QI's were then programmed into the digital platform such that they can be instantly assessed in real-time. Starting in 2020, the data have been assessed prospectively.



## TRANSDISCIPLINARY REAL-WORLD DATA Registry Setup ([www.adjumed.ch](http://www.adjumed.ch))



## Figures

1 top left, RWD-registry structure; 2 top right, organization of Registry; 3 bottom left: demographics; 4 bottom right: QI's

## Discussion

Our efforts involving numerous institutions throughout Switzerland using a digital platform (2), to create a real-world data base registry (1) allow now to assess the demographics (3) of all sarcomaboard presentations and patients including all disciplines and decisions instantly in real time. A versatile analysis of all combinations of demographic data as well as QI's (4) allow the definition of outcome and quality parameters. Benchmarking among involved institutions, as well as on the international level becomes possible. Further, our efforts prove that the definition of QI's is possible and that these efforts need to be extended for each single discipline possibly throughout the geography. In a next step, PROMS/PROVES will be included.

## Conclusion

Such real-world data registry with the capacity to report on QI's paves the way to create a novel ecosystem for sarcoma patient care in the future.

| 09/2017 - 08/2020   | Total       | 1. Präsentation | FU - Präsentation |
|---|-------------|-----------------|-------------------|
| Fallpräsentationen (alle)   | 1494 / 100% |                 |                   |
| Primärfallpräsentationen  | 733 / 49%   |                 |                   |
| Follow up -Präsentationen   | 760 / 51%   |                 |                   |
| Dignität der Diagnosen  |             |                 |                   |
| • Benigne   | 20.7%       | 14.5%           | 7.2%              |
| • Intermediär   | 17.9%       | 8.6%            | 1.2%              |
| • Maligne   | 43.4%       | 12.4%           | 30.9%             |
| -----   |             |                 |                   |
| • Simulatoren   | 7.2%        | 5.4%            | 1.8%              |
| • Metastasen  | 3.2%        | 1.6%            | 1.6%              |
| • Hämatologische Tumore   | 1.2%        | 1.0%            | 0.2%              |
| • andere  | 6.4%        | 5.6%            | 0.8%              |
| Lokalisierungen, alle   |             |                 |                   |
| • Knochen (total / primär / follow up)                                      | 22.2%       | 11.6%           | 16.6%             |
| • Weichteile epifaszial (total / primär / follow up)                        | 11.4%       | 7.4%            | 3.8%              |
| • Weichteile subfaszial (total / primär / follow up)                        | 62.4%       | 29.9%           | 17.7%             |
| Anteil sarkomatöse 1 <sup>o</sup> Diagnosen (vs alle 1 <sup>o</sup> Diagn.) | 43%         |                 |                   |
| Anteil sarkomatöse 1 <sup>o</sup> Diagnosen (vs alle Vorstellungen)         | 21%         |                 |                   |
| Anzahl Biopsien, total  | 702         |                 |                   |
| • Feinnadel   | 5.1%        |                 |                   |
| • Stanze  | 73.5%       |                 |                   |
| • offene Inzision mit Sarkomverdacht  | 2.6%        |                 |                   |
| • offene Inzision ohne Sarkomverdacht                                       | 3.4%        |                 |                   |
| • Exzisionsbiopsie mit Sarkomverdacht                                       | 4.7%        |                 |                   |
| • Exzisionsbiopsie ohne Sarkomverdacht                                      | 32.1%       |                 |                   |

| QUALITY INDICATORS: Standards of care based on CPG's |  |
|--|--|
| Quality indicators / Outcome measures                |  |
| QI-1   | appropriate local imaging before biopsy/treatment initiation (yes/no)  |
| QI-1.1   | Diagnosis of malignant tumor considered/noted in the radiological report (yes/no)  |
| QI-2   | time from 1 <sup>st</sup> patient contact to biopsy (if performed)   |
| QI-3   | type of biopsy: FNA, tru-cut (CT- or US-guided), open incisional, excisional biopsy, enucleation/whoops  |
| QI-4   | time from biopsy to establishing diagnosis (1 <sup>st</sup> path review & reference review)  |
| QI-5   | time from biopsy until sarcoma board presentation  |
| QI-6   | biopsy before initiation of treatment (yes/no)   |
| QI-7   | biopsy performed in the center where the patient is operated: (yes/no)   |
| QI-8   | extent of disease at diagnosis   |
| QI-9   | time from SB to initiation of treatment  |
| QI-10  | margin status (R0, R1, R2) at definitive surgery (STS)   |
| QI-11  | preoperative radiation therapy: (yes/no)   |
| QI-12  | postoperative radiation therapy: (yes/no)  |
| QI-13  | neo-adjuvant chemotherapy: (yes/no)  |
| QI-14  | adjuvant chemotherapy (yes/no)   |
| QI-15  | local relapse: yes/no  |
| QI-16  | local recurrence: yes/no within 1 <sup>st</sup> year of tumor resection (Bone)   |
| QI-17  | metastatic relapse: yes/no   |
| QI-18  | Latest follow-up: no evidence of disease (NED); alive with disease (AWD); dead of disease (DOD); dead of other reasons (DOR); no assessment possible; lost to follow-up; other status: unknown |