Arthritis Research & Collaboration Hub

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on behalf of the ARCH study group

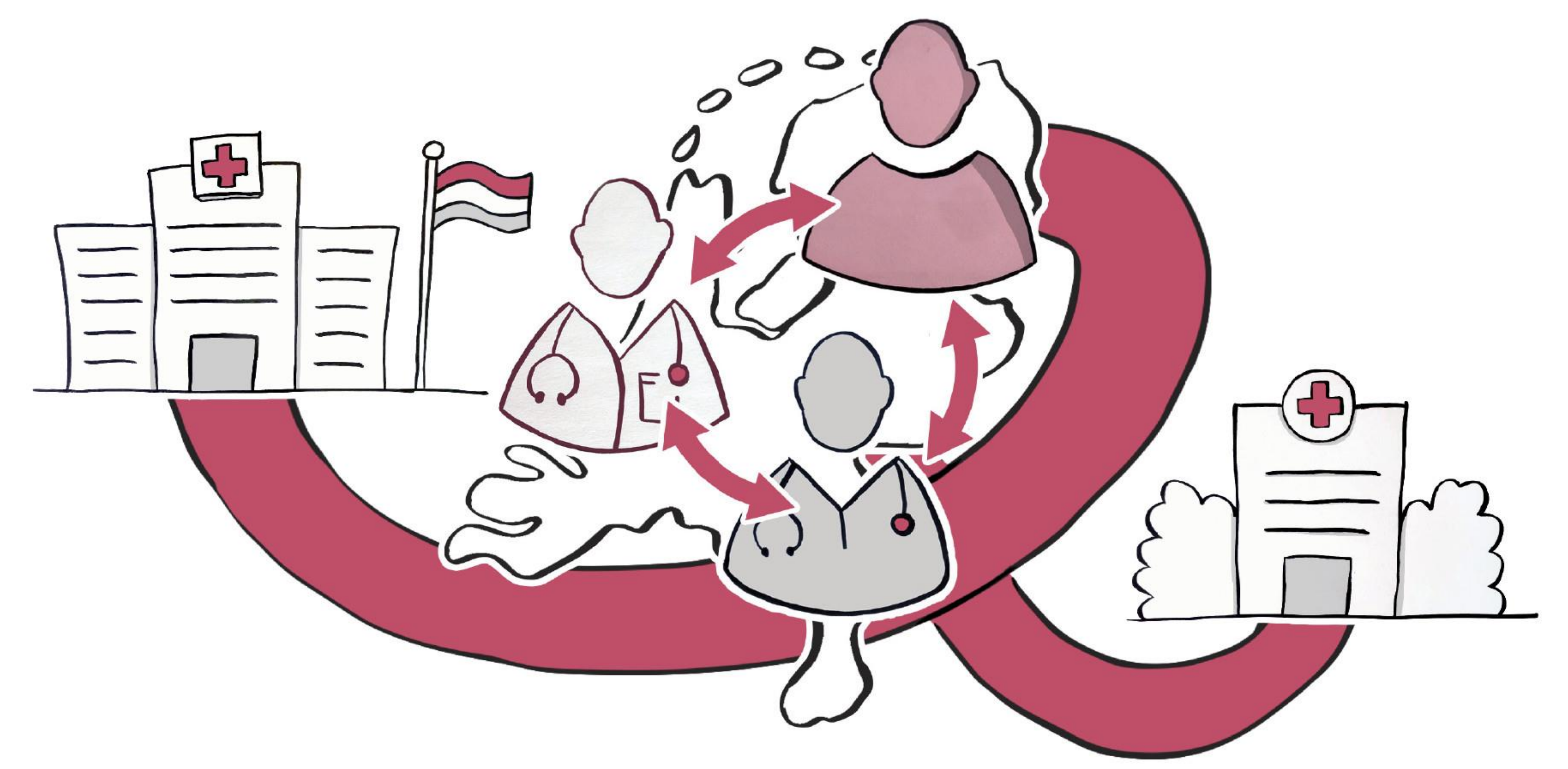
# The Autoimmune Research and Collaboration Hub (ARCH) in The Netherlands: aiming to improve health-care for all patients with rare, systemic autoimmune diseases

**Purpose** Improve care for patients with rare, systemic autoimmune diseases in The Netherlands by

- facilitating access to (inter)national expertise,
- decreasing diagnostic delay,
- and improving disease outcomes and Health Related Quality of Life for patients

**Results – stakeholder discussions** At the start of ARCH, several group discussions between experts in the field and patient representatives were organised to identify the main goal and the ways to reach this. Next, thematic working groups were formed, each focusing on a specific disease (including Systemic Sclerosis [SSc], SLE/antiphospholipid syndrome [APS], ANCA vasculitis and Sjögren [SS]) and on a specific workpackage.

**Methods** In 2016 the ARCH initiative was launched in The Netherlands, which was initiated and supported by ReumaNederland, the Dutch society for patients with rheumatic diseases. ARCH is an independent and interdisciplinary organisation in which medical specialists from different backgrounds and affiliations and patient representatives collaborate with the aim to improve outcomes for patients suffering from rare, systemic autoimmune diseases. Here, we report on the goals defined and the deliverables accomplished, with the aim to share clinical practice with our colleagues in ERN ReCONNET.



The **central goal** as defined by the stakeholders is to foster equal access to expertise healthcare for all patients with rare, systemic autoimmune diseases, including but not limited to SSc, SLE/APS, ANCA vasculitis and SS. During these meetings new and complex cases with systemic autoimmune disease are discussed with a diagnostic/ therapeutic purpose.

**Results – regional networks and digital platform** Regional networks of expertise have been formed, including the recognized centers of expertise and hospitals in the area, which organise online, multidisciplinary team meetings (MDT) on a weekly base. During these meetings new and complex cases with systemic autoimmune disease are discussed with a diagnostic/ therapeutic purpose. ARCH supports these meetings by providing a digital platform where patient information can be shared. Patients have access to this platform and can add by completing PROMs. To date 7 regional networks have been identified of which 6 are up and running.

**Table 1: number of patients with rare, systemic autoimmune disease discussed in the ARCH regional networks of expertise**

| | Vasculitis | SLE | SSc | APS | SS | Complex cases |
|---|---|---|---|---|---|---|
| 2021<br>*MDT, digital platform* | 58 | 40 | 5 | - | - | - |
| 2022<br>*MDT, digital platform* | 84 | 28 | 10 | - | - | 22 |
| 2022<br>*Regional network MDT, no platform* | 130 | 13 | 3 | 7 | 12 | 11 |

**Results – patient support charts** In addition, clinical practice guidelines, and disease specific support charts have been developed that help patients to prepare for their consultation with their physician.

**Conclusion** ARCH is an example of how healthcare for patients with rare, systemic autoimmune diseases can be organised on a national level. By identification and organisation of regional networks of expertise, access to expertise is increased for patients and physicians, and physicians from different backgrounds are encouraged to share best practices. For the future, broad implementation of the patient support charts and establishment of a national registry are planned, all with the aim to improve of disease outcomes for patients with rare and systemic autoimmune diseases.

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