

Huntington's Disease Pathway

James Mitchell
Health & Social Commissioning Manager (Rehabilitation)



Project Team

Gloucestershire Integrated Care Board (ICB)

James Mitchell (Chair)	Health and Social Care Commissioning manager- Rehabilitation
Srikesavan Sabapathy	Clinical Lead Therapist
Helen Vaughan	Bank Senior Commissioning Manager
Lindsey Hunt	Business Support Administrator
Holly Beaman	Head of Integrated Commissioning (Learning & Physical Disabilities)
Jane Reid	Outcome Manager Integrated Disabilities Commissioning Team
Louise Matthews	Commissioning Officer Learning & Physical Disabilities

Gloucestershire Hospitals NHSFT

Dr Sian Alexander	Consultant Neurologist
Dr Aileen Thomson	Clinical Psychologist

Gloucestershire Health & Care NHSFT

Dr Emma Phillips (with Dr David Ogden and Dr Emily Rackley)	Consultant in Liaison and Older Adult Psychiatry
Jane Fifield	Clinical Specialist Physiotherapist
Melissa Reed	Consultant OT for Recovery & Inclusion
Amy Wadley	Community Occupational Therapy Lead for the FoD / TNS ICT

Huntington's Disease Association

Carol Dutton	HDA Specialist Advisor
Ruth Sands	Head of Advisory Service
Charlotte Gerada	Policy and Public Affairs Manager

Gloucestershire County Council (GCC)

Jane Blackett	LD/PD & OP In-house Services Manager
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Lay Members

Julie Stockwin
Emma Terranova
Andrew Crolla

About the project

Gloucestershire's Integrated Care System does not have a dedicated HD service. The local HD 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.

The review seeks to map the HD pathway in the county, whilst highlighting the various gaps and challenges the lack of such pathway presents on patients, their families and carers and the wider health system.

Aims & Objectives

The project group aims to:

1. Complete a full review of the Huntington's Disease pathway.
2. Develop a map of the current HD pathway, inclusive of services and practitioners.
3. Gain critical feedback from lay members and people with lived experience to inform the mapping process and engage in the design of further recommendations.
4. Present an evidence – based options appraisal, using information & data gathered from aims 1,2 & 3

Measures Used

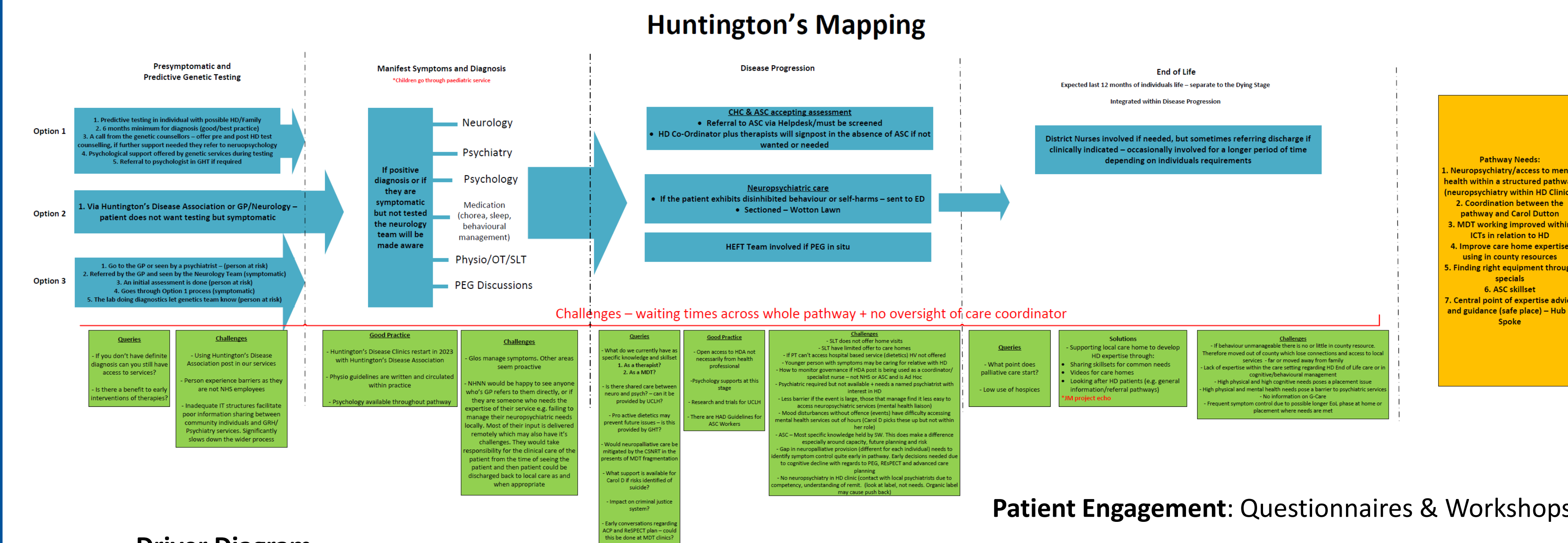
Currently, the project is in the review phase. However, it is anticipated that there will be a significant number of metrics used to measure the success of the recommendations / change initiatives which will be designed and delivered within a business case.

These metrics will be inclusive of:

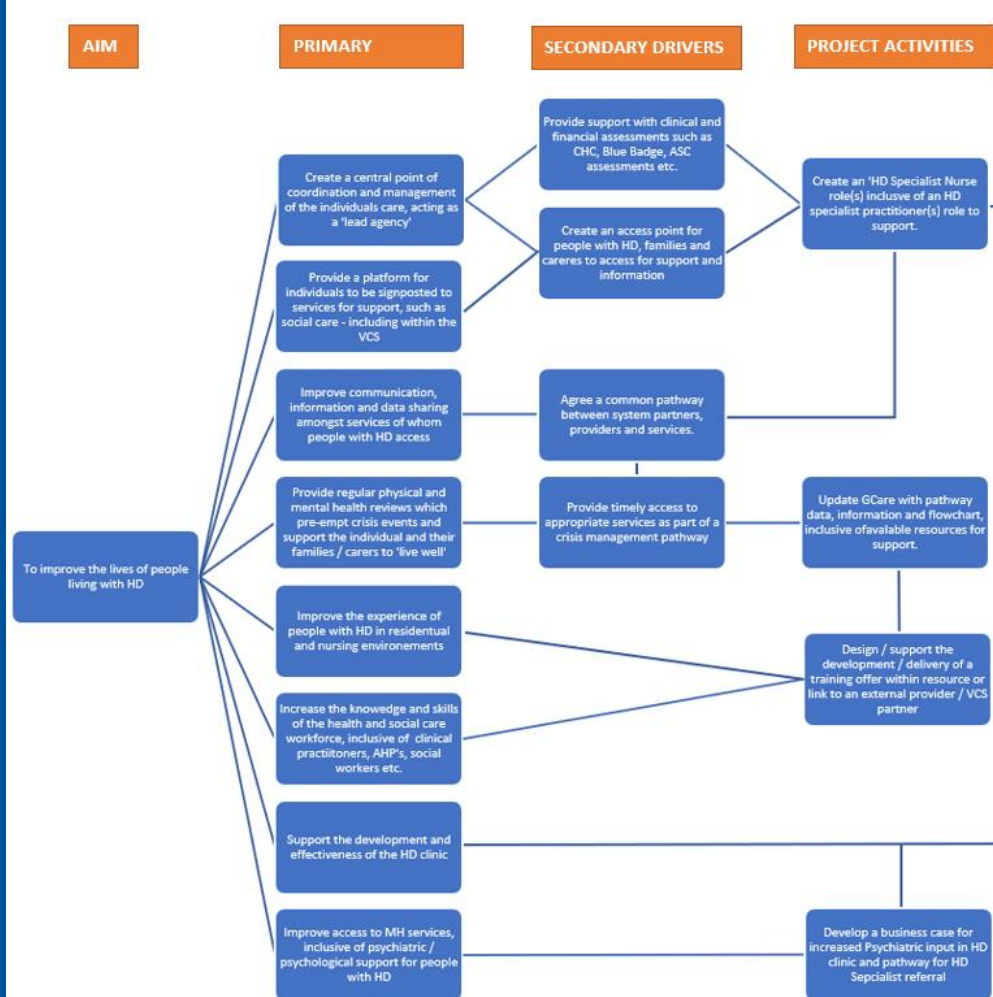
- Hospital admissions avoidances (comparative data analysis)
- HD specialist referrals and activity data (KPI's)
- HD clinic data
- Cost / benefit data analysis
- Patient experience feedback (i.e. MyCaw)
- Neurology audit

Quality Service Improvement and Redesign (QSIR) Tools: Methodologies used and contribution to project

Process mapping of current HD pathway in Gloucestershire



Driver Diagram



Stakeholder Management: Four Sector table

HIGH POWER	SATISFY	Lay representatives	JR LM JF JA MJ	HIGH IMPACT / STAKEHOLDING
	MANAGE	HB SA AT ED CP RS LC		
LOW POWER	MONITOR	MR AW Patient experience participants	CS CL	LOW IMPACT / STAKEHOLDING
	INFORM	CG JB KS		

Patient Engagement: Questionnaires & Workshops

Gloucestershire Hospitals NHSFT, One Gloucestershire, NHS Gloucestershire, One Gloucestershire, NHS Gloucestershire

HD Questionnaire

Please give two examples of what matters to you, living with HD?

1. **EXAMPLE: "Understanding what the future holds, or being able to call someone at a time of crisis"**

On a scale of 1 to 10 how important is this to you? (1 being not important, 10 being very important)

2. **EXAMPLE: "Understanding what the future holds, or being able to call someone at a time of crisis"**

On a scale of 1 to 10 how important is this to you? (1 being not important, 10 being very important)

Gloucestershire Huntington's Disease Review

Lived experience workshop – for people with HD, families and carers.

NHS Gloucestershire is undertaking a review into its Huntington's disease (HD) services and would like to hear from you regarding your experience of either living with, or supporting someone with HD. We understand the significant, life changing impact HD has on people and their families, and we want to ensure that we deliver the highest quality and most accessible services for those that need them. As we all know, HD affects people in such different ways and it's vital that we listen to and act upon the needs of our local population, in order to ensure the services we offer and provide are tailored to meet those needs.

We are therefore holding an engagement workshop which will seek to explore three specific themes, which have been identified from patient and carer feedback we have already heard:

1. What positive experiences have you had with the services you've encountered relating to HD?
2. What experiences have you had which didn't go so well with the services you've encountered with regards to HD?
3. What matters to you in either living, or caring for someone, with HD?

During the workshop, we will be able to discuss these questions in more detail and ensure we capture your feedback. We would be delighted to welcome you all, though we are only able to accommodate 25 spaces. If we are over-subscribed, we would be happy to visit you at a location / in a setting of your choice, to ensure your voice is heard.

If you would like to share your thoughts but would rather provide these outside of a large event such as this, please respond as per the contact details below and we will arrange a suitable time and location with you.

We would therefore be grateful if you could respond to this invitation at your earliest convenience, should you wish to attend.

DATE: 3rd July 2022, 13:30 – 15:30.

WHERE: Sanger House - Board/IT/HR Room, 5220 Valiant Court, Gloucester Business Park, Brockwells, GL3 3FE.

Light refreshments will be made available. Photos of us know if you need any accessibility support to attend the workshop.

For further information on this event, please contact James Mitchell, Health and Social Care Commissioning Manager at:

Email: James.Mitchell@nhs.uk
Post: FAD, James Mitchell, Sanger House, 5220 Valiant Court, Gloucester Business Park, Brockwells, GL3 3FE

@NHSGLos
www.nhs.uk

Project Outcomes, Progress and Impact

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
One HDA specialist shadowing day with patient 'Go see'
'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, Dr Sian Alexander, GHT Consultant Clinical Psychologist Dr Aileen Thomson and HDA Specialist Advisor, Carol Dutton

PROJECT MEETINGS
14th September 2022
7th December 2022
15th February 2023
26th April 2023
21st June 2023

MAPPING MEETINGS
9th November 2022 29th November 2022 14th December 2022

Learning for the Improvement Community

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.