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Summary

Measuring disease burden in Crohn's disease: How nurses assess disease

Shellie Radford

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Nurses

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The speaker presented a plan to develop a composite disease burden index for Crohn's disease that integrates patient-reported outcomes with clinical, endoscopic, and real-world health data to address gaps in current quality-of-life measurement and treatment decision-making.

KEY POINTS

- The speaker stated that 300,000 people in the UK live with Crohn's disease at a cost exceeding 3 billion annually, yet existing patient-reported outcome measures are inconsistently used and clinical trial endpoints focus primarily on symptom resolution rather than broader life impacts.
- A previously published composite index tool called the advocate tool was developed by the speaker to support decision-making conversations about advanced therapies in IBD.
- The proposed disease burden index, also called bridge, is currently in the co-design phase and will integrate patient-reported outcomes, clinical data, endoscopic findings, medical imaging, biosamples, histology, and digital health records from multiple UK sources including NHS digital and the IBD Bioresource.
- The development plan includes validation, toolkit preparation, and initial use in clinical research before potential application in clinical consultations, with the speaker stating the goal is to standardise how clinicians communicate and make treatment decisions.
- International collaborations include institutions in Canada, Australia, and the USA, with a study at Nottingham aligned with AstraZeneca informing the model.
- In the Q&A, the speaker explained the index would harmonise existing validated tools using statistical modelling and could enable treatment decisions based on high disease burden from factors like fatigue even when patients are in clinical remission, representing the speaker's view of future clinical application.

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