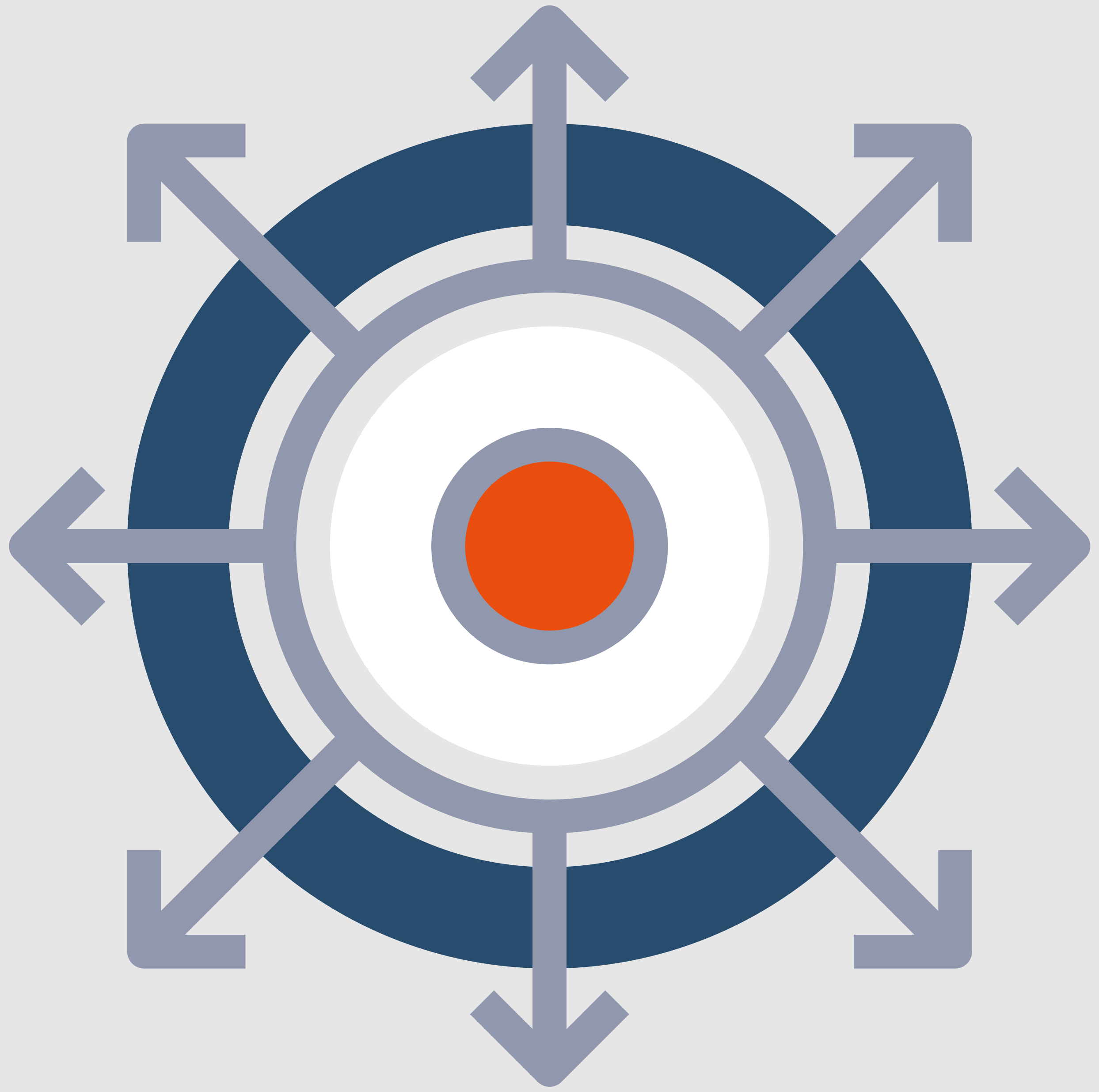
Kent Surrey Sussex
Academic Health Science
Network

Roche

Huntington's
Disease
Association

Surrey Heartlands
HEALTH AND CARE PARTNERSHIP



Huntington's disease (HD)

Co-production of a proposed new service model for patients in Surrey Heartlands Health and Care Partnership

February 2022

This project is partially funded by and developed in collaboration as part of a collaborative working agreement with Roche Products Limited

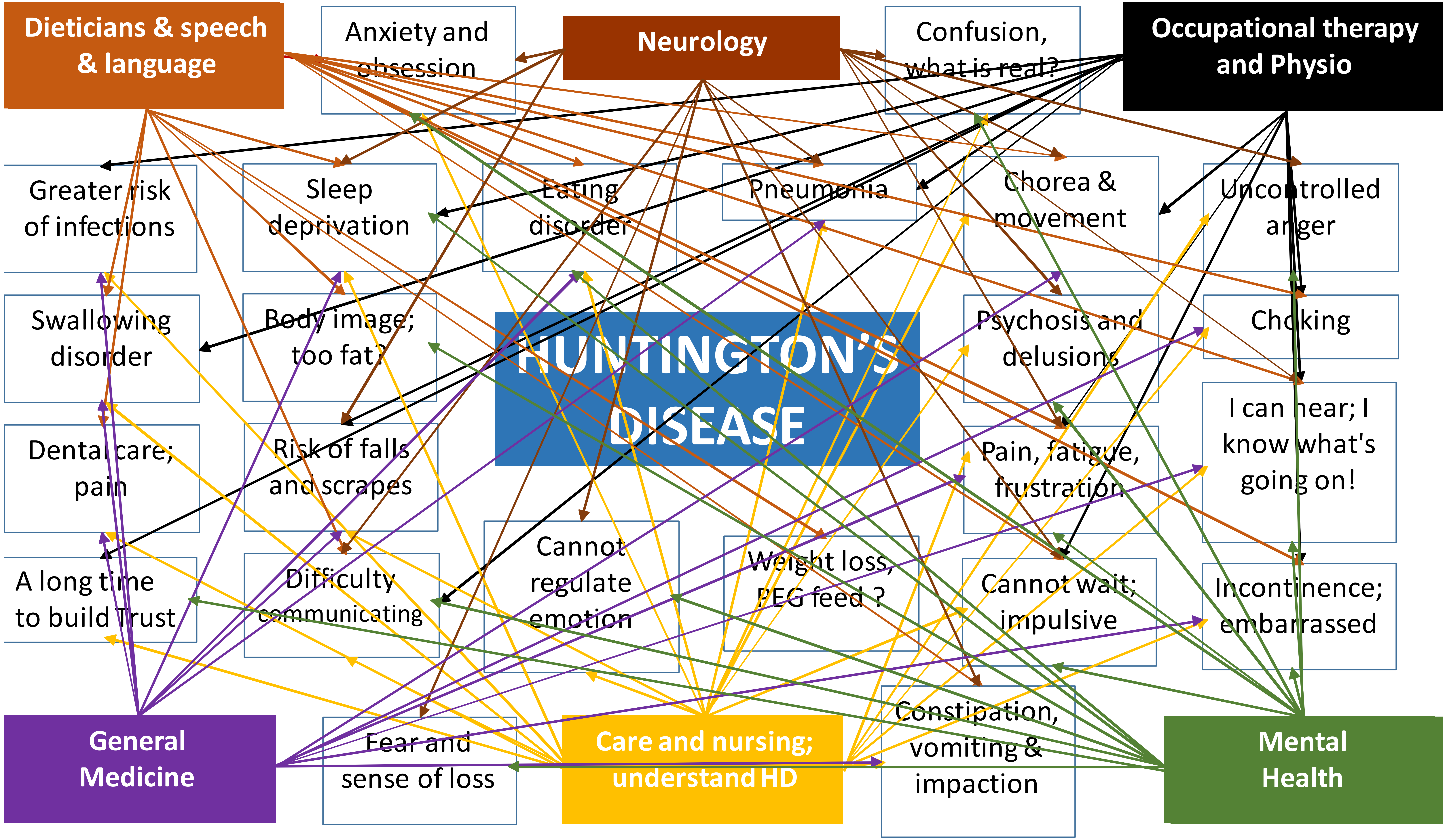
Background

Huntington's disease (HD) is a rare, inherited, neurodegenerative disease, with onset usually in mid-adult life. HD progressively affects a person's everyday functions with particular impact on movement, thinking, personality and behaviour. HD has a devastating impact across generations, due to the inherited nature of the disease but also due to the effect on family members and carers living with affected individuals.

Whilst there are medications and interventions that can help control some of the effects of the disease, there is currently no way to prevent, slow or stop disease progression. HD is ultimately fatal and progresses relentlessly from appearance of symptoms to loss of functional capacity and disability, with a median survival of 15 years from onset of motor symptoms. Living with HD can be very challenging, getting the right information and support is vital.

The NHS does not currently have a service model that outlines the delivery of care for patients with HD. This means that the standard of care for patients can vary across the country.

HD is a complex disease and requires numerous clinical professionals to support patients, family members and carers as shown in the diagram on the next slide.



Dieticians & speech & language

Anxiety and obsession

Neurology

Confusion, what is real?

Occupational therapy and Physio

Greater risk of infections

Sleep deprivation

Eating disorder

Pneumonia

Chorea & movement

Uncontrolled anger

Swallowing disorder

Body image; too fat?

HUNTINGTON'S DISEASE

Psychosis and delusions

Choking

Dental care; pain

Risk of falls and scrapes

Pain, fatigue, frustration

I can hear; I know what's going on!

A long time to build Trust

Difficulty communicating

Cannot regulate emotion

Weight loss, PEG feed ?

Cannot wait; impulsive

Incontinence; embarrassed

General Medicine

Fear and sense of loss

Care and nursing; understand HD

Constipation, vomiting & impaction

Mental Health

Ben Walters June 2019

Aims and objectives

This project is a collaborative partnership with Surrey Heartlands Health & Care Partnership (SHHCP), Kent Surrey Sussex Academic Health Science Network (KSS AHSN), Roche Products Ltd. and the Huntington's Disease Association (HDA).

The project aims to build on existing services to develop a service model that is fit for purpose and provides equitable care for HD patients, family members and carers.

A co-production/co-design approach was taken with stakeholders from SHHCP, St George's Hospital, local health and social care professionals, Roche, HDA, patients, families and carers impacted by HD.

The service model will be introduced for the care of patients with HD, their family members and carers residing in Surrey.

Our approach

Stakeholder engagement

Telephone interviews were held with a range of stakeholders to identify the key challenges they faced supporting people living with HD, their family members and carers. Stakeholders were also asked to suggest potential solutions to those challenges.

Patient & carers survey

A survey was launched across England and Wales to seek the views of patients, families and carers, to understand where current care services provided by the NHS and organisations such as the HDA are working well.

July – September 2021

Co-design workshops

Two co-design workshops were held.

The first workshop examined themes emerging from the stakeholder interviews and the survey results to inform the draft service model.

The second workshop tested the service model and role of a HD coordinator.

Refine & develop

Feedback from the workshops was amalgamated into the draft service model and job description for a care co-ordinator.

Final comments were sought from stakeholders to enable final documents to be signed off by SHHCP.

October 2021 – January 2022

Stakeholder engagement

Key challenges to stakeholders

Telephone interviews were held with a range of stakeholders to identify the key challenges they faced supporting people living with HD, their family members and carers. Stakeholders were also asked to suggest potential solutions to those challenges.

The challenges were grouped into 4 themes:

1. **Communication**
2. **Support**
3. **Knowledge & awareness**
4. **Care homes**

1 Communication

Challenges

- Lack of coordinated support across services/organisations – acute, mental health teams, community teams, palliative care teams
- Lack of appropriate pathways between neurology and mental health services and social care
- Main challenges for patients are mental health issues both cognitive and psychiatric. Different phases of the illness will need different care provision
- Patients have complex care needs which can result in rapid deterioration
- Social workers not able to link to Psychiatrist or Neurologist
- Person with HD not linked in with any specialist care centre/clinic e.g National Hospital for Neurology, Queens Square London or St George’s
- Lack of specialist support (or not knowing who/where to signpost them to) when patient in the “maintenance” phase
- Lack of specialist support (or not knowing who/where to signpost them to) when behavioural changes/ challenging behaviour phase starts

Solutions

- Care Co-ordinator (potentially joint role with another neurological disease or across a wider geographical area)
- MDT approach across the whole system
- Review service specification for current local services and adapt it to ensure HD patients get equitable services.
- Joint or poly clinics between all services involved in the patients care
- Trigger points to recognise the palliative phase
- Referral to HDA built into pathway
- Referral to a regional or national HD Specialist Clinic on diagnosis and a 6-12 monthly follow up or earlier should clinical symptoms need reviewing

2

Support

Challenges

- Lack of mental health support e.g you have access to mental health advisor who gives advice to GP but then patient are not under the umbrella support of mental health team so not supported and treated as 1-off episode
- Not getting right pharmacological management in respect of mental health and wellbeing
- No local support groups/networks for patient/carers/family members
- Brigette Trust neurological support group won't accept HD patients
- Knowing how to access continuing health care funding
- Input provided by appropriate HD specialists for continuing health care funding requests

Solutions

- MDT approach
- Care co-ordinator
- Neuro psychology input for HD patients in conjunction with other neuro conditions
- Review service specification for current local services and adapt it to ensure HD patients get equitable services
- NHS to consider funding HD amongst some of the existing local support groups across Surrey
- Signposting to Citizens Advice for funding support built into the pathway
- Checklist for continuing healthcare completed when patient deteriorates from their normal baseline/functional level and that change is irreversible. This should be completed by someone who knows the knows the patient

3 Knowledge and awareness

Challenges

- Lack of understanding of complexities of needs amongst health (including mental health) and social care professionals
- Lack of knowledge and understanding of HD by clinicians on the continuing health care assessment panels
- Lack of training for paid carers

Solutions

- Care co-ordinator who can support professionals who don’t have a specialist knowledge of HD
- Commission a training and awareness programme

4

Care homes

Challenges

- Lack of guidance/guidelines especially for those HD patients who are care home residents with clear directives of not wishing to go to hospital
- Uncertainty around symptom control measures to put in place for care home residents with HD e.g. feeding and medication adherence
- Limited choice of residential care due to complex needs/ challenging behaviour of patients
- Care home or care provider say they might accept someone but once seen and accessed the patient they are refused

Solutions

- Care co-ordinator who know the patient and supports them across the disease progression, including in a care home
- Peer agreed guidelines / guidance on how to care for HD patients with input from Neurologists and Geneticists and palliative care
- Identify barriers as to why care providers feel they can't meet HD patients needs
- Commission a training/awareness programme

Stakeholders we have consulted

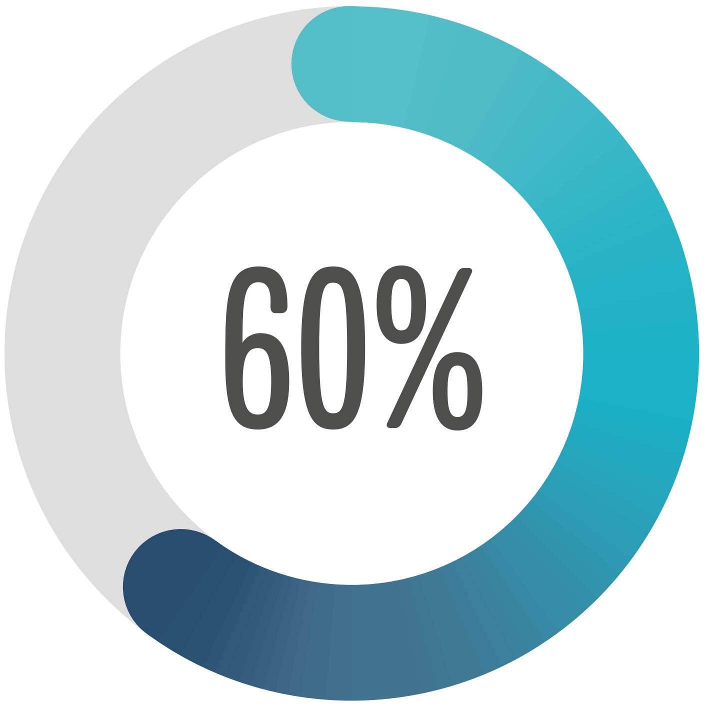
- AMD for Older Adults, Surrey & Borders Partnership NHS FT
- New Ways of Working Programme Director, NHS Surrey Heartlands CCG
- Dementia Connect Local Services Manager, Alzhiemer's Society
- Commissioning Manager MH & LD, NHS Surrey Heartlands CCG
- Continuing Care Contract Manager, NHS Surrey Heartlands CCG,
- Consultant Neurologist & Clinical Director, Ashford & St Peters NHS FT
- Clinical Psychologist, Leicestershire Partnership NHS FT
- Professional Lead Community Matrons, ProCare
- Associate Medical Director Specialist Services & Community, Surrey & Borders Partnership NHS FT
- GP & Governing Body GP Rep, NHS Surrey Heartlands CCG
- Senior Commissioning Manager, Surrey County Council
- Palliative Care Consultant, Ashford & St Peters NHS FT
- Consultant, St George's NHS FT
- Specialist Nurse MND & Neuro Conditions, First Community Health & Care CIC
- GP & Governing Body GP rep, Guildford & Waverley ICP
- Consultant Clinical Geneticist & Trustee HD Association, St George's NHS FT
- Lead Pharmacist General Medicine, Royal Surrey Hospital
- Consultant Neurologist & Clinical Director St George's NHS FT
- Head of Service, Royal Hospital for Neuro Disability
- Carers and family members
- Medical Director, Phyliss Tuckwell Hospice
- Neuro OT Clinical Specialist, Royal Surrey Hospital
- Consultant in Palliative Medicine, Princess Alice Hospice
- Assistant Team Manager, Adult Social Care, Surrey County Council
- Consultant Neurologist, Royal Surrey Hospital
- Research Officer, Health Watch Surrey

Patient and carer survey

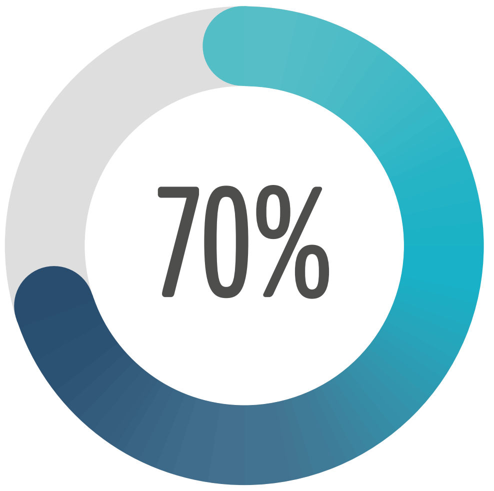
Patient and carer survey

The purpose of the survey was to seek the views of patients, families and carers, to understand where current care services provided by the NHS and organisations such as the HDA are working well.

The online survey was launched across England and Wales in partnership with the HDA and ran for 10 days. It was open to anyone who is directly affected by HD. This included those who have tested positive, those at risk of developing HD or those who have had a negative test result, as well as family members and carers. Support from the HDA was available for anyone wishing to complete the survey by telephone.

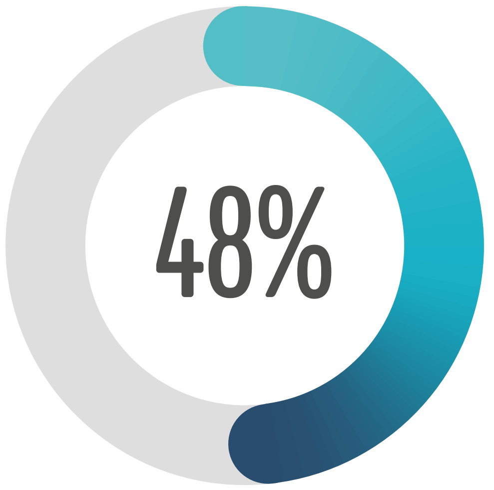


A total of **167 responses** were received with **60% in the age group of 32 – 65 years.**



70% of respondents completed the survey for themselves,

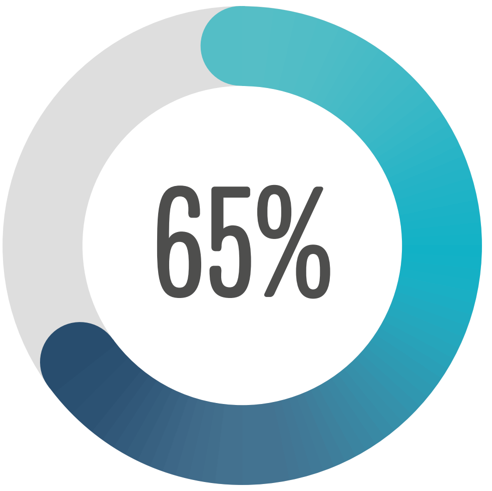
with **30%** being completed on behalf of someone else,



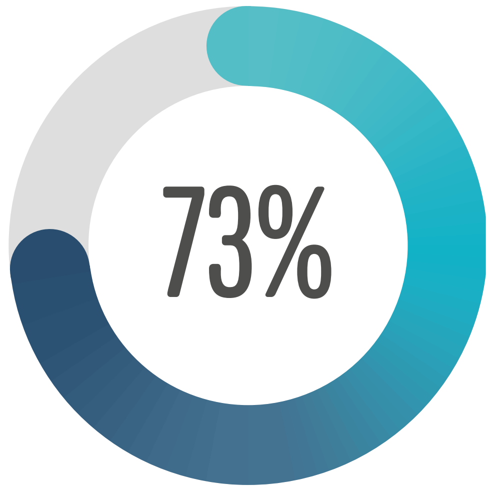
48% of respondents were carers of people living with HD.

Survey results

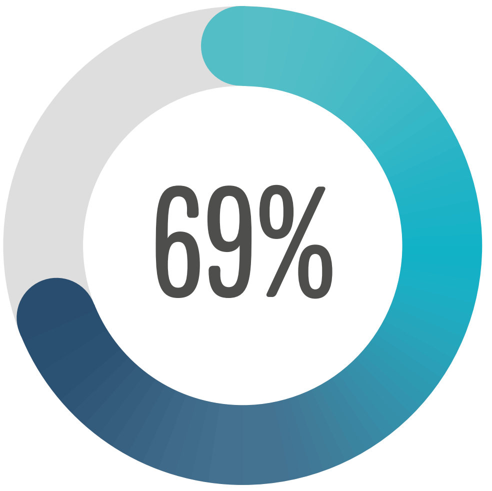
The good…



Agreed with the statement that they had a named HD specialist



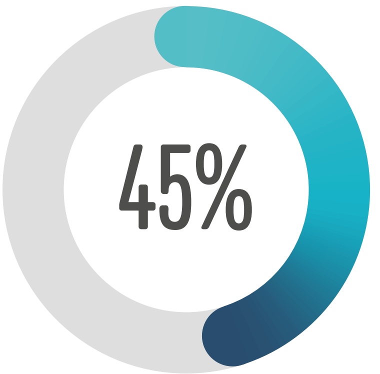
Agreed with the statement that they had support from the HDA



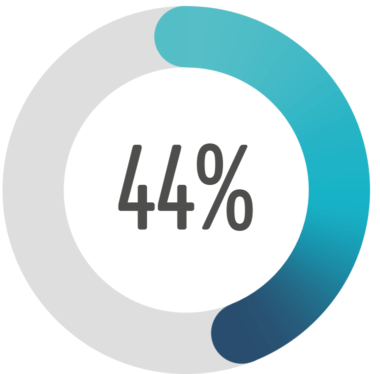
Agreed with the statement that they were able to contact their HD specialist

It should be noted that when reviewing the comments in the free text boxes for these questions people were indicating that their HD specialist was someone from the HDA rather than a HD specialist from within the NHS.

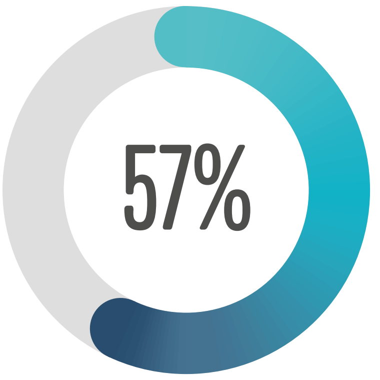
The not so good…



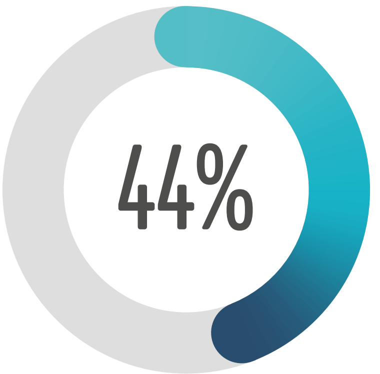
Disagreed with the statement that following diagnosis / test results follow up support from a HD professional was provided



Disagreed with the statement that they had personalised care and treatment plans in place



Disagreed with the statement that their main unpaid carer had received a carers assessment



Disagreed with the statement that their main unpaid carer knew who to contact for their own support

People completing the survey were asked “which services do you currently NOT receive that would impact positively on your care and quality of life?” This was a free text question and have been grouped into the categories below

Mental Health Support

Psychological support

Counselling

Respite care

Day services

Support groups

HD Nurse Specialist

Support from Social Services

Annual MH assessment

Neurological Nurse Specialist

Emotional support for carers

End of life care support

Palliative Care Support

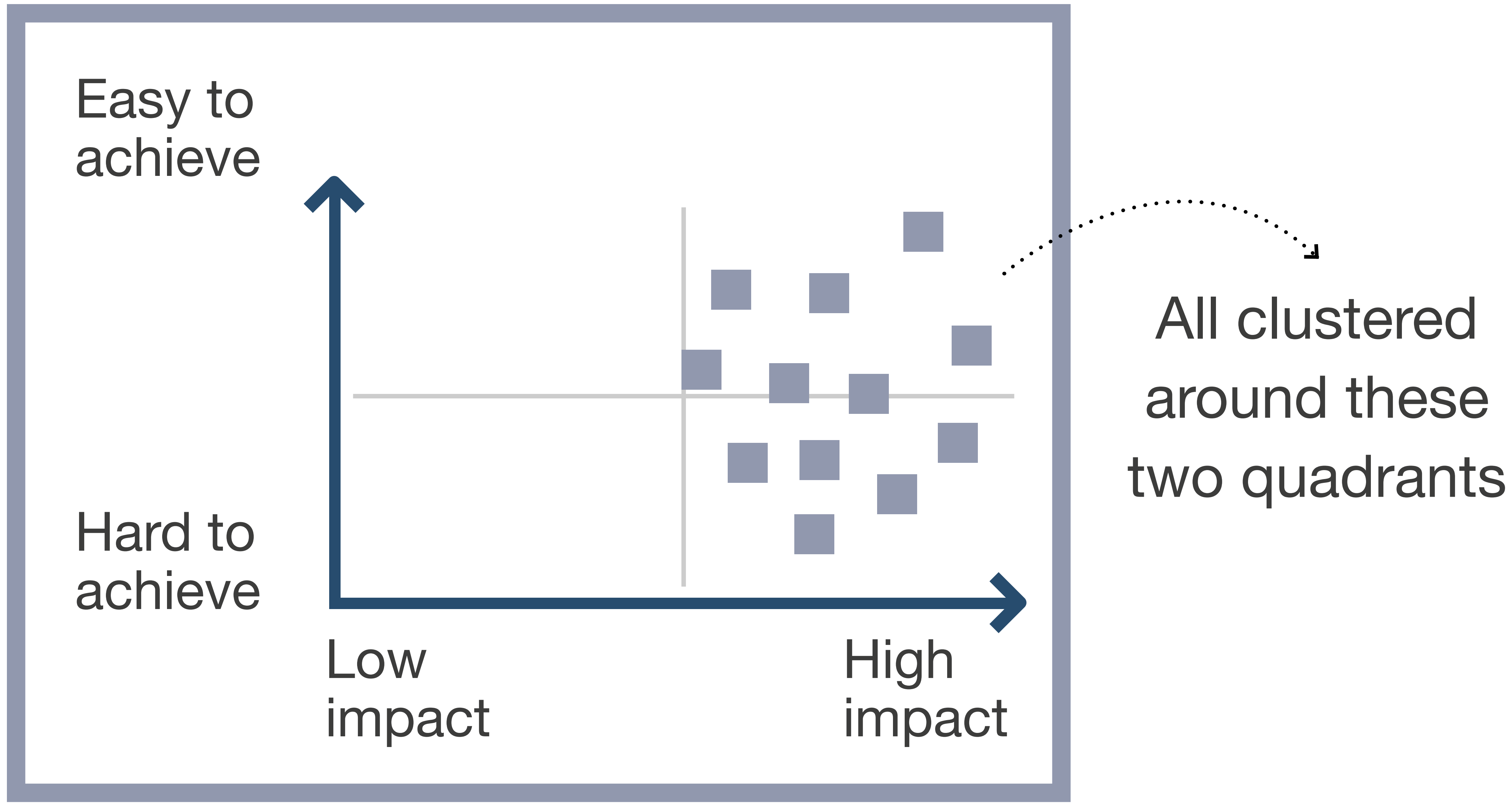
Holistic approach

Co-design workshop 12th October 2021

The purpose of the online workshop was to set the scene for the project; hear from a family member who gave a carers perspective of MDT care; to share the themes from the stakeholder engagement and patient/carer survey and identify potential solutions to help shape a service model.

25 people attended which included clinicians, commissioners, service providers, carers as well as representation from the project's collaborative partners.

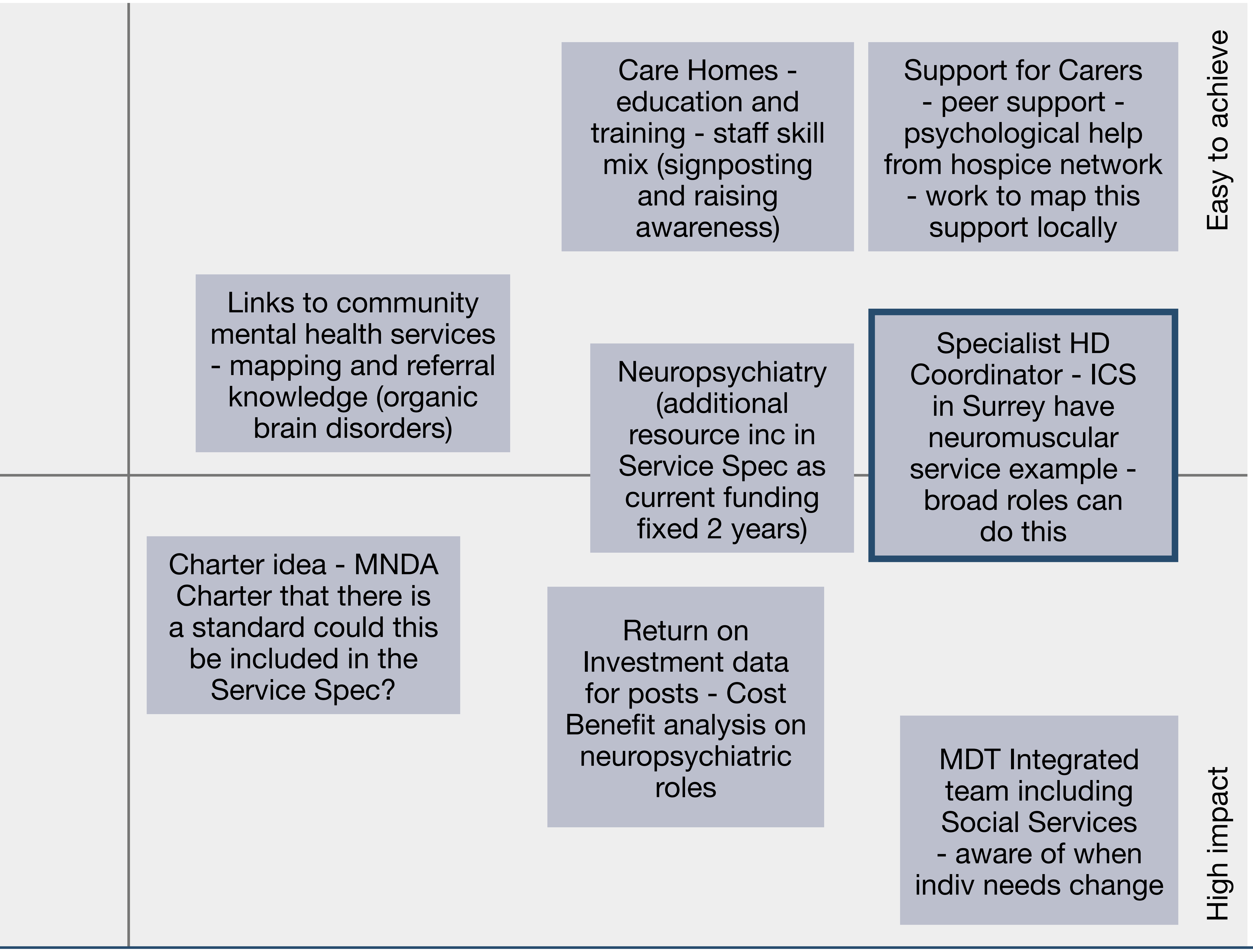
During the workshop facilitated breakout groups were formed which enabled attendees to discuss potential solutions to the themes identified by the stakeholder discussions and survey results. Each breakout group used the Boston matrix to capture their discussions – as shown on the following 2 slides.



All clustered around these two quadrants

Huntington’s Disease Workshop 12th October 2021: Continued over…

Breakout room with Wendy



Care Homes - education and training - staff skill mix (signposting and raising awareness)

Support for Carers - peer support - psychological help from hospice network - work to map this support locally

Links to community mental health services - mapping and referral knowledge (organic brain disorders)

Neuropsychiatry (additional resource inc in Service Spec as current funding fixed 2 years)

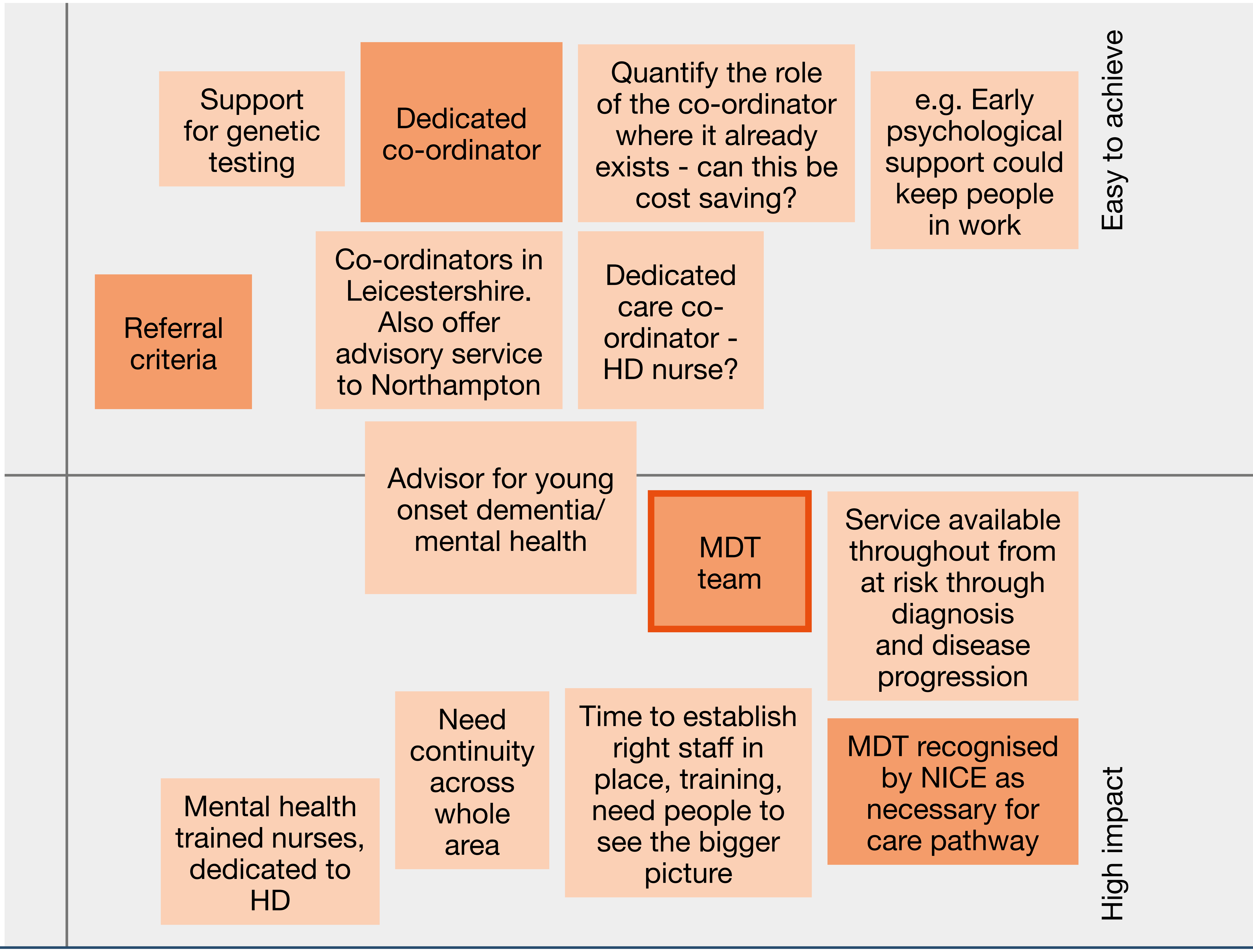
Specialist HD Coordinator - ICS in Surrey have neuromuscular service example - broad roles can do this

Charter idea - MNDA Charter that there is a standard could this be included in the Service Spec?

Return on Investment data for posts - Cost Benefit analysis on neuropsychiatric roles

MDT Integrated team including Social Services - aware of when indiv needs change

Breakout room with Jo



Support for genetic testing

Dedicated co-ordinator

Quantify the role of the co-ordinator where it already exists - can this be cost saving?

e.g. Early psychological support could keep people in work

Referral criteria

Co-ordinators in Leicestershire. Also offer advisory service to Northampton

Dedicated care co-ordinator - HD nurse?

Advisor for young onset dementia/ mental health

MDT team

Service available throughout from at risk through diagnosis and disease progression

Mental health trained nurses, dedicated to HD

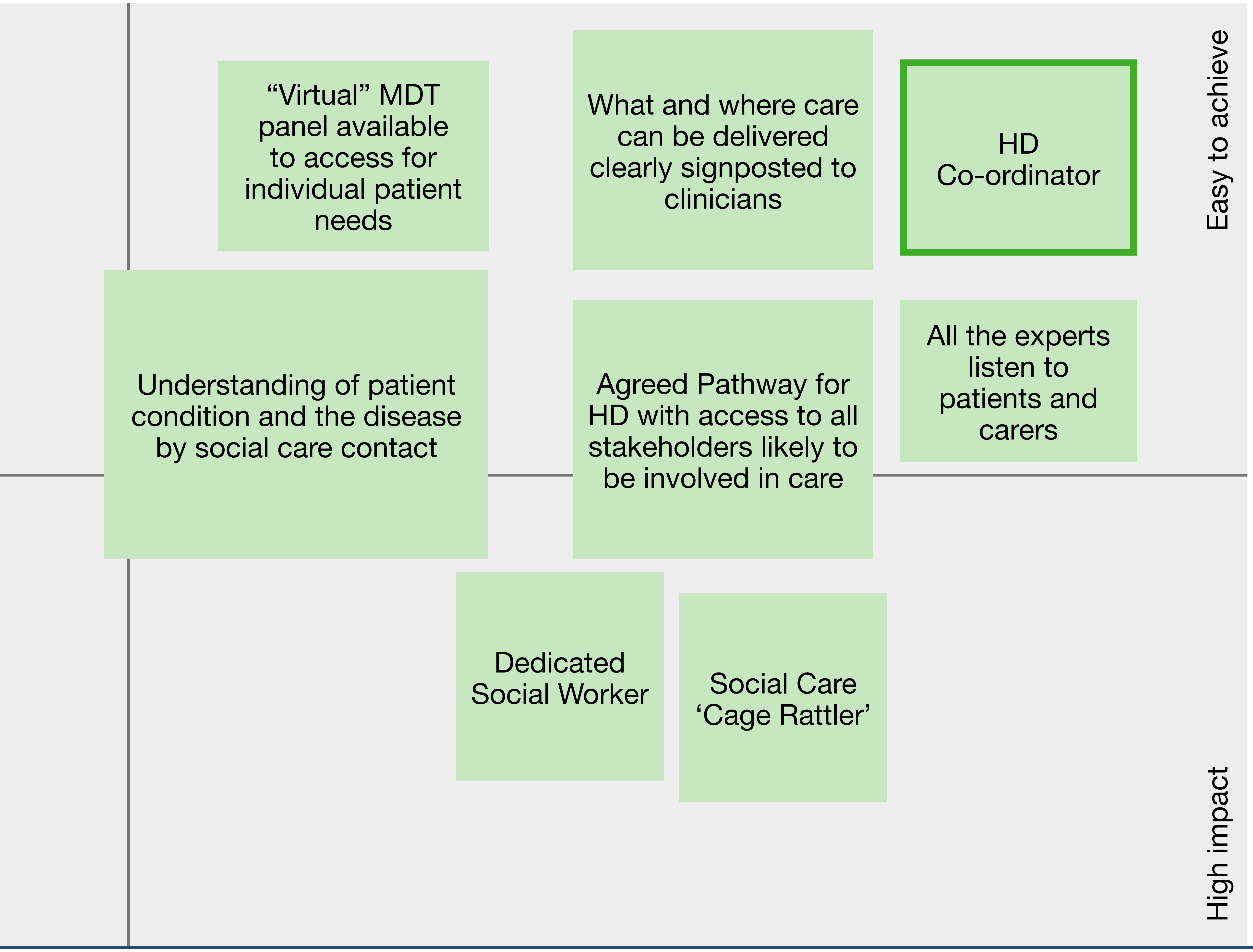
Need continuity across whole area

Time to establish right staff in place, training, need people to see the bigger picture

MDT recognised by NICE as necessary for care pathway

Huntington’s Disease Workshop 12th October 2021: Continued from previous

Breakout room with Mike



“Virtual” MDT panel available to access for individual patient needs

What and where care can be delivered clearly signposted to clinicians

HD Co-ordinator

Understanding of patient condition and the disease by social care contact

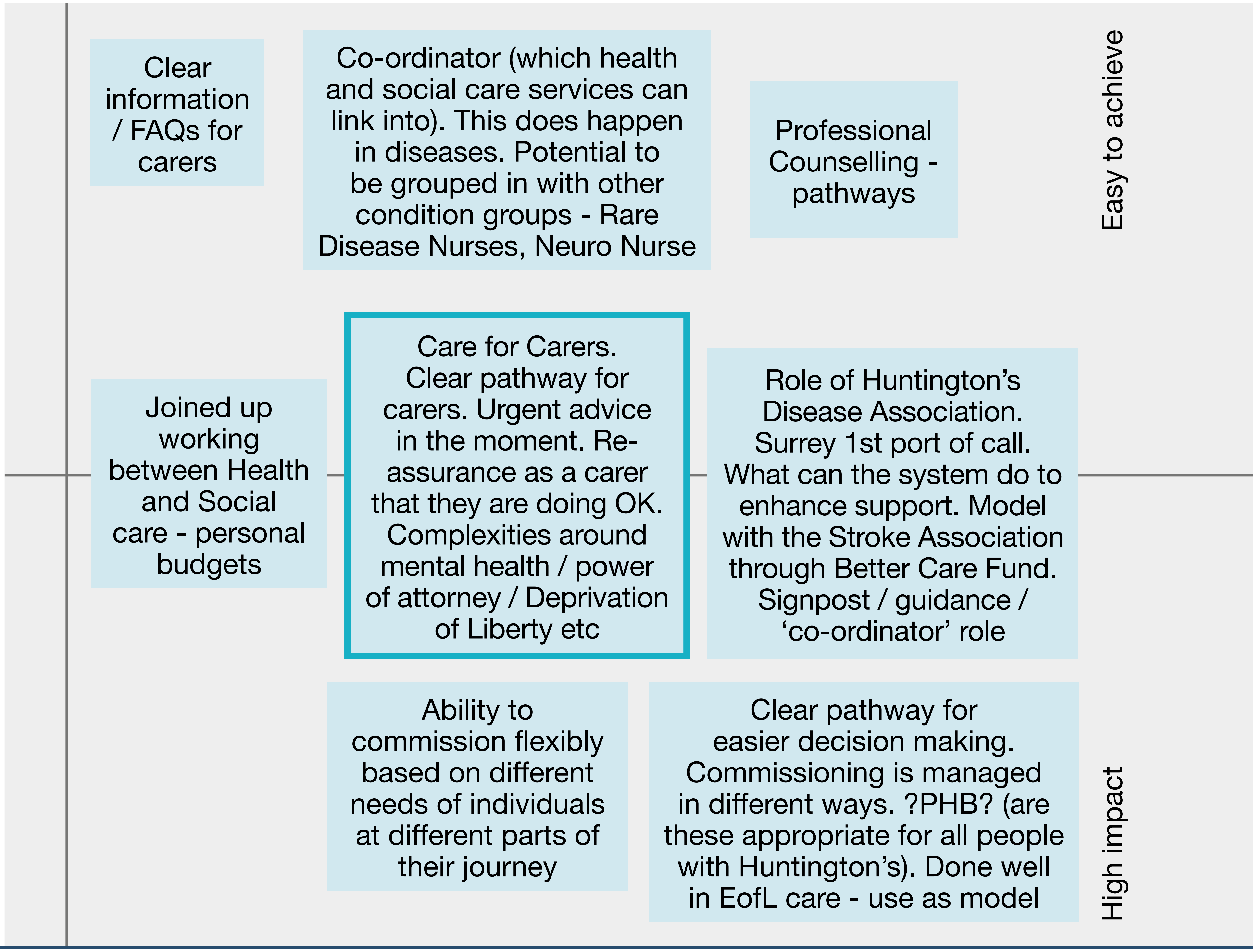
Agreed Pathway for HD with access to all stakeholders likely to be involved in care

All the experts listen to patients and carers

Dedicated Social Worker

Social Care ‘Cage Rattler’

Breakout room with Ruth



Clear information / FAQs for carers

Co-ordinator (which health and social care services can link into). This does happen in diseases. Potential to be grouped in with other condition groups - Rare Disease Nurses, Neuro Nurse

Professional Counselling - pathways

Joined up working between Health and Social care - personal budgets

Care for Carers. Clear pathway for carers. Urgent advice in the moment. Re-assurance as a carer that they are doing OK. Complexities around mental health / power of attorney / Deprivation of Liberty etc

Role of Huntington’s Disease Association. Surrey 1st port of call. What can the system do to enhance support. Model with the Stroke Association through Better Care Fund. Signpost / guidance / ‘co-ordinator’ role

Ability to commission flexibly based on different needs of individuals at different parts of their journey

Clear pathway for easier decision making. Commissioning is managed in different ways. ?PHB? (are these appropriate for all people with Huntington’s). Done well in EofL care - use as model

The main theme captured from each breakout session were as follows:

1

Specialist HD Coordinator - ICS in Surrey have neuromuscular service example - broad roles can do this

2

MDT team

3

HD Co-ordinator

4

Care for Carers.
Clear pathway for carers.
Urgent advice in the moment. Re-assurance as a carer that they are doing OK.
Complexities around mental health / power of attorney / Deprivation of Liberty etc

The following people participated in the co-design workshop held on 12th October 2021

- Head of Service Development, Huntington’s Disease Association
- Social Media Officer, Huntington’s Disease Association
- Communications Manager, Huntington’s Disease Association
- Dementia Connect Local Services Manager, Alzheimer’s Association
- Service Delivery Director, KSS AHSN
- Continuing Healthcare Contracts Manager, NHS Surrey Heartlands CCG
- Speech & Language Therapist, Royal Surrey County Hospital
- Clinical Psychologist, Leicestershire Partnership NHS Trust
- GP & Governing Body Representative, NHS Surrey Heartlands CCG
- Senior Commissioning Manager, Surrey County Council
- Commissioning Support Manager, NHS Surrey Heartlands CCG
- Consultant, St George’s Hospital NHSFT
- Health Systems Partner, Roche Products Ltd
- Specialist Nurse MND & Neuro Conditions, First Community Health & Care CIC
- GP & Governing Body GP Representative, Guildford & Waverley ICP
- Conditions Partner Huntington’s Disease, Roche Products Ltd
- Consultant Clinical Geneticist, St George’s Hospital NHSFT
- Consultant in Palliative Medicine, Princess Alice Hospice
- Medical Affairs Partner, Roche Products Ltd
- Consultant in Palliative Medicine, Severn Hospice
- Carers and family members
- Guildford & Waverley Director of Integrated Delivery, NHS Surrey Heartlands CCG

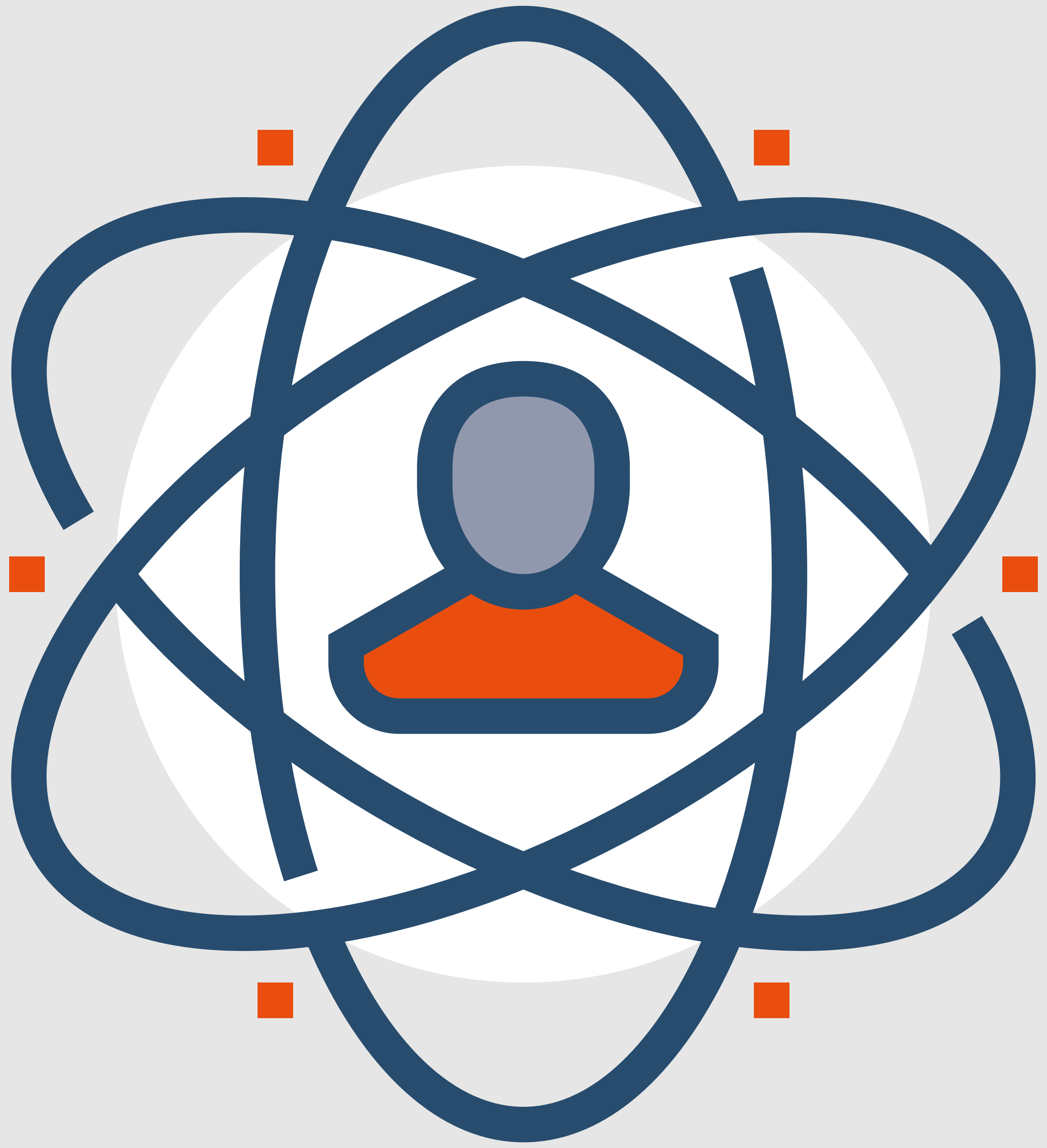
Co-design workshop 25th November 2021

The purpose of this second online workshop was to test the proposed service model which enables the provision of co-ordinated MDT holistic care as HD patients progress along the stages of the disease.

15 people attended which included clinicians, commissioners, service providers, carers as well as representation from the project's collaborative partners.

The following people participated in the co-design workshop held on 25th November 2021

- Head of Service Development, Huntington's Disease Association
- Service Delivery Director, KSS AHSN
- Continuing Healthcare Contracts Manager, NHS Surrey Heartlands CCG
- Commissioning Support Manager, NHS Surrey Heartlands CCG
- Consultant, St George's Hospital NHSFT
- Health Systems Partner, Roche Products Ltd
- Partnership Manager (Carers) NHS Surrey Heartlands CCG
- Specialist Nurse MND & Neuro Conditions, First Community Health & Care CIC
- Conditions Partner Huntington's Disease, Roche Products Ltd
- Consultant Clinical Geneticist, St George's Hospital NHSFT
- Carers and family members
- Medical Affairs Partner, Roche Products Ltd
- Guildford & Waverley Director of Integrated Delivery, NHS Surrey Heartlands CCG



Refine and develop

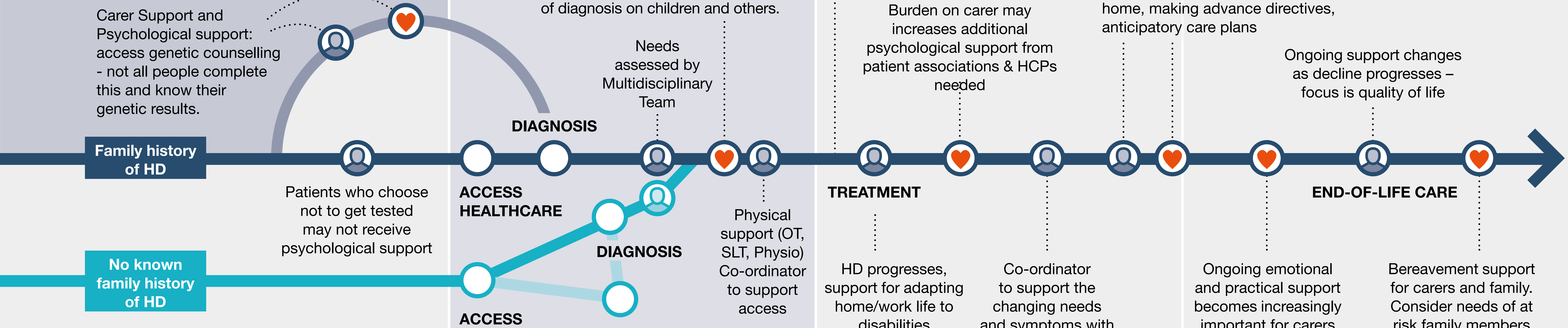
Production of service model

Feedback from the workshops was amalgamated into the draft service model and job description for a care co-ordinator.

Engagement with NHS providers outside of the Surrey region was undertaken resulting in documentation being shared to assist with producing the service model and care co-ordinator job description.

Final comments were sought from stakeholders on the draft documentation.

Huntington’s Disease Care Pathway



Presymptomatic and Predictive Genetic Testing

PREDICTIVE TESTING

Only a small minority choose to access genetic testing and for some this process can take several years.

Carer Support and Psychological support: access genetic counselling - not all people complete this and know their genetic results.

Family history of HD

No known family history of HD

Patients who choose not to get tested may not receive psychological support

Key:

👤 *Patients’ needs*

♥ *Care partner needs*

HCP - healthcare professional; HD - Huntington’s disease; OT,- occupational therapist; SLT - speech and language therapist; Physio - Physiotherapist; Dietician

Manifest symptoms and diagnosis

- Open access to support, at a time when they can digest the information
- Carer referred to Carer Support Service and needs assessed. Consider impact of diagnosis on children and others.

DIAGNOSIS

Needs assessed by Multidisciplinary Team

ACCESS HEALTHCARE

Physical support (OT, SLT, Physio) Co-ordinator to support access

DIAGNOSIS

ACCESS HEALTHCARE

Experiencing unknown symptoms - access genetic testing & counselling for diagnosis

POTENTIAL MISDIAGNOSIS

Initial symptoms may not be immediately recognised

Disease progression

Treatments only available to help manage the symptoms. May be suitable to participate in research or clinical trials.

Burden on carer may increases additional psychological support from patient associations & HCPs needed

TREATMENT

HD progresses, support for adapting home/work life to disabilities

Co-ordinator to support the changing needs and symptoms with the Multidisciplinary Team and HCPs such as - Physio, OT, SLT, Dietitian

End of Life Care

- Support needed with planning for the future - Wills, Guardianship, Power of Attorney
- Support with choosing a care home, making advance directives, anticipatory care plans

Ongoing support changes as decline progresses – focus is quality of life

END-OF-LIFE CARE

Ongoing emotional and practical support becomes increasingly important for carers & family as the patient progresses

Bereavement support for carers and family. Consider needs of at risk family members

Ongoing Support - help with accessing and coordinating changing health, psychological, social care & financial care needs

Presymptomatic › **Early** › **Moderate** › **Advanced** ›

The project has delivered

1. **HD service model**

2. **Successful proposal for the development of and recruitment to a HD coordinator post**

3. **Successful collaborative partnership**

Lessons learned

Engagement

- Strong engagement with patients, family members, carers, clinicans and commissioners both locally and nationally despite the challenges and restrictions posed by COVID
  What would we do differently: *The power of clinicians could be used more to encourage innovation at a grass roots level*
- Carers were given the opportunity to share their stories and voice their opinion on how improvements could be made to the care and support they and their family members receive through the patient and carers survey and engagement workshops
  What would we do differently: *Establish a small focus group after the engagement workshops to help finalise deliverables/ outcomes*
- Raising awareness of the patient and carers survey by the HD Association's communications team via newsletter and social media
  What would we do differently: *Reword some of the questions in the patients and carers survey so that respondees could focus their answers more on the support provided by NHS and social care rather than support provided by the HD Association.*
- National engagement through the patient and carers survey
- Patients and carers at the heart of what was achieved
- Family members and carers validated the challenges identified by clinicians

Partnership working

- The open and honest approach to collaborative working between KSS AHSN, Surrey Heartlands ICS, Roche Products Ltd and the Hungton's Disease Association
- Working with an AHSN enabled safe brokerage between the NHS and industry
- All partners were collaborating towards a common goal with all the support that they could offer being fully utilised
- Strong and equal involvement by partners to deliver in scope and on time
- Ways of working and governance arrangements put in place before the project started

Project Management

- An agile project that adapted as and when required
- Robust project management which enabled momentum to be maintained

Outcomes

- The outputs from the project have provided a strong foundation to build on in respect of developing the service model and recruitment to a Care Coordinator post

Feedback

“The project highlighted the strength in a partnership approach across both National and Regional neurological teams. At it’s heart, the project worked with those families who had lived experience of Huntington’s Disease and the impact of service configuration and care support. It was a powerful insight into how services need to wrap around patients and carers. The AHSN provided support and coordination that worked across multiple stakeholders and clinical leads engaged with passion and vision. I look forward to seeing the next steps of this project.”

Jane Williams, Guildford & Waverley Director of Integrated Delivery, NHS Surrey Heartlands CCG

“The project sought to identify the unmet needs for care for families with Huntington’s Disease. It was successful in bringing together multiple stakeholders from a number of different backgrounds across the breadth of care needs in Huntington’s Disease and highlighted a need for improved partnership working and co-ordination of care. KSS successfully navigated a complex area and drew together multiple strands to create a workable service specification and identify roles that could serve as a model for improved care and partnership working.”

Dr Nayana Lahiri, Consultant Geneticist, St George’s Hospital

“We are proud to have partnered with Surrey Heartlands, Kent Surrey Sussex AHSN and the wider Huntington’s disease community to address the needs of a small and often unheard number of Huntington’s Disease patients and make a real difference to their lives. Collaborating in this new way has enabled everyone to help shape this patient pathway. We hope that this work will inspire others across the healthcare system in ensuring there are effective and equitable local services for these patients.”

Mike Hills, Health Systems Partner, Roche UK

“The resounding message from families affected by Huntington's disease is that having a specific care co-ordinator with knowledge of health and social care, to help them navigate the complex systems, and enable them to access the care and support they need, is the thing that they would value more than anything. The strength in this project is its engagement with the Huntington's community, and hearing the lived experiences of those affected by this illness. It should be considered a blueprint for others to follow.”

Cath Stanley, Chief Executive, Huntington’s Disease Association

Feedback

“It has been a privilege to be part of the Huntingdon’s project which at its heart was about improving care and support outcomes for patients and their families. The engagement with patients, families and clinical staff made it clear that better co-ordination of care is needed. I think it is a great outcome to see new Care Co-ordinator roles be commissioned from the work and also for a clearly defined pathway be set out. I hope this may also be useful to others up and down the country. I would like to thank all who helped make this partnership work possible, particularly Surrey Heartlands Integrated Care Partnership, the Huntington’s Disease Association, Roche and of course the clinical and operational teams – but most importantly patients, families and carers who made themselves available to collaborate with us.”

Peter Carpenter, Service Delivery Director, Kent Surrey Sussex Academic Health Science Network

“The work of Surrey Heartlands in this area is fantastic new for the HD population in the area. I hope that my thoughts around a Multi-Disciplinary Team approach, and my “Spaghetti diagram” helped in some way to make the case for the HD Care Coordinator. This is a role that in my opinion is vital across the board as a minimum support for those suffering from HD, their families and carers”

Ben Walters, Family Member

“As a family carer who also had past professional medical experience I have been repeatedly and profoundly shocked that coordination and MDT style working for such a complex illness is so rarely considered or commissioned. It has been shown to be cost effective for other specialities such as cancer, stroke treatment and rehabilitation and rare genetic illnesses such as cystic fibrosis for many years. The ripple effect of HD on families, including children at risk is massive "like a nuclear bomb" when the HD secret is shared. It is tough for families to navigate and negotiate the complex care pathway. I have found it more traumatic advocating for my affected family to receive adequate healthcare, as their cognitive abilities and speech declined, than the awful impact of the Huntington's Disease itself.”

Carer

Appendices

Project outcome documents

Please find below links to the following documents:

Patient and carer survey questions

HD service delivery model

HD care co-ordinator job description

Reference documents

Frontiers | International Guidelines for the Treatment of Huntington's Disease | Neurology (frontiersin.org)

NHS Long Term Plan

The UK Strategy for Rare Diseases (publishing.service.gov.uk)

Contact details

For any further information
about the project please contact
enquiries@kssahsn.net