Case report: cost-benefit of earlier diagnosis in a patient with Behçet's disease using CTV3 codes at primary care UK

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Introduction

- It is challenging to build robust economic models for rare diseases since few epidemiologic and economic studies exist.
- We sought to establish a cost-benefit model for earlier diagnosis using real-world data collected from primary care Electronic Health Records (EHR) using Clinical Terms Version 3 (CTV3) codes².
- Our aim was to determine the healthcare utilisation and costs saved by making an earlier diagnosis of a patient with Behçet's disease.

Methods

- We analysed the Electronic Health Record (EHR) of a patient with Behçet’s disease, who could have been diagnosed four years earlier by using digital encoding of an established clinical guideline³.
- We extracted the Clinical Terms Version 3 (CTV3) codes from their primary care EHR. We then calculated the time to diagnosis. This was defined as the first time a coded entry of a clinical feature associated with Behçet’s disease was encoded until the time that a diagnosis was recorded.

We identified all the codes at the diagnostic odyssey that could be related to Behçet’s disease (GP visits, signs & symptoms, tests, referrals, interventions and misdiagnosis.

- We assigned for each identified code a cost attributed to the National Health Service (NHS)⁴. Then we calculated the potential total health service utilisation and the possible cost of the diagnostic odyssey.
- We compared costs incurred during the patient's real diagnostic odyssey (six years), to the shorter journey to diagnosis (two years) had the digitally encoded diagnostic criteria been used.

Results

- Total healthcare costs over the 6 year period were £1038. Of which £812 was incurred as costs during the 4 years after the earlier potential diagnostic date had the digital diagnostic criteria been used, a 78% reduction.

- Annual healthcare costs were highest in the 4 years prior to diagnosis.

- This saving in health care utilization included the potential avoidance of 3 unnecessary referrals, investigations and 1 misdiagnosis.

Discussion

- Data from primary care EHR allows the stratification of healthcare resources and calculation of costs.
- This study demonstrates that developing economic models at an individual patient level can help quantify the cost savings of earlier diagnosis in Rare Diseases.
- Further work is needed to replicate these findings in other cases and diseases.

References