

Project Name: hATTR amyloidosis Therapeutic Review

Partner Organisation(s): The Royal Free London NHS Foundation Trust, National Amyloidosis Centre (NAC)

Completion Date: March-2024

Outcome Summary:

All the specific objectives of this joint working project were met, including increasing capacity of the NAC to review all relevant patients, providing continued support for patients who may change therapy during the course of Therapeutic Review and completion of a Patient Satisfaction Questionnaire.

In addition to this, the TTR nurse is now a full-time funded position at the NAC.

Key Project Outcomes Data:

The joint working project was designed to and successfully met 3 specific objectives::

- **Objective 1:** Improve patient outcomes and experiences by offering all Relevant Patients a therapeutic review with clinicians at the NAC;
- **Outcome Measure:** hATTR Patients normally have an annual therapeutic review. During the term of the Joint Working project, the NAC were able to review all 187 patients in approximately 6 months, thereby almost doubling the capacity of the NAC to deliver these reviews.

- **Objective 2:** Provide patients who have been prescribed a different therapy as a result of the therapeutic review with better support and information in relation to the new therapy they are prescribed;
- **Outcome Measure:** In addition to the initial patient review, 67% of patients received an additional 6 month follow up. The level of support received by was highlighted in the patient satisfaction questionnaire:
 - ‘having a specialist TTR nurse to give expert advice knowledge of treatment. All the other questions I asked were covered with great assurance’
 - ‘I am very happy with my visit and results of todays appointment’
 - ‘the staff that dealt with my care today were excellent’
 - ‘[the] nurse explained next steps and gave us clear guidelines’

- **Objective 3: Assess patient experiences by completing a “Pre & Post” patient satisfaction questionnaire with all Relevant Patients who undergo a therapeutic review.**
- **Outcome Measure:** 80% patients completed the Questionnaire, with 100% of respondents rating the Service received by the TTR nurse as ‘worthwhile’. With quotes including:
 - ‘the National Amyloidosis Centre provides excellent and unique patient care’
 - ‘having a specialist TTR nurse is a considerable improvement on previous visits’
 - ‘I thought the nurse was excellent, really friendly and helpful’

Quote from Partner:

"The patients have been universally grateful to have a single and responsive point of contact at NAC (the TTR specialist nurse) who has in depth knowledge of their individual case."

Prof Julian Gillmore

Conclusion:

The hATTR therapeutic Review demonstrated that providing additional resources can increase the NAC capacity to see patients with greater speed and frequency, whilst also increasing patient satisfaction.

Following the successful Joint Working project, the dedicated TTR nurse role is now a full-time funded position at the NAC.

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