**SUMMARY**

Clinicians with interest and expertise in connective tissue disease and vasculitis (CTDV) across the East of England (EoE) established the Eastern Network for Rare Autoimmune Disease (ENRAD) in 2016 in order to improve the quality and value of services for patients with CTDV in the region. The ENRAD Video Case Conference (ENRAD VCC) has run twice monthly from Cambridge University NHS Foundation Trust (CUHFT) since August 2016 with objectives:

- To improve diagnosis and management of patients with CTDV.
- To provide governance for high-tariff drug (HTD) services used in CTDV.

**THE CHALLENGE**

- Patients with CTDV have complex needs requiring support from multiple medical specialties across different hospitals.
- The designation of specialised rheumatology centres (Cambridge, Norwich and Ipswich in the Eastern Region) promoted redirection of many complex cases from their local Trusts.
- The development of policies by NHS England, governing use of HTDs in rare autoimmune disease, required expertise in disease activity monitoring and facilities for data collection and governance.
- Specialised centres lack capacity to accommodate management of all complex CTDV cases from across the region.
- Local Trusts wished to retain and/or to develop expertise in CTDV.
- Patients wish to be treated at their local Trust by a clinician with expertise in CTDV but also wish to have access to specialised centres when appropriate.

**THE SOLUTION**

- ENRAD is a network of clinicians across the EoE with an interest in CTDV that formed in 2016 and is run by a consultant rheumatologist at a specialised rheumatology centre and a steering committee.
- The overarching objective of ENRAD is to increase the quality, value and sustainability of services for patients with CTDV.
- A priority for the steering committee was the establishment of the ENRAD VCC service.
- The ENRAD VCC is a series of meetings (twice monthly) via videoconference and teleconference to discuss complex cases of CTDV. Figure 1 provides details on the key stakeholders, workflow and activities involved in the implementation of the ENRAD VCC service, which provides a forum for discussion and advice regarding the diagnosis and management of complex CTDV cases in the EoE.

**SERVICE AND FINANCIAL PERFORMANCE OUTCOMES**

**Service Outcomes**

- Prior to the introduction of the ENRAD VCC, access to HTDs required either organisng a “Group Prior Approval” arrangement between an individual Trust and commissioners, or submission of an individual funding request by the consulting physician. This resulted in uneven access for patients to HTDs across the EoE region.
- The ENRAD VCC has resulted in both improved access to HTDs across the Eastern Region and provided transparent governance of the use of these HTDs with careful consideration of alternatives.
- NHS England has sanctioned delivery of rituximab for SLE and for ANCA-associated vasculitis at local Trusts with the proviso that the decision to treat is made via the ENRAD VCC and that ENRAD can demonstrate expertise of at least one local clinician in the activity assessment tools for the relevant disease.

**Clinical Outcomes**

- The collaborative approach of the VCC improves diagnosis of rare autoimmune diseases with reduced need for patient referral to specialised centres.
- Discussion at the VCC clarifies unmet needs for pathway development and for clinician training—both of which can be addressed by network working groups and educational meetings, respectively.
- Epic et也希望CUHT underpins the collection of regional data into auditable files, thereby underpinning the governance of HTD use and future service evaluation.
- The ENRAD VCC promotes access for patients to relevant clinical trials.

**Financial Outcomes**

- HTD eligibility was considered for 98 CTDV patients during the first 18 months of ENRAD VCC. In 62% of cases (61/98), ENRAD recommended against using HTDs, proposing an alternative, preferred or equivalent management strategy.
- This led to an annual estimated cost-saving of £242,710. However, the estimated savings are associated with the following caveats:
  - These calculations assume that all patients considered for HTDs at VCC would have received an HTD if the VCC did not exist; this is unlikely.
  - In England, autoimmune CTDV patients with complex needs, including those with systemic lupus erythematosus (SLE), anti-neutrophil cytoplasmic autoantibody (ANCA)-associated vasculitis, idiopathic inflammatory myopathies, Sjögren’s syndrome and systemic sclerosis or scleroderma are managed through specialised rheumatology processes.
  - In total, ENRAD (a network of clinicians across the EoE with an interest in CTDV) established the VCC services to increase the quality, value and sustainability of services for patients with CTDV.

**INNOVATIVE APPROACH AND SCALABILITY**

- ENRAD is the first specialised rheumatology network to have established a VCC service and is innovative in a number of areas:
  - The use of videoconferencing software for meetings ensures flexibility and accessibility, and supports participation of all centres across the region.
  - The service supports effective data collection, sharing, analysis and evaluation through use of the Epic ePhsotol tool, supporting the ENRAD VCC activities.
  - The regional database (of audit data, case categories, HTD eligibility/response, metrics on the use of CTDV services, for example) provides material for audits that can drive the iterative nature of ENRAD activities; for example, the development of diagnosis, referral and management pathways for scenarios not adequately supported by existing guidelines or policies.
  - The aims and objectives of the ENRAD VCC meetings could be translated to address needs for a range of chronic diseases. It would be particularly suitable for diseases that are rare or complex and require expert secondary care concentrated in specialist centres or fragmented across several sites in a region.
  - ENRAD has been approached for advice regarding setting up the VCC by representatives from the North West, South West and Yorkshire and Humberside regions.

**PATIENT FOCUS AND SATISFACTION**

- The ENRAD VCC service improves patient experience by:
  - Minimising fragmentation of care by harmonising management pathways and treatment access across the network.
  - Improving diagnosis efficiency and initiation of effective management pathways by improving patient care via expert advice.
  - Facilitating Shared Care practices, reducing the need for patient referral to specialist centres.
- Informal discussion with experienced patients with CTDV suggests that they are strongly supportive of the ENRAD VCC.
- anecdotal reports indicate that patients appreciate the combination offered by the ENRAD VCC, of access to regional expertise with local service delivery whenever possible.

**REFERENCES**