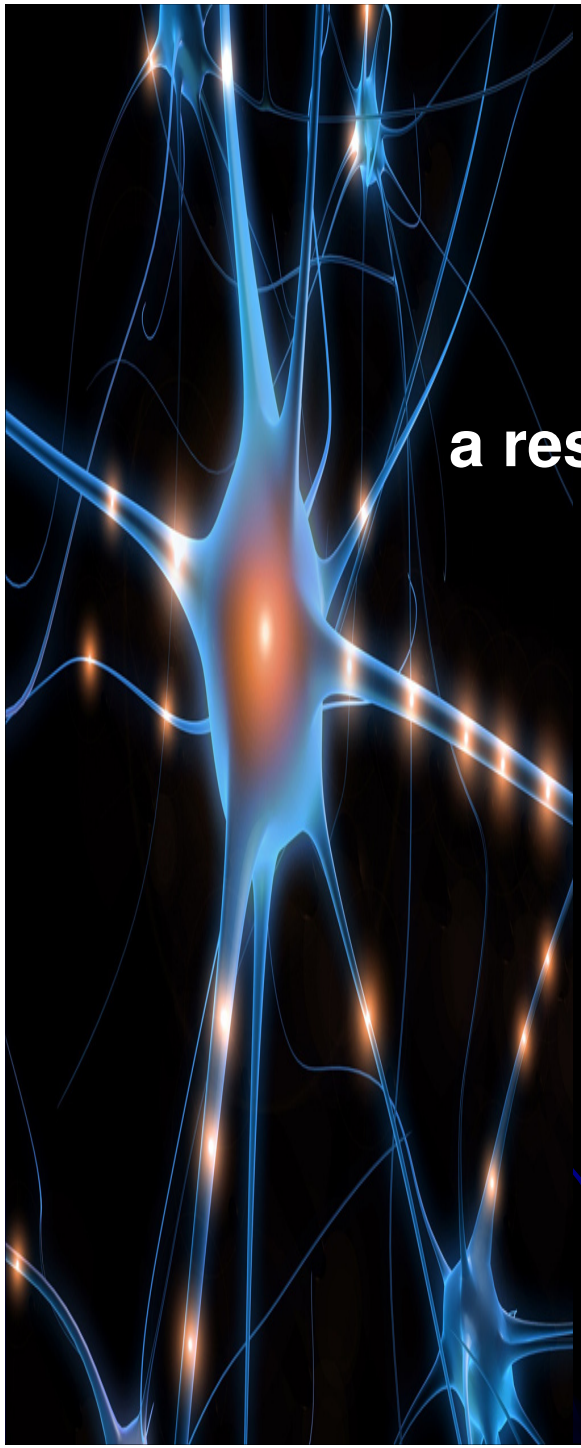


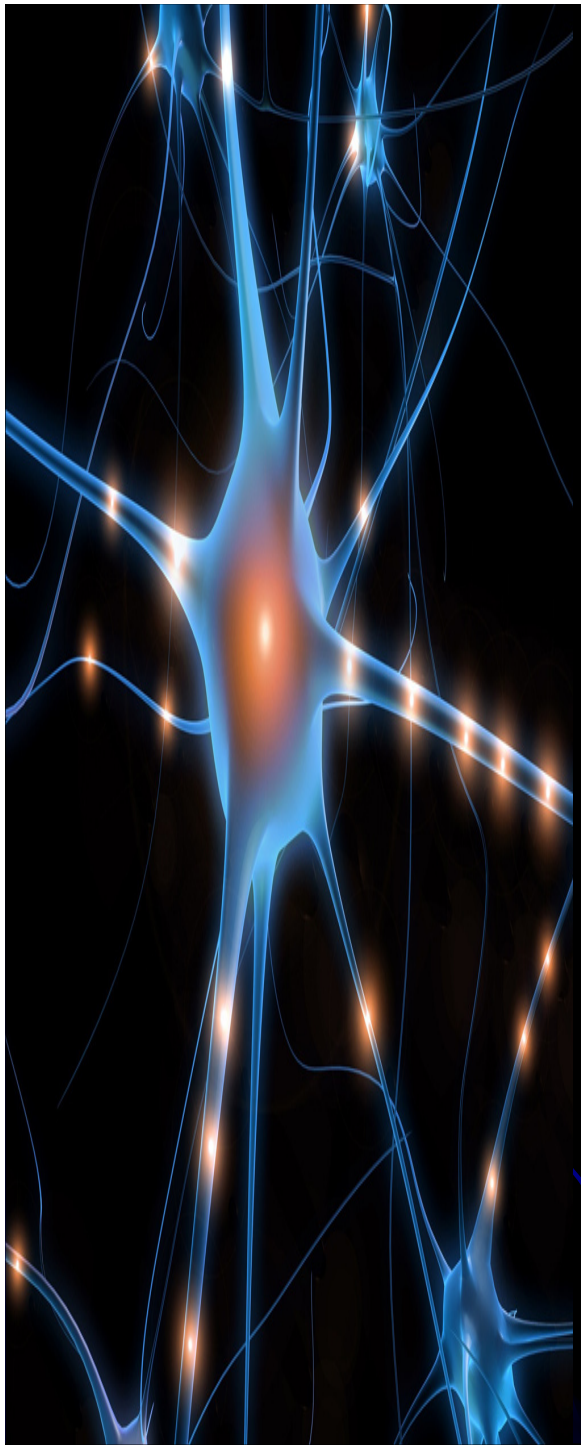
Neuro Palliative Care

a responsive pathway for high value health care

Presenters:

Liz Garrood
Dr Ana Draper
Emma Day

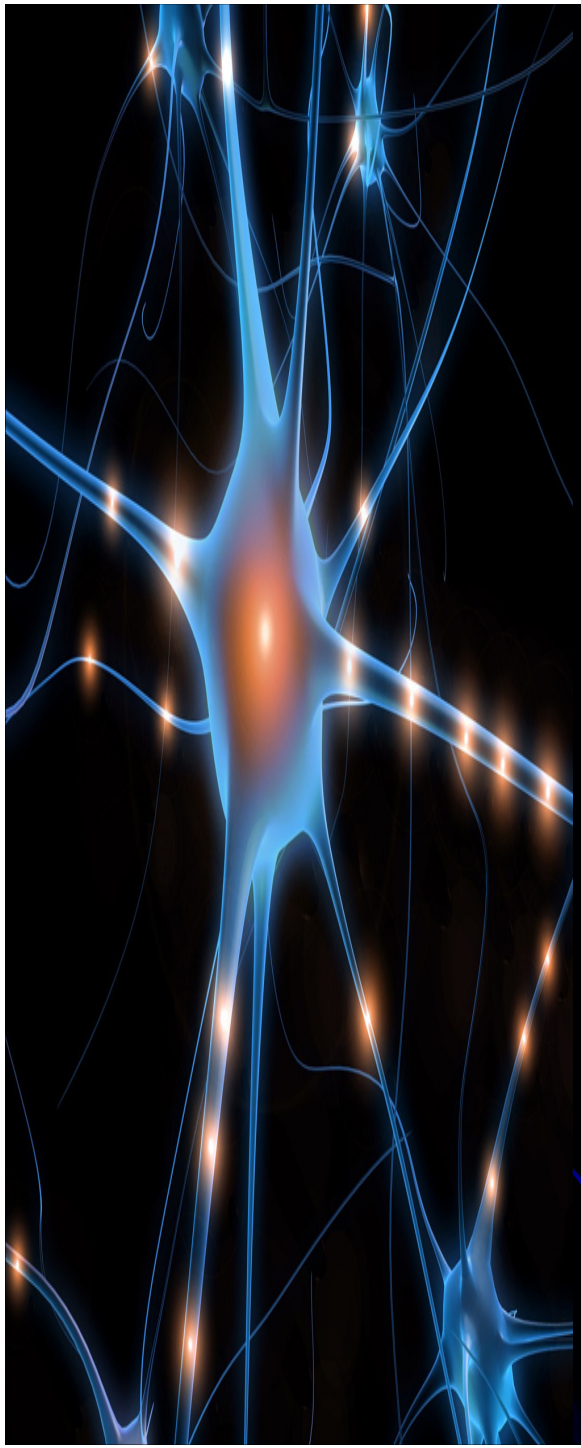
Hertfordshire Community NHS Trust



'After the first meeting you were left with a great comfort feeling that someone was there for you and the initial help and support given during those first traumatic stages was a great help in being able to come to terms with the situation and knowing from here on in all parties were linked together through the coordinator to try and give the best possible care…

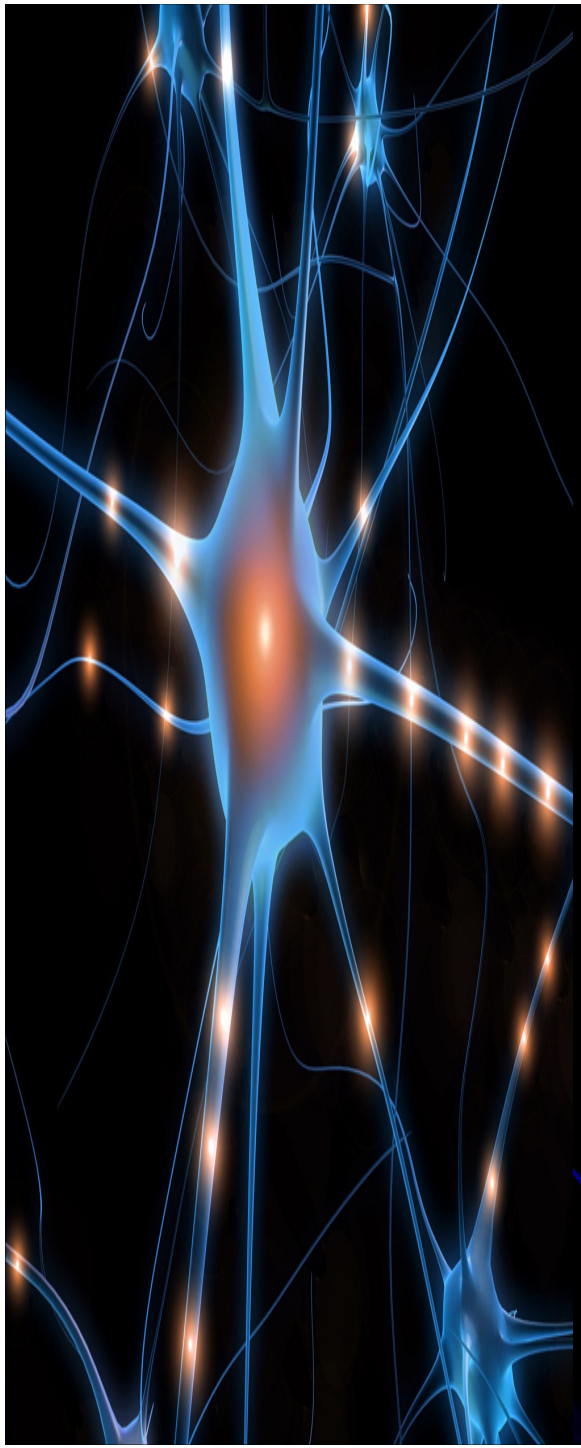
So far it has been a faultless journey'.

Hertfordshire Community NHS
NHS Trust



Why;

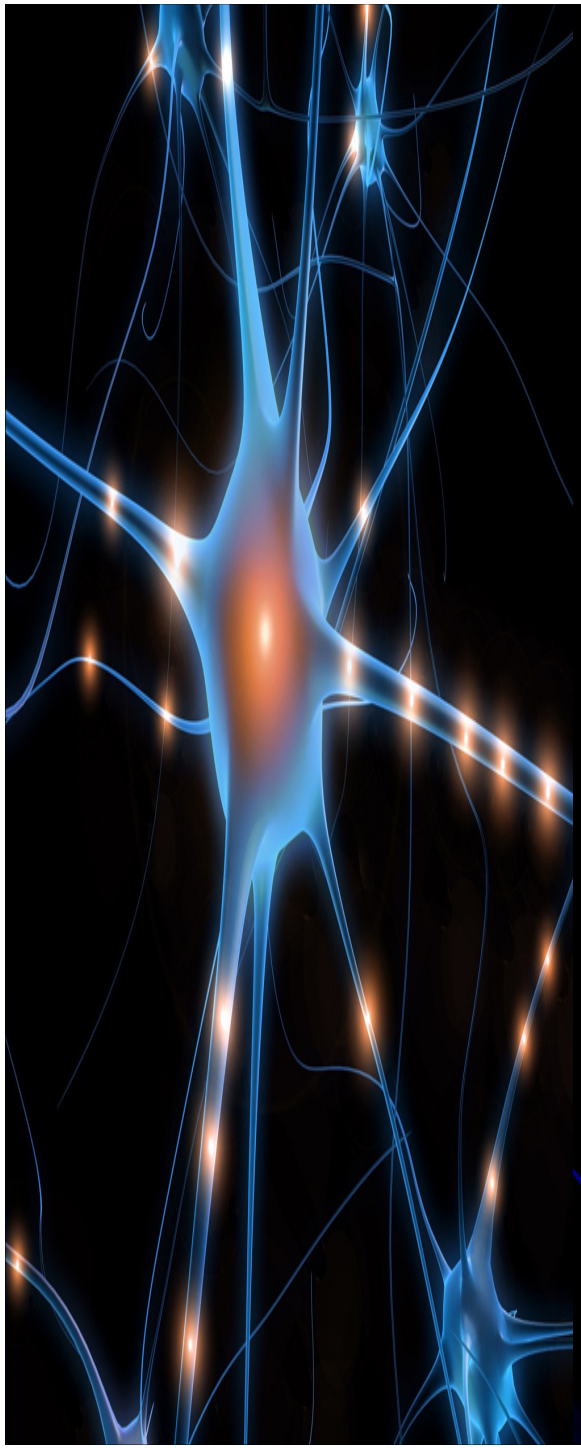
Hypothesis - patients with rare and often rapidly progressing neurological diseases did not receive adequate, appropriate clinical support post diagnosis; with reports of being left feeling isolated and experiencing high levels of psychological distress.



Why continued;

The proposed transformational model was designed to test the benefits of a clinical specialist co-ordinator in terms of high value healthcare. The main objectives of the project have been developed in line with the Herts Community NHS Trust paradigm of service provision:

- Excellent clinical outcomes
- Outstanding patient and families experience
- Improved patient safety
- Highly efficient and cost effective service

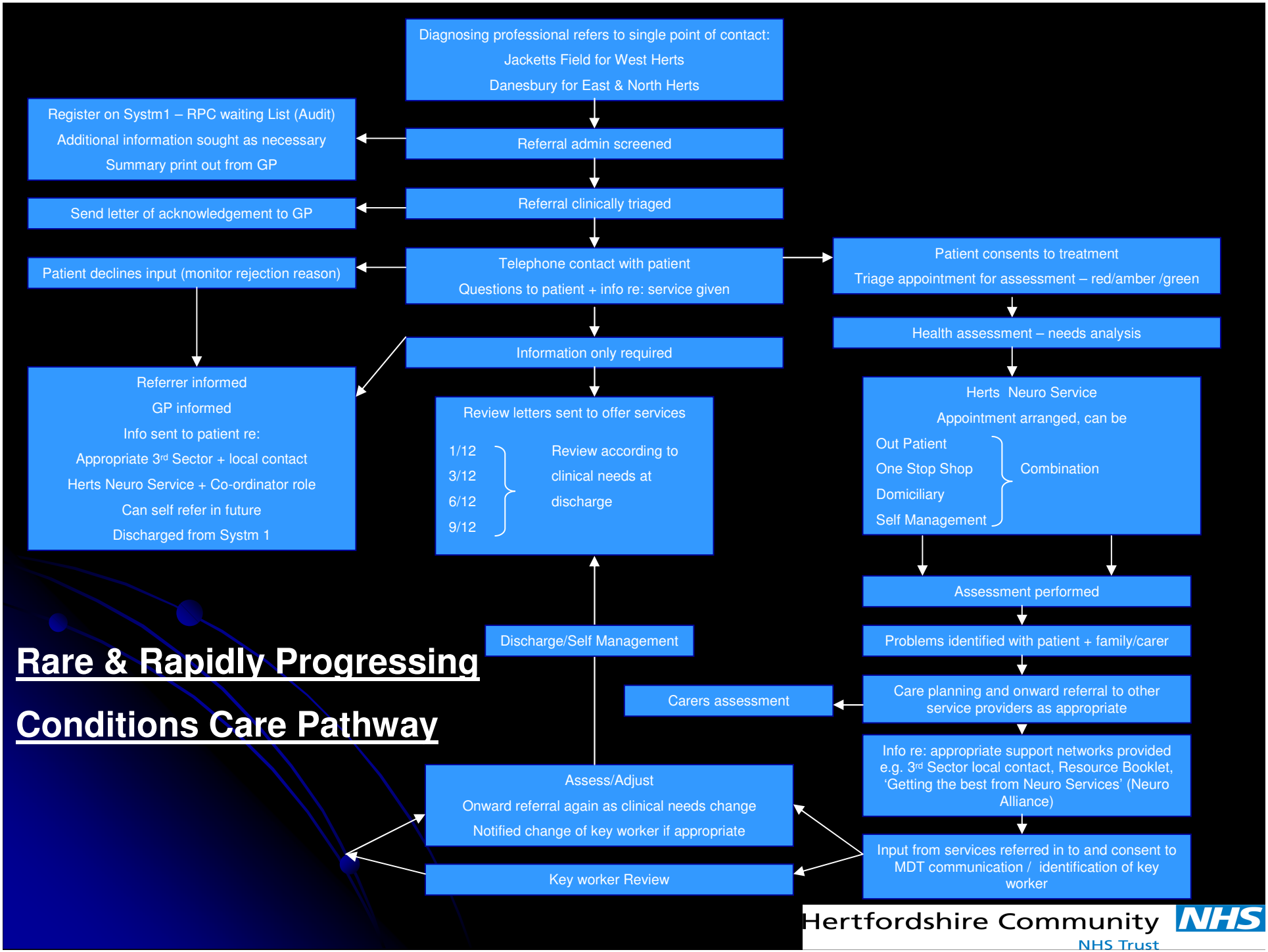


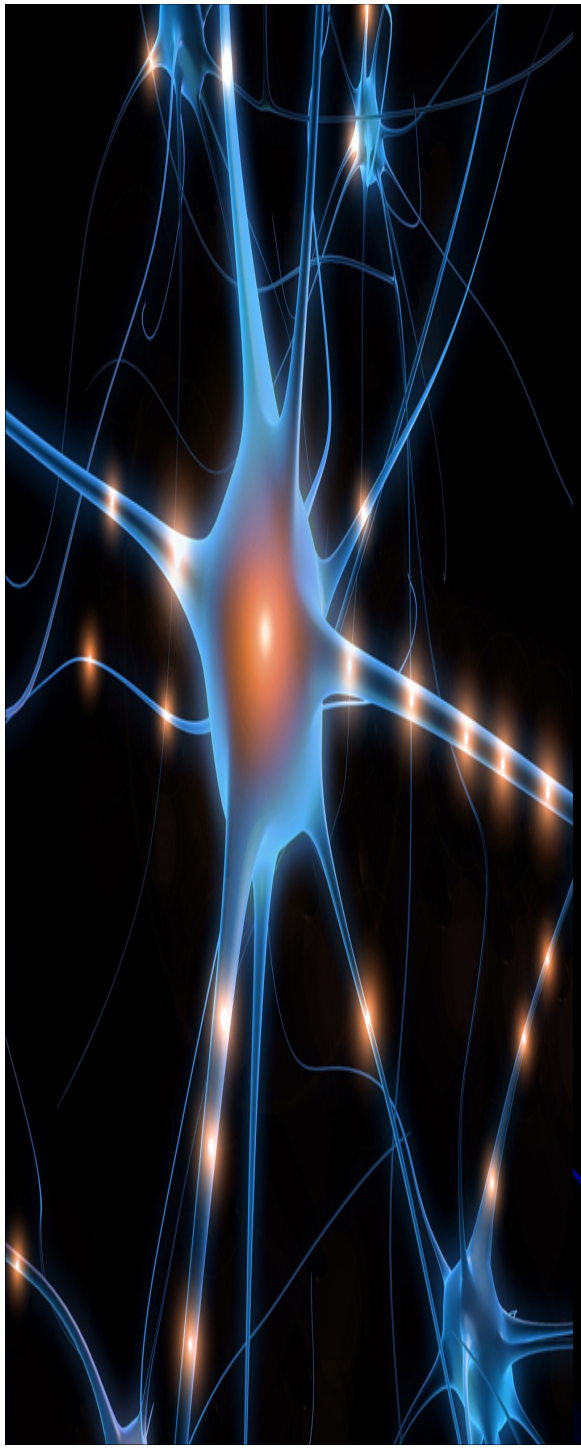
First Steps;

Identification of the disease groups for the pilot:

- Motor Neurone Disease
- Progressive Supranuclear Palsy
- Cortico Basal Degeneration
- Multiple Systems Atrophy
- Huntington's disease

Development of the care pathway for the service

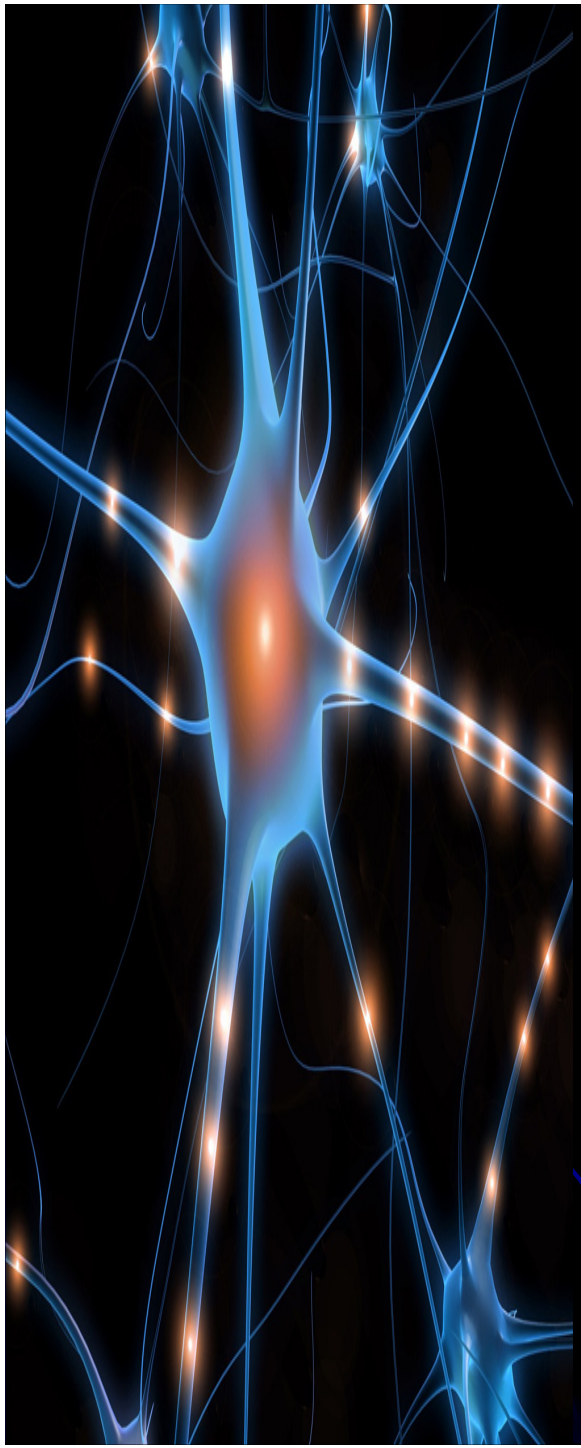

Diagnosing professional refers to single point of contact:
Jacketts Field for West Herts
Danesbury for East & North Herts
Register on Systm1 – RPC waiting List (Audit)
Additional information sought as necessary
Summary print out from GP
Referral admin screened
Send letter of acknowledgement to GP
Referral clinically triaged
Patient declines input (monitor rejection reason)
Telephone contact with patient
Questions to patient + info re: service given
Patient consents to treatment
Triage appointment for assessment – red/amber /green
Health assessment – needs analysis
Information only required
Referrer informed
GP informed
Info sent to patient re:
Appropriate 3rd Sector + local contact
Herts Neuro Service + Co-ordinator role
Can self refer in future
Discharged from Systm 1
Review letters sent to offer services
1/12
3/12
6/12
9/12
Review according to clinical needs at discharge
Herts Neuro Service
Appointment arranged, can be
Out Patient
One Stop Shop
Domiciliary
Self Management
Combination
Assessment performed
Problems identified with patient + family/carer
Discharge/Self Management
Carers assessment
Care planning and onward referral to other service providers as appropriate
Info re: appropriate support networks provided e.g. 3rd Sector local contact, Resource Booklet, 'Getting the best from Neuro Services' (Neuro Alliance)
Assess/Adjust
Onward referral again as clinical needs change
Notified change of key worker if appropriate
Key worker Review
Input from services referred in to and consent to MDT communication / identification of key worker
Rare & Rapidly Progressing Conditions Care Pathway
Hertfordshire Community NHS
NHS Trust



Voices;

The project is supported by:

- Patients and their carers
- Clinicians in the Neurological and Specialist Palliative Care Services in HCT
- The Voluntary sector
- Local Neurologists and GP's.



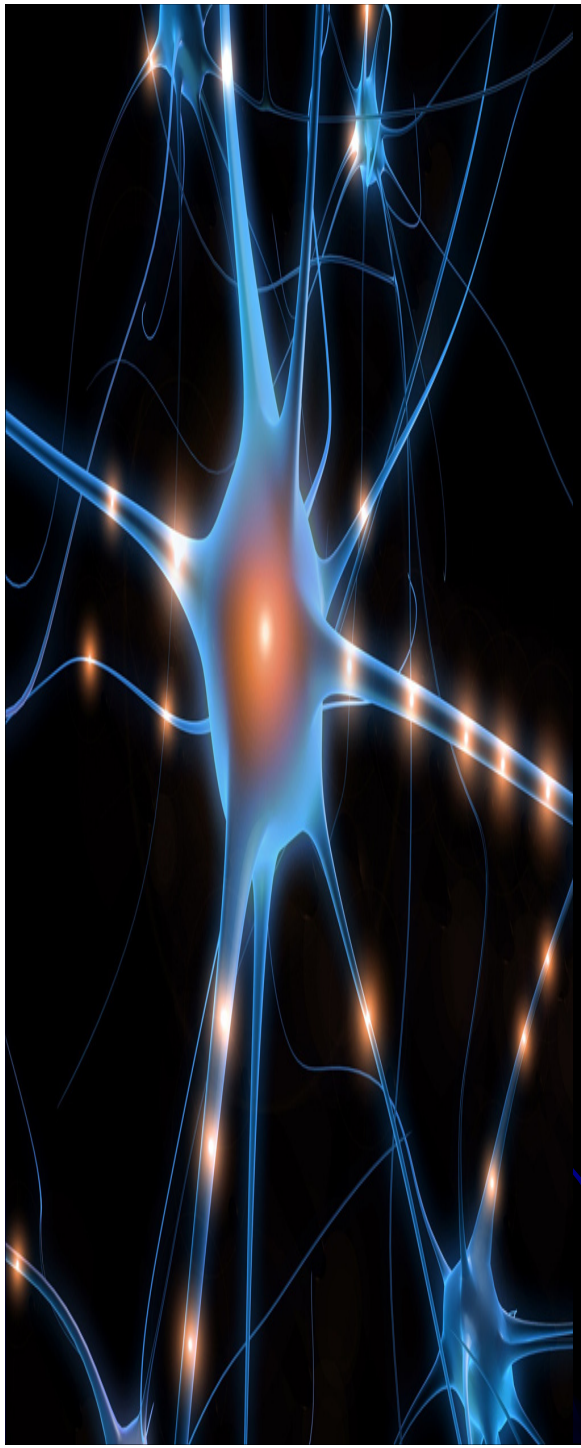
Outcomes;

Development of a care pathway for patients with rare and rapidly progressing neurological conditions

An established single point of access within the Herts Neurological Service

Patients are reporting an enhanced quality of life

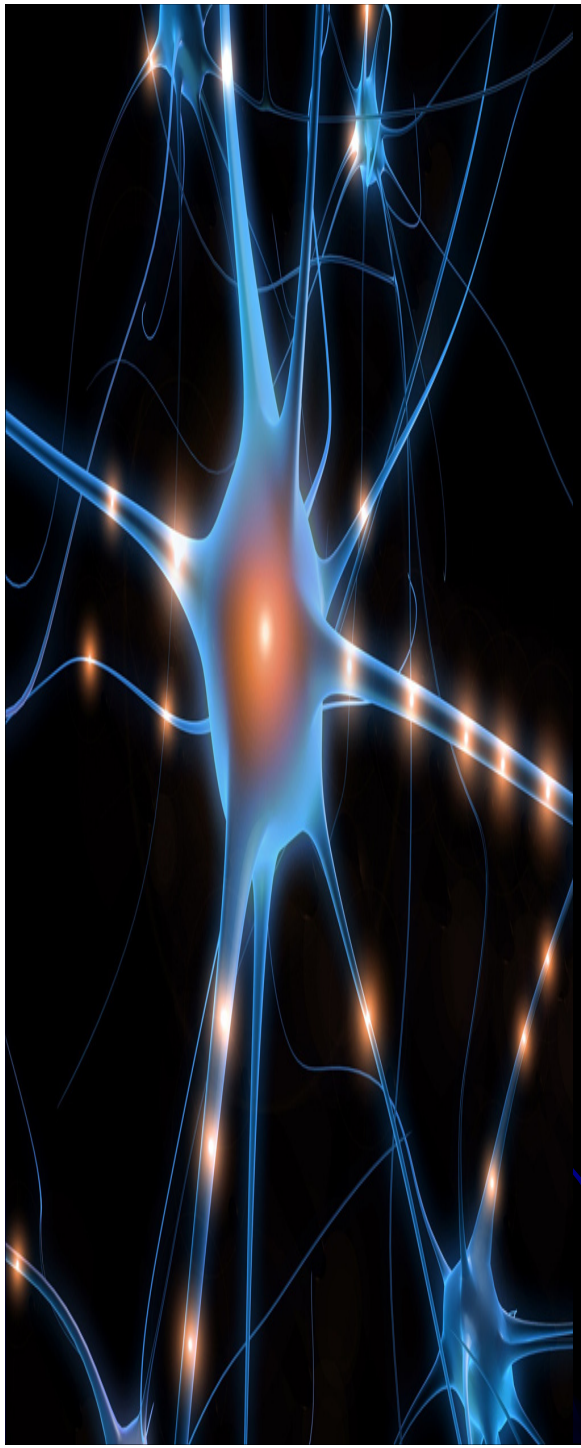
100% of patients who state a preference die in their preferred place of death



Outcomes;

Patients and carers have reported that it has helped them to receive timely access to specialist knowledge and care. This has reduced the feelings of isolation that these debilitating conditions can create.

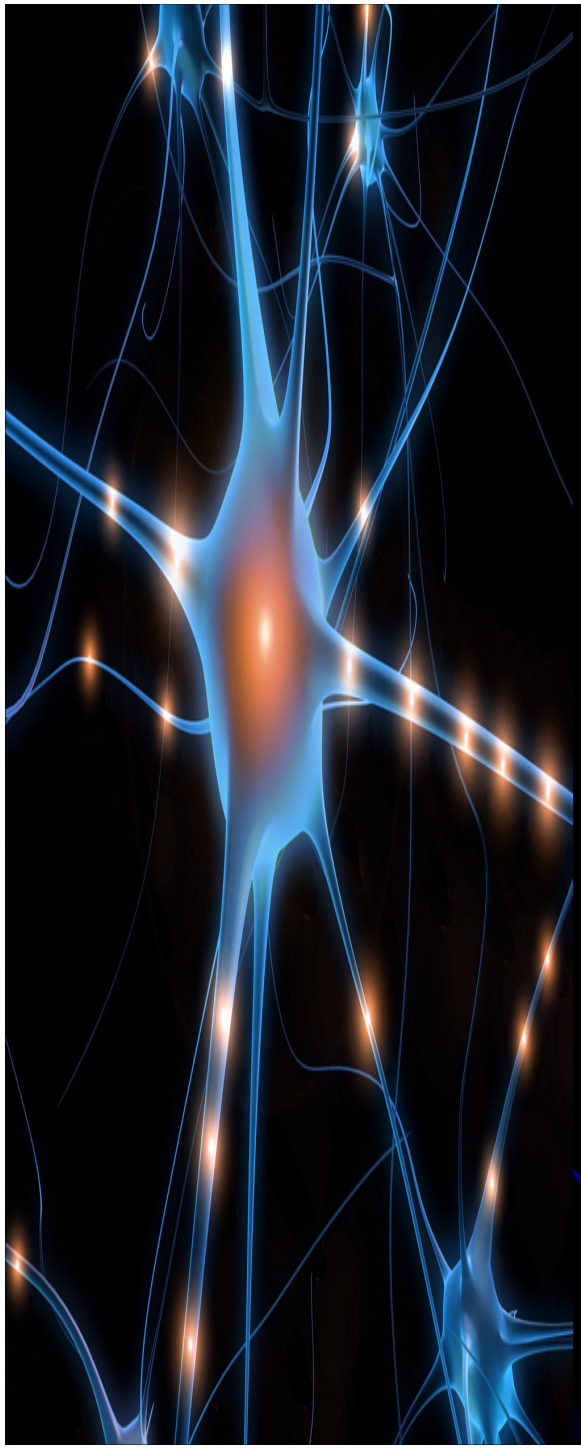
All newly diagnosed patients are reporting an enhanced quality of life. Many with existing conditions have expressed that they wish they had had access to the Coordinator earlier in their disease journey.



Outcomes;

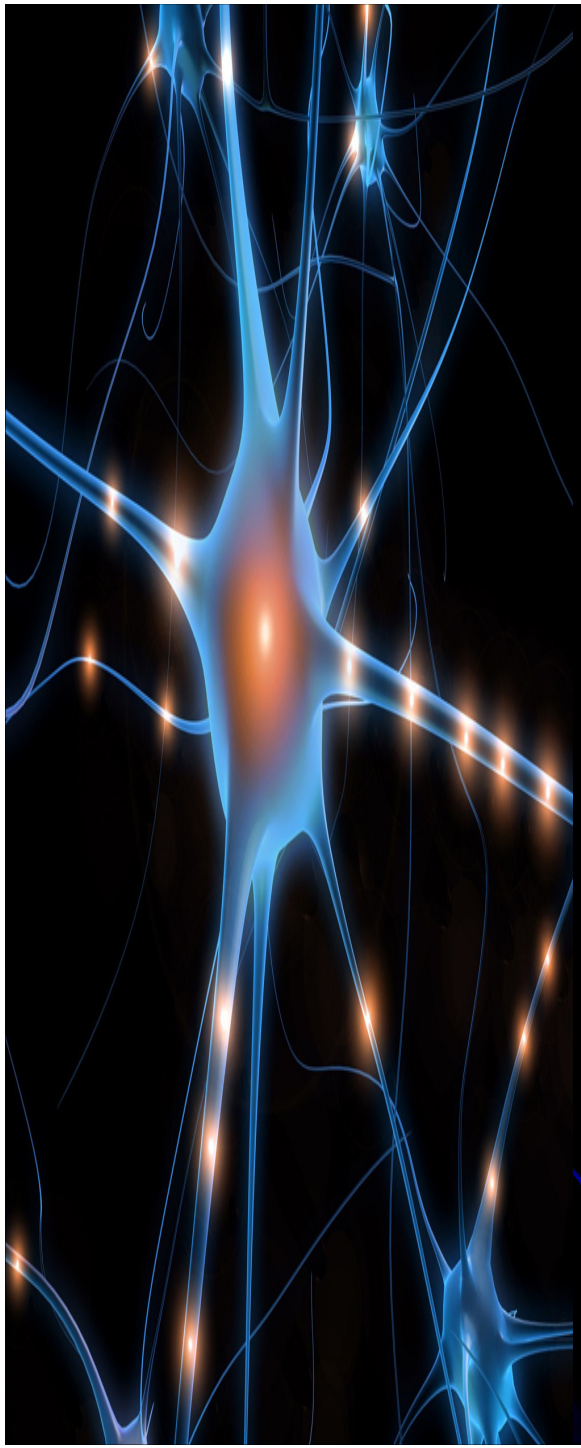
Patient's report feeling valued and known beyond their illness. They talk about the familiarity of the clinical relationship which understands their vulnerability and what helps resilience to be present.

Shaping bespoke control mechanisms for the patient and their carers to aid psychological and emotional resilience.



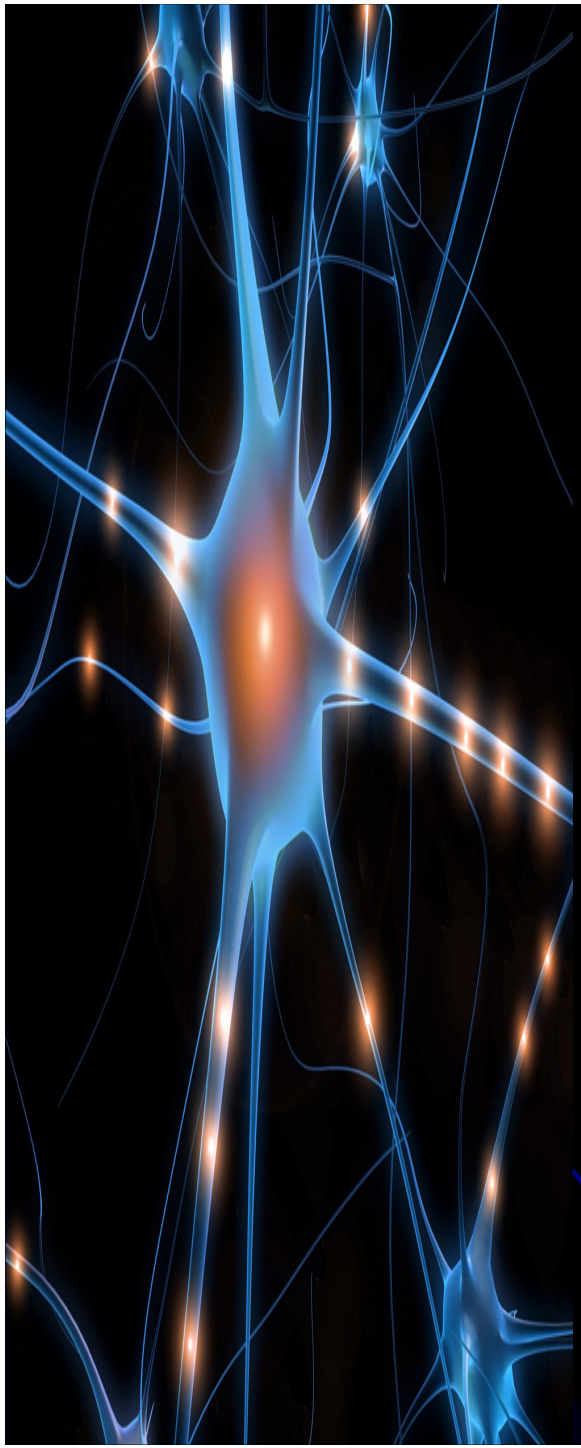
Outcomes;

- Increased ability for this client group to access services in a timely responsive way
- 93 referrals have been received into the neurological service from patients within the identified patient groups since the project going ‘live’ compared to 31 in the previous 12 months
- This is more than a200% increase, demonstrating improved patient access to service provision



Outcomes;

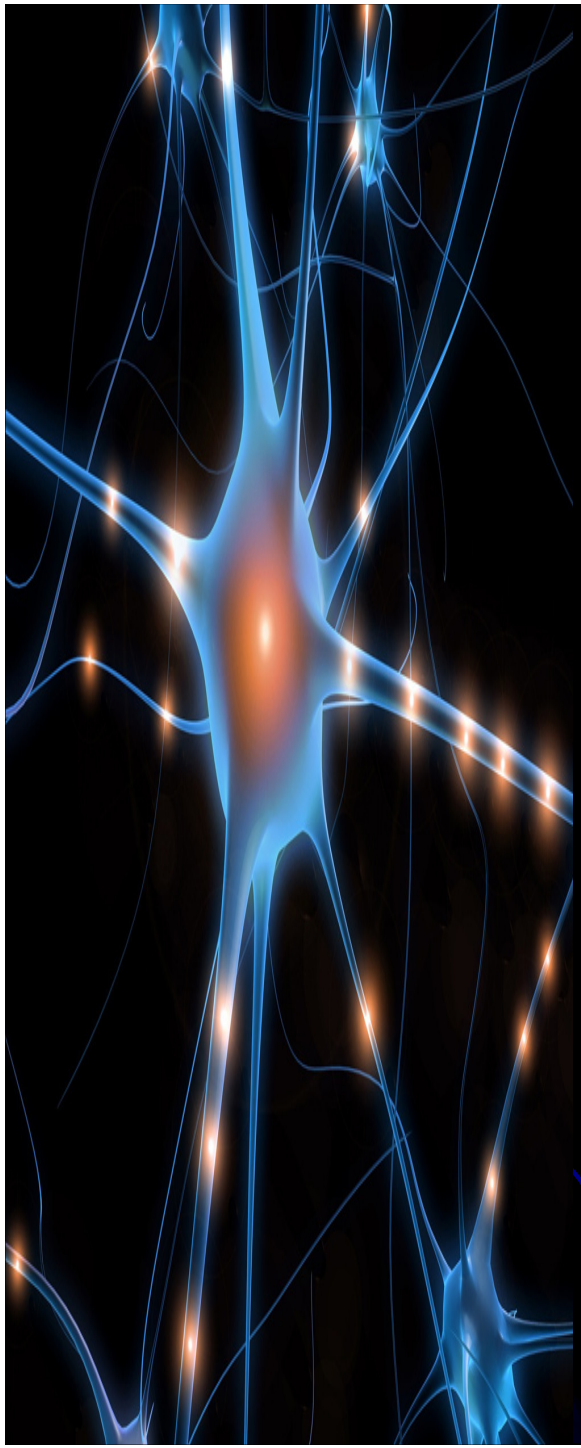
- Patients who have had access to the project were 98% less likely to be admitted to hospital with a possible cost saving of £125,000
- 75% of patients died at home compared to 67% in 2010
- The project has demonstrated high areas of prevalence - above national average for MND / HD enabling the opportunity for the Community Healthcare Trust to plan development of service provision



Outcomes;

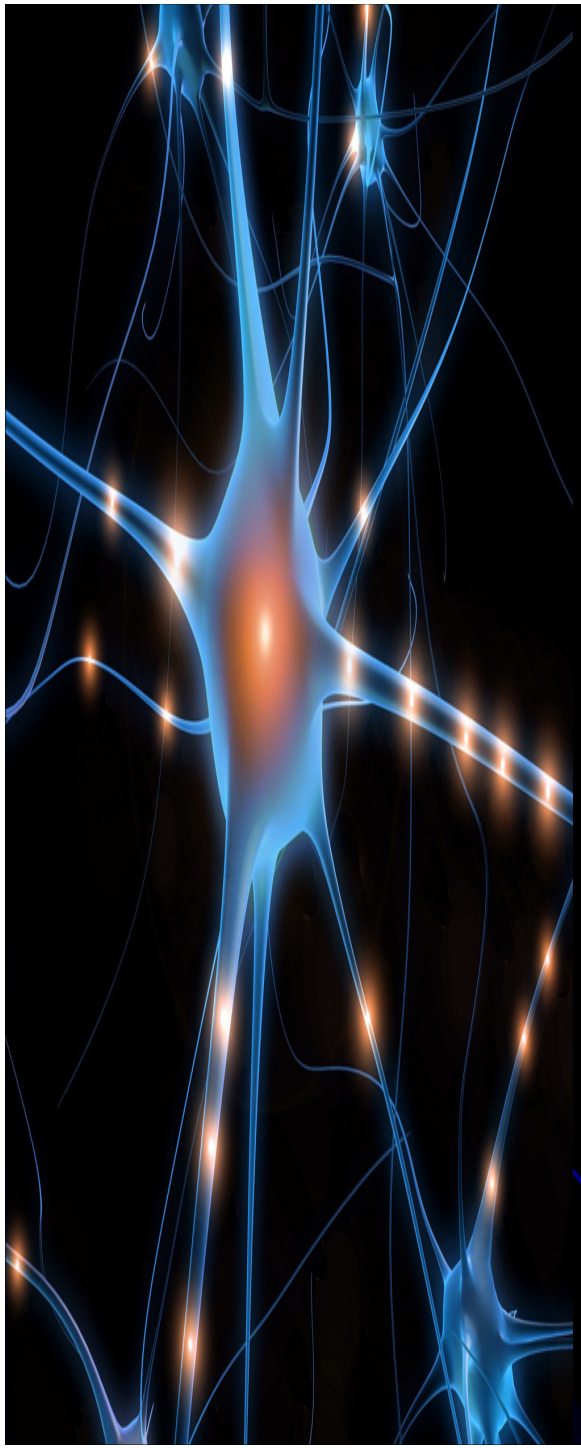
An integrated pathway is seen to reduce number of hospital admissions by at least 42% with a potential saving of over £232,000
(Maximum anticipated Acute Services savings would be £524,000)

This figure does not include the reduced average length of hospital stay from 38 to 12 days (Public Health Office statistics - January 2013)



Conclusion;

- The project has improved the lived experience for the patient and family/carers
- Evidenced that HCT is helping to meet the requirements of the NSF for Long Term conditions, MND Association standards of care and the outcomes/priority objectives of the initial project plan as proposed to the SHA
- Demonstrated a cost effective model of service provision



Lived Experience;

‘I don't know how people like me ... can cope without someone like her [patient gets very upset]. Yeah. She means a lot to me’

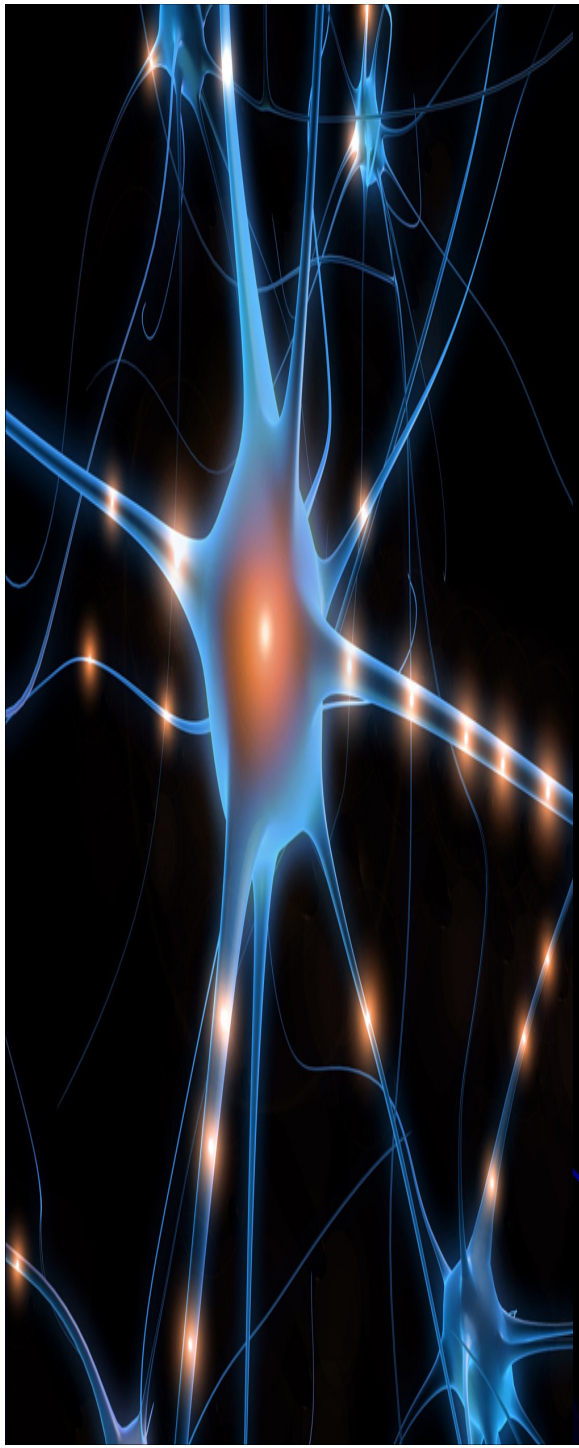
‘Calls from the health professionals rather than us calling them, would be the major thing, reassuring to think someone is thinking ‘I wonder if they’re ok?’

‘You get overwhelmed with too much information that isn’t personal to you’

Neuro Palliative Care

a responsive pathway for high value health care

Hertfordshire Community NHS
NHS Trust



Patients story;

GP

Voluntary Sector

Hospital 1

Co-ordinator

Patient

Co-ordinator

Social Services

Hospital 2

Dietician

Hospital 3

Occupation Therapist


THANK YOU FOR LISTENING