

Support for people with Huntington's Disease

Gaining insights into the Huntington's Disease pathway in the county, highlighting gaps and challenges and their impact on patients, their families and carers, and the wider health system.

Background

Gloucestershire's Integrated Care System does not have a dedicated Huntington's Disease service. The local Huntington's Disease pathway, such as it is, is attributed to a small number of experienced individuals with an understanding of the care system and confidence to act as positive risk takers. They navigate an informal and fractured network that allows them to negotiate and co-ordinate support for their clients and colleagues within a limited scope, at the same time facing challenges in engaging system partners and upholding effective communication between services.

Aim

Present an evidence-based options appraisal, using information & data gathered from:

- A complete a full review of the Huntington's Disease pathway.
- Mapping current Huntington's Disease pathway, inclusive of services and practitioners.
- Gaining critical feedback from lay members and people with lived experience to inform the mapping process and engage in the design of further recommendations.

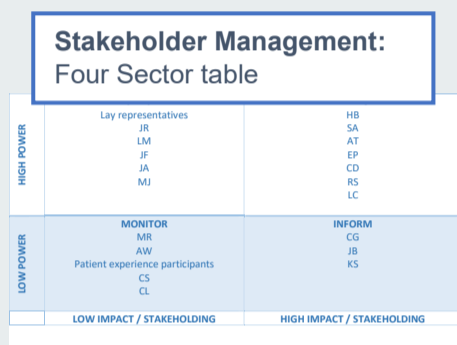
Measurement

Currently, the project is in the review phase. However, it is anticipated that there will be a significant number of metrics used to measure the success of the recommendations / change initiatives which will be designed and delivered within a business case.

These metrics will be inclusive of: Hospital admissions avoidances (comparative data analysis); HD specialist referrals and activity data (KPI's); HD clinic data; Cost / benefit data analysis; Patient experience feedback (i.e. MyCaw); Neurology audit.

Method/Design

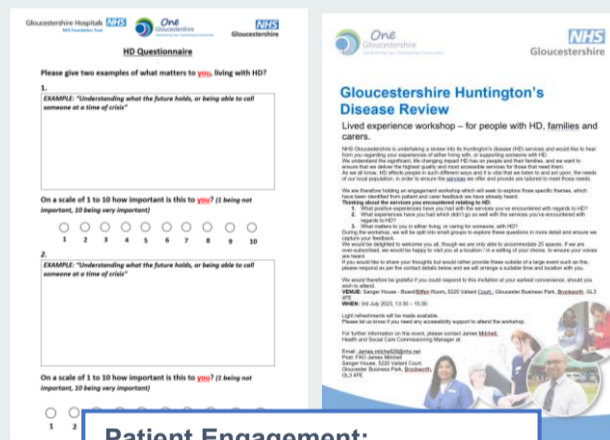
Stakeholders: Gloucestershire Integrated Care Board (ICB); Gloucestershire Hospitals NHSFT; Gloucestershire Health & Care NHSFT; Huntington's Disease Association; Gloucestershire County Council (GCC); Lay members and patients with lived experience



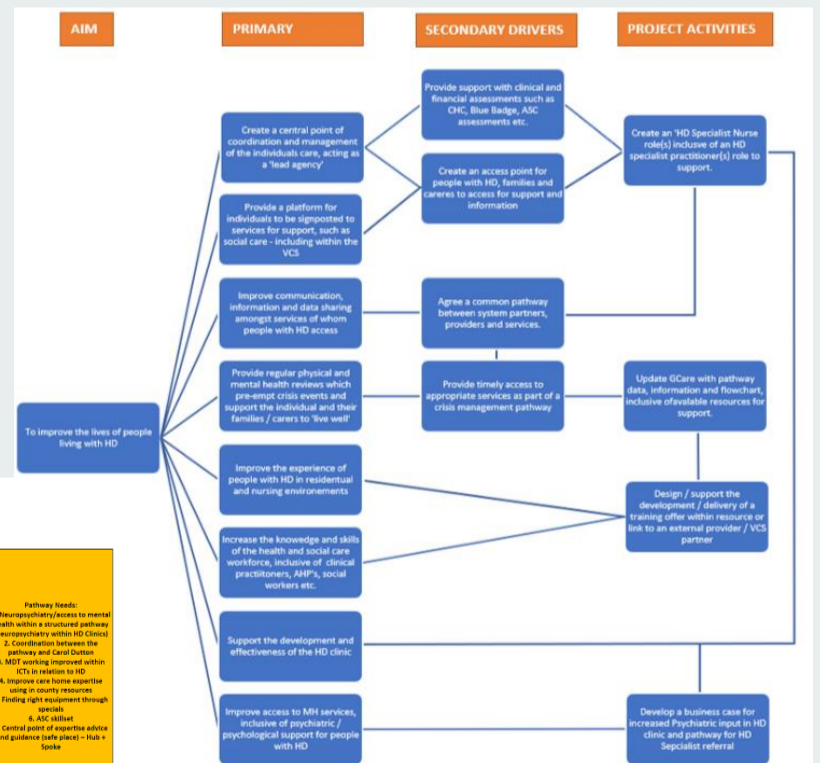
Learning

Engagement with patients, people with lived experience, their families and carers opened up the review to new areas of investigation that we as clinicians had not even considered. The perspectives and feedback of these populations were essential in driving change in the right direction and ensure that their needs are understood and play a significant part in how services, roles and pathways are designed and delivered.

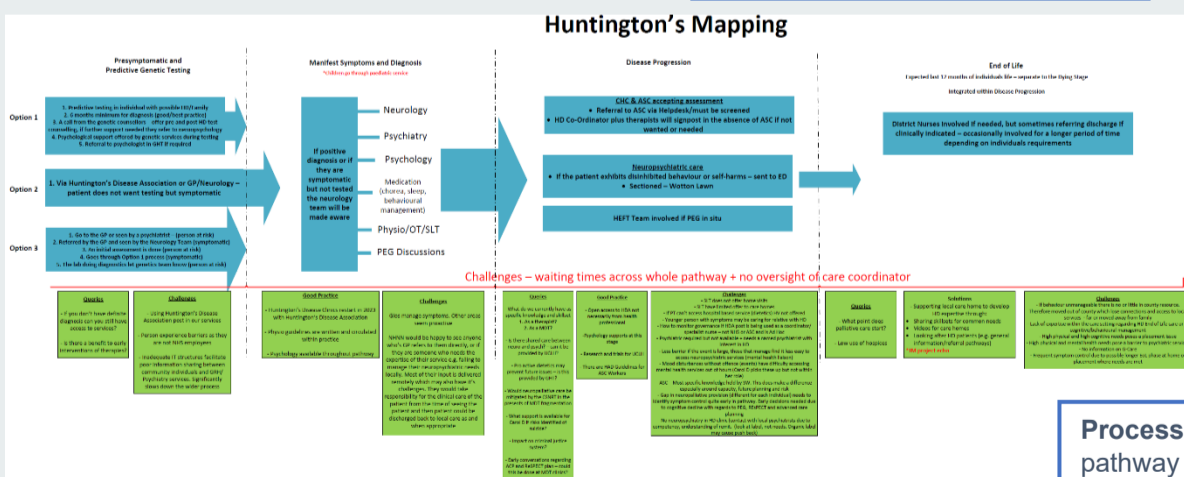
- Project meetings
- Clinical pathway mapping workshops
- Patient engagement workshop
- Patient engagement questionnaire
- Detailed case studies
- Shadowing day with patient



Patient Engagement: Questionnaires & Workshops



Driver diagram describing how to improve the lives of people living with Huntington's Disease



Process mapping of current pathway in Gloucestershire

Conclusion and Next Steps

- 9 successful project meetings held
- Two clinical pathway mapping workshops completed
- One patient engagement workshop held
- 15 Patient engagement questionnaire completed
- 7 detailed case studies
- What Matters to Me' & 'Personalised Care and Support Plan' being co-designed with HDA specialist.
- HD clinic set up and run by GHT inclusive of GHT neurologist, GHT Consultant Clinical Psychologist, and HDA Specialist Advisor

Tools and/or Models Applied

- Patient engagement
- Pathway mapping
- Driver diagrams
- Stakeholder analysis