



Improving the Pathway after Brain Injury

ABIL- September 2016

Agenda

- 2.00 – 2.05 **Welcome** – Tony Hart, Chair ABIL
- 2.05 – 2.35 **Improving the neuro- rehabilitation pathway: The role of neuro navigators in London** - Susan Brown - Complex Neuro Navigator, Ealing Clinical Commissioning Group, and Jodie Carolan - Interim Clinical Manager, South East London Neuronavigation Service.
- 2.35 – 3.05 **The commissioner’s perspective: Improving local rehabilitation for people with brain injury - experience from Barnet** - Alan Brackpool - Head of Continuing Healthcare & Neuroscience Lead, Barnet Clinical Commissioning Group
- 3.05 - 3.25 **Break for Refreshments and Networking**
- 3.25 – 3.55 **Headway Early Intervention Services at Major Trauma Centres in London - challenges and benefits** - Seán Kinahan, Case Work Manager, Headway East London
Brian Sladen, Development Manager, Headway South East London/North West Kent
Penny Cooke, Link Worker, Headway West London
- 3.55 – 4.25 **Case studies - Neuro Navigator & Headway services**
- 4.25 – 4.45 **Discussion**
- 4.45 – 5:00 Close, Refreshments and Networking



The Role of Neuro-Navigators in London

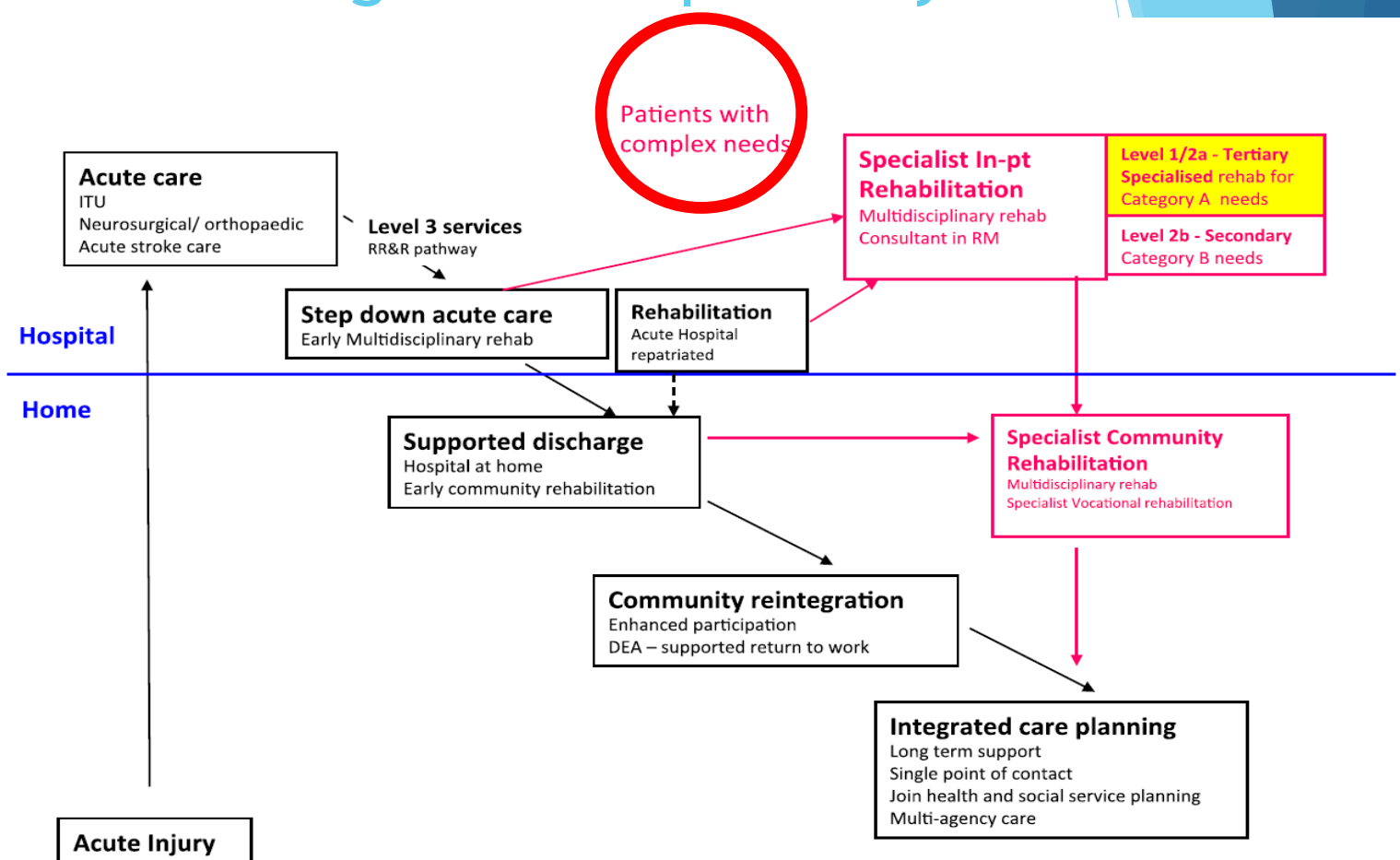
ABIL Conference, 13th September 2016
Presented by Susan Brown & Jodie Carolan

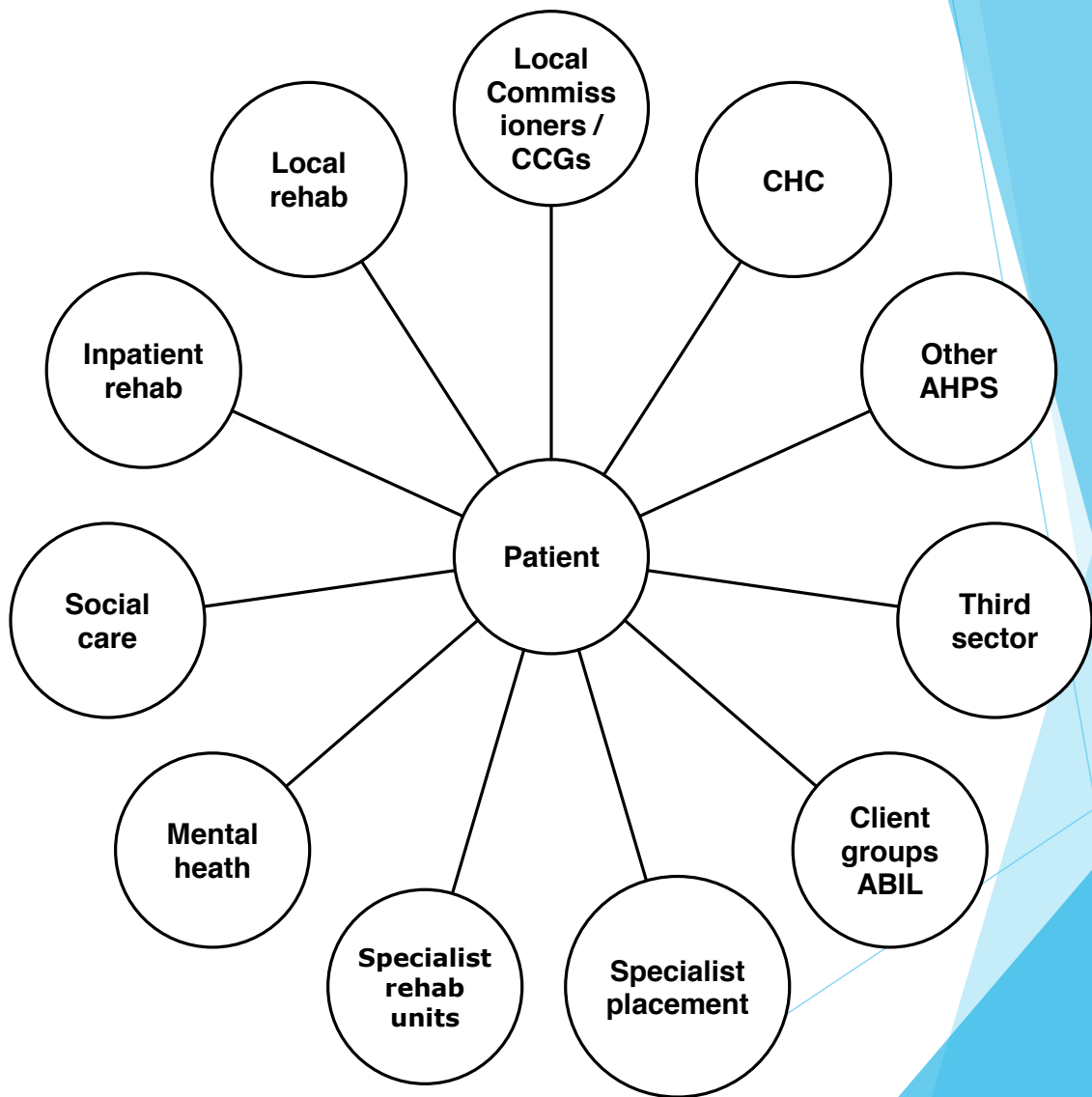
Summary

- ▶ Introduction to specialised neurological rehabilitation (rehab) pathway
- ▶ Background to ‘levels’ of specialist neurological rehab in London
- ▶ What is a neuro navigator? What do they do?
- ▶ Neuro Navigator cover across London



Neurological care pathway







Level 1 or 2?

Placement?

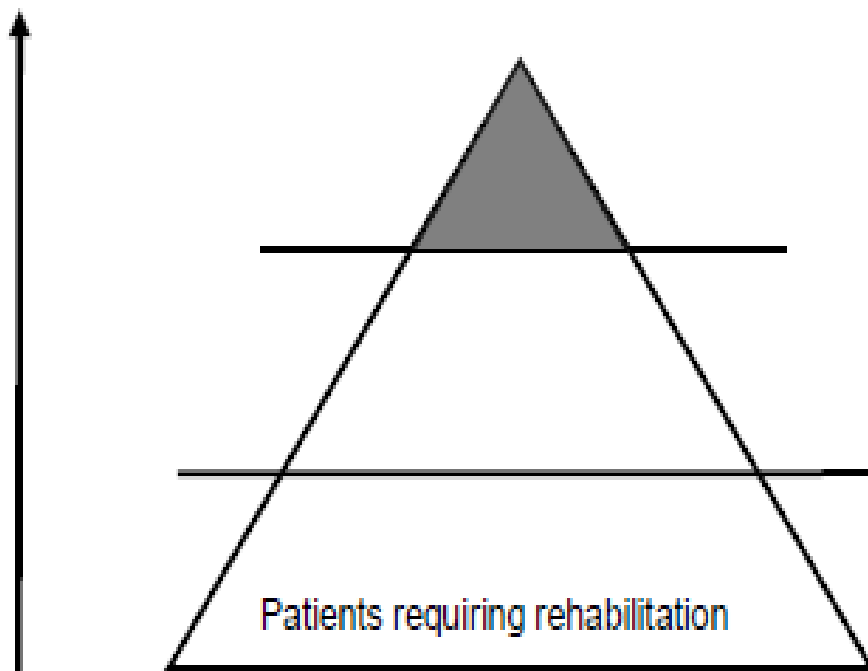
Level 3?

How Specialised Neuro-Rehab Services are Structured

- ▶ Classified into 'Levels' 1, 2 or 3
- ▶ Level 1 'Tertiary Specialised' services are commissioned by NHS England
- ▶ Level 2 'Local Specialised' and Level 3 'Local Non-Specialised' services are commissioned by local Clinical Commissioning Groups (CCGs)
- ▶ Each service has its own criteria
- ▶ Patients' rehabilitation needs are assessed to identify the appropriate service for the patient at that time
- ▶ Patients move 'through' services as their needs change

Structure of Specialised Services

Complexity
of need

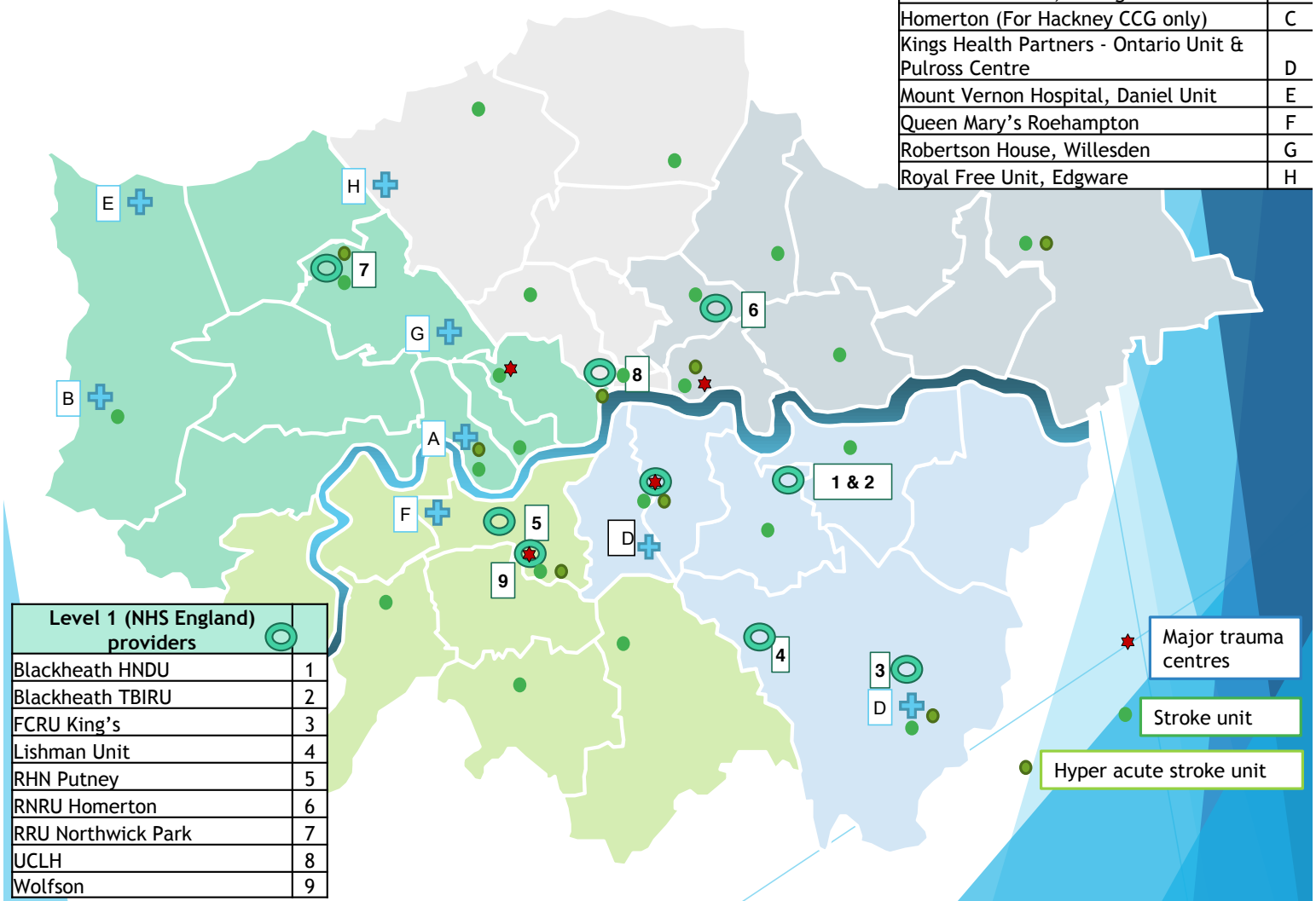


Level 1: Complex specialised rehabilitation services (CSRS)
Catchment population >1 million
1a – High Physical Dependency
1b - Mixed disability
1c – Cognitive behavioural

Level 2: Specialist rehabilitation services (SRS)
2a – Supra-district services
2b - Local district services

Level 3: Non-specialist rehabilitation services (NSRS)
3a – Other specialist services
3b - Generic rehab services

London 1 & 2b Provision



Level 1 (NHS England) providers	
Blackheath HNDU	1
Blackheath TBIRU	2
FCRU King's	3
Lishman Unit	4
RHN Putney	5
RNRU Homerton	6
RRU Northwick Park	7
UCLH	8
Wolfson	9

Level 2b (CCG) providers	
Albany Unit, Charing Cross Hospital	A
Alderbourne Unit, Hillingdon	B
Homerton (For Hackney CCG only)	C
Kings Health Partners - Ontario Unit & Pulross Centre	D
Mount Vernon Hospital, Daniel Unit	E
Queen Mary's Roehampton	F
Robertson House, Willesden	G
Royal Free Unit, Edgware	H

Major trauma centres

Stroke unit

Hyper acute stroke unit

What is a Neuro Navigator? What do we do?

- ▶ Identify right place right service right time
- ▶ Facilitate smooth transitions between hospitals and specialist neurological rehabilitation services
- ▶ Use knowledge of local resources to direct referrals to appropriate local services
- ▶ Work with referrers to identify which service is most appropriate for the individual at that time

What is a Neuro Navigator? What do we do?

- ▶ Monitor patients whose needs may be changing whilst waiting specialist rehabilitation provision
- ▶ Act as an advocate for both patients, and for services
- ▶ Provide information about specialist neuro-rehab services to help manage expectations of rehabilitation for patients, families and carers
- ▶ **Work in collaboration with patients, their family/carers and treating clinicians**

What questions do we ask?

- ▶ Could the patient manage in the community?
- ▶ Is specialist neuro rehab indicated?
- ▶ Which unit is most appropriate?
- ▶ What are current waiting lists like?
- ▶ Likely discharge options post-rehab?

What questions do we ask?

- ▶ How long is the patient likely to need rehab?
- ▶ Can the patient be discharged earlier?
- ▶ Who needs to help them once they go home? Community therapy? Voluntary services? Social services?
- ▶ Does the patient have realistic expectations of rehab?

Criteria for Referral to the Neuro Navigator

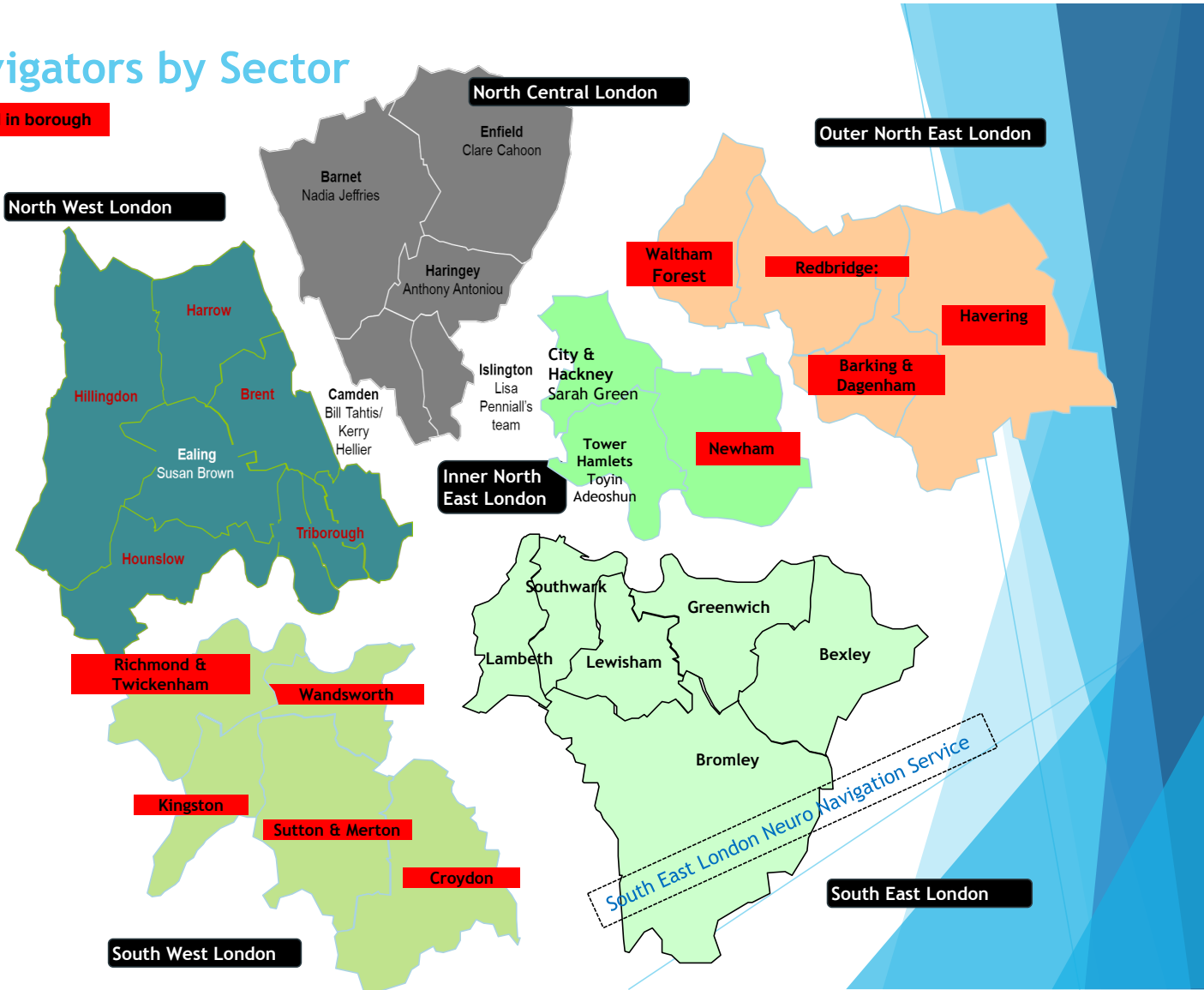
- ▶ Detail varies depending on CCG and local requirements
- ▶ Clients with complex neurological rehab needs, who require specialist neuro-rehabilitation.
 - ▶ Those who don't fit the established pathways (e.g. stroke)

Who are the neuro-navigators?

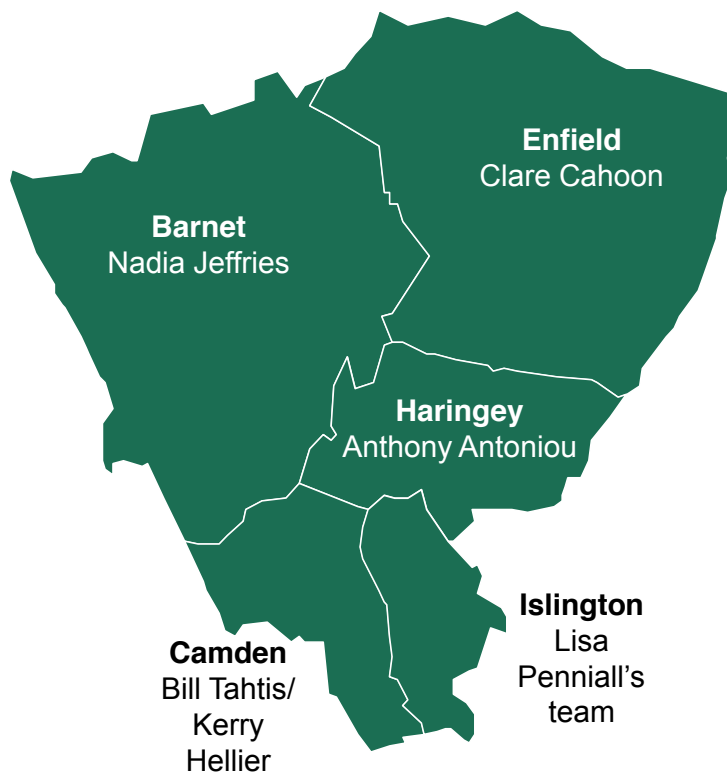
- ▶ Allied Health Professionals/Nurses with specialist knowledge and experience in neuro-rehabilitation
- ▶ The posts cover geographical areas of London and often work in conjunction with CCGs

Navigators by Sector

= nil NN in borough



North Central London



North West London



Prakash Pote & Richard McKinlay

- Triborough
- Hounslow
- Hillingdon
- Harrow
- Brent

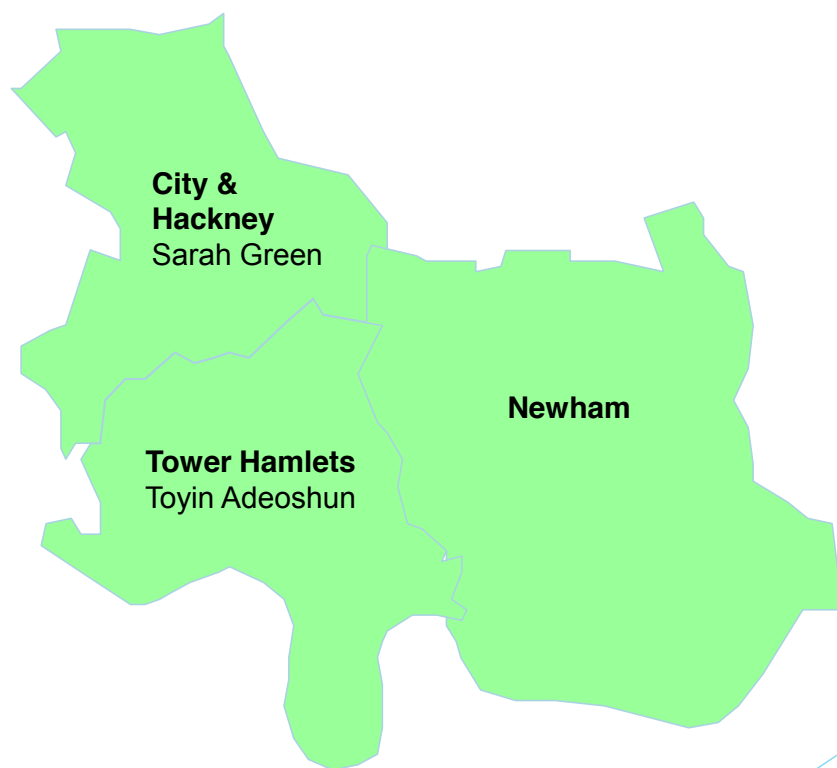
Triborough

- Kensington & Chelsea
- Hammersmith & Fulham
- Westminster

South West London



Inner North East London



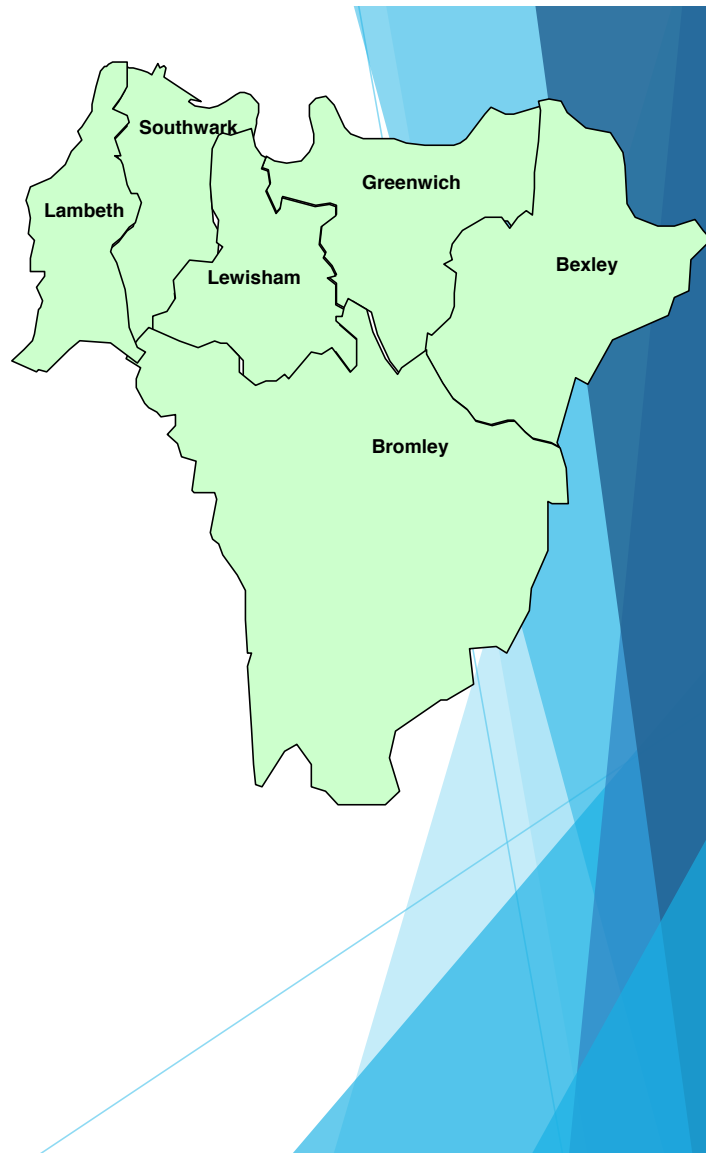
Outer North East London



South East London

SE London Neuro Navigation Service

- ▶ 6 navigators + clinical manager working as a team across the 6 SE London boroughs
- ▶ Initially started as pilot project in Southwark & Lambeth
- ▶ Recently the 6 CCGs joined together to commission the service across SE London as part of the 'South East London Neuro Rehabilitation Service' which also includes 20 level 2B neuro rehab beds
- ▶ Currently recruiting the last navigators now!



Neuro Navigators Group

- ▶ Chair - Nadia Jeffries
- ▶ Meet Quarterly
- ▶ Share best practice
- ▶ Formal engagement with NHSE and providers
- ▶ Terms of Reference and a work plan - standardising roles and outcome measurement



Improved outcomes with Neuro Navigation

- ▶ Reduction in inappropriate referrals to level 1 (plus monitoring role)
- ▶ Reduction in the number of DTOC's to/from level 1 units
- ▶ Reduction in out of borough rehabilitation placements from Level 1 units
- ▶ Borough variation however some Navigators have had over 30% of patients whose needs were originally identified as Level 1 that were redirected to Level 2/3 units.

Case Examples

- ▶ 51 year old man with new stroke (mixed physical / cognitive) discharged home from stroke unit while awaiting admission to Level 1 unit
 - ▶ Patient did not meet criteria for local stroke Early Supported Discharge so was referred to neuro community therapy team
 - ▶ Neuro community therapy team had 18 week wait so patient was not receiving therapy at home
 - ▶ Long waiting list for Level 1 unit; late referral to alternate Level 1 unit
 - ▶ NN assessed patient at home - patient had category B needs with primarily physical impairments; accepted for 2b bed at Orpington hospital

Case Examples

- ▶ 67 year old man with recurrent steroid responsive encephalopathy with new tracheostomy admitted to Level 1 unit for trache weaning
 - ▶ Patient likely to need long term trache
 - ▶ Family adamantly want patient to be cared for at home, but there is no service in the borough to provide trache care in community
 - ▶ NN involved to investigate options with treating team and local commissioner
 - ▶ Eg. Identify services / care agencies providing community trache care in other boroughs; review trache care provision with local commissioner

Case Examples

- ▶ 34 year old woman with new traumatic brain injury admitted to major trauma centre; referred and accepted to Level 1 unit
 - ▶ Patient had supportive family and wanted to go home while waiting for level 1 rehab bed
 - ▶ Local borough had Enhanced neuro rehab team who could offer intensive therapy at home in interim
 - ▶ NN involved to facilitate referral to enhanced community team and liaise with Level 1 unit to remain on waiting list
 - ▶ NN monitored progress - patient improved quickly and no longer required Level 1 unit, so she remained at home and continued therapy with Enhanced Neuro therapy team



Any questions?

More information/ List of Navigators

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Bill Tahtis & Kerry Hellier (Camden)
Neuro-navigator Group vice chairs
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Developing and implementing a pathway for brain injury – a commissioning perspective

Alan Brackpool
Head of Continuing Healthcare & Neuroscience Lead
13 September 2016



Local clinicians working with local people for a healthier future



A CCG context – the delivery challenge

- In 2014 the NHS Five Year Forward View, outlined the transformation needed in our health and care system in order to meet the changing needs of our population
- During 2016/17 NHS England is asking every health and care system to come together to create their own local blueprint – a Sustainability and Transformation Plan (STP) – based not on individual institutions but local populations to underpin delivery in 2017/18 and beyond
- Significant re-organisation across North Central London (NCL) to support STP delivery and the financial challenge in health and social care at a local, sector and national level
- A number of NCL wide transformation programmes in place following planning in 2015/16 – Cancer, Learning Disabilities and Stroke for example
- A significant focus on A & E Improvement in 2016/17 – rapid implementation for local systems – and restore performance to 95%

Local clinicians working with local people for a healthier future



A CCG context – the delivery challenge

- NHS RightCare programme and Commissioning for Value – comparing each CCG to the 10 most demographically similar CCGs
- Focus pack on Neurology published in April 2016 – looking at spend on Elective Admissions
- 9 condition groups to include Traumatic and Spine Injuries
- In Barnet MS, PD and Epilepsy identified as priority stand-alone clinical pathways for 2016/17 rather than transforming neurology
- Still need to deliver business as usual and achieve financial balance



Who has lead commissioning responsibility for Brain Injury at a local CCG level?

- At a local CCG level there should be a lead commissioner and clinical lead for Brain Injury beyond neurology in general
- Commissioners are key to initiating transformation of care from the process-driven asset-based system to a needs-led community-based coordinated service because they hold the statutory responsibility for commissioning care services for people with long-term neurological conditions to include Brain Injury
- Will all local CCGs recognise The Transforming Community Neurology Transformation guide published on 20 June 2016
- Fully integrated thinking and delivery is required across the whole system this includes working with NHS England and Local Authority beyond social care to recognise the socio-economic impact to society as a whole
- Has there been any specific work on developing a fully integrated care pathway for people with a Brain Injury and do we really understand the current level of spending and outcomes?

Local clinicians working with local people for a healthier future



The challenge we have?

- Brain Injury is not perceived as a long term condition
- Do we know and understand the current pathway? Have we a current pathway?
- The local group is not visible and across continuing healthcare, social care across and different teams to include mental health
- Existing resource allocation (if we can define) is fixed and transformation and can be seen as a 'cost pressure' which inhibits the ability to commission
- Commissioners across NHSE, CCGs and Local Authorities need work in a more integrated way



How do **we** raise the profile of neuro rehabilitation and brain injury?

- Need to use the STP opportunity to work across NCL and to identify brain injury as a clinical pathway priority – all conditions are equally important
- To work with our NHSE commissioning colleagues to support the delivery in improving Level 1 neuro rehabilitation services following the current review
- To seek agreement to extend The Community Neurology Project set up by NHS England into NCL and London
- For NCL to set up a Task & Finish Group to undertake initial process mapping and understanding the existing pathways
- Time to get brain injury onto the CCG planning requirements for 2017/18 as part of Transforming Community Neurology and align with the Local Authority through the Health & Well-Being Board

Seán Kinahan – Headway East London

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- History / Set-Up
- Remit
- Progress to Date
- Challenges
- Future developments/
Opportunities





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Hospital
NHS Foundation Trust

HEADWAY SE London/NW Kent (SELNWK)

**Early Intervention at Kings College
Hospital**

Brian Sladen



King's College 
Hospital
NHS Foundation Trust

SELNWK Region

SE London Boroughs of Bexley, Bromley,
Greenwich, Lambeth, Lewisham, Southwark,

NW Kent Gravesham/Dartford

Medway Towns Chatham, Gillingham, Rainham,
Rochester, Strood.



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Headway SELNWK Services

- Early Intervention Services
- Centre Based Activities
- Community Support Programme
- Advice, Support, Legal Clinic
- Business Development
- Fundraising



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Early Intervention Services

- Kings College Hospital
- Frank Cooksey Rehab Unit
- Blackheath Brain Injury Unit
- Lishman Brain Injury Unit
- Community Neuro Rehab Teams
- Neuro Navigators



History

- Headway SELNWK service at Kings since 2006
- Initially one half day a week
- Developed in to full time post, half funded by Kings Charitable Trust
- Partnership working with Neuro Consultant and Nurse Specialist to develop Brain Injury Team which included follow up clinics.
- Good example of voluntary/statutory working together.



Kings College Hospital

- Working in partnership to develop care pathways
- Working to support patients and families with advice, information and a listening ear.
- 3 Acute Surgical Wards, Critical Care, Trauma Wards
- Working together with Consultants, Ward Managers, Doctors, Discharge Co-ordinators and Therapists
- Project has been responsible for SELNWK developing working partnerships along the pathway - post discharge



Frank Cooksey Rehabilitation Unit -Orpington

- The Frank Cooksey Rehabilitation Unit (FCRU) provides intensive inpatient neuro-rehabilitation for patients who are recovering from a severe neurological event.
- FCRU is a level 2a specialised rehabilitation service commissioned by NHS England to serve an extended local population.
- There are also 14 level 2b beds commissioned by CCG serving local population also at The Ontario ward hence the greater opportunities for joint working with SELNWK.
- There are also 6 stepdown beds for those awaiting rehab and not ready to go home.



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South East London
and North West Kent

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Blackheath Brain Injury Unit

There are two purpose-built units located at Blackheath site: the Thames Brain Injury Rehabilitation Unit (17 beds) and the Heathside Unit (18 beds). Together they provide specialist rehabilitation, complex disability management including communicative impairments and behavioural problems.



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Lishman Brain Injury Unit (South London & Maudsley NHS Trust)

Assessment, investigation and treatment of adults with an acquired brain injury, including traumatic and anoxic brain injuries, stroke, and encephalitis. The 15 bedded unit treats cognitive, behavioural and psychiatric issues. Also people with a primary mental illness diagnosis, who may also have suffered a brain injury, and individuals who may have sustained brain injuries in the context of drug or alcohol use.



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Community Neuro Rehabilitation Teams

- Bexley
- Bromley
- Greenwich
- Gravesend/Dartford
- Lambeth
- Lewisham
- Medway
- Southwark



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Neuro Navigation Services

Community Neurological Services for SE London

Neuro Navigators are expert neuro therapists that in reach in to hospitals, rehab units and other community services to identify patients who would benefit from specialist rehabilitation at home.

Successful pilot project in Lambeth and Southwark now being 'rolled' out to Bexley, Bromley, Greenwich, Lewisham.



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Case Study

- 5th Dec 2011 – Admission to Kings College Hospital from Darent Valley Hospital following an acute subarachnoid haemorrhage secondary to bleeding from an aneurysm
- 2nd Feb 2012 – Transferred to rehab at Frank Cooksey during which time she was referred and assessed by EARLY INTERVENTION CO-ORDINATOR. Progress on the unit was monitored by co-ordinator and support and information provided for patient and family about work issues, benefits and SELNWK services. Patient was working in the service industry
- 9th March 2012 – Discharge home from Frank Cooksey and referred to assessments team at SELNWK



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24TH March 2012 – Assessment at home by SELNWK recommendation for 1 day centre placement and 4 hours community support each week to assist with patients problems included , social isolation (family at work all day) cognitive/emotional issues and word finding difficulties. Patient was self managing with personal care. No mobility problems apart from weakness in the left leg.



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Client was in SELNWK service as part of the Bexley Grant for 3 months and then personal budget agreed.

Plan - to develop strategies for memory retention, weekly planning for activities including shopping/housework and travel training and participation in the communication group at the Abbey Wood Centre



Goals

- Goal setting plan set in accordance with need, with a long term goal of a return to work. Strategies included :
- monitoring and management of levels of physical activity and fatigue
- increase tolerance and stamina by exercise
- social interaction
- monitoring outcomes with communication group including memory work
- Regular reviews initiated and goals adjusted
- Practical support initiated with benefits, housing, debt problems and family support.



Client was in the SELNWK service for 2 years and over that time centre activity and community support was gradually decreased and client was able to return to work with SELNWK support and employers.

Example of intervention at all levels from initial injury along the pathway. Without EI project risk of clients having very little input or support or information.



West
London

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**Acquired Brain Injury
Pilot Support Services Project
St Mary's Hospital, Paddington
The First 12 months – September 2015 to
2016**

**Joint working with Imperial College
Healthcare Trust**



The Brief

Headway West London and Imperial Healthcare Trust aims were to

- create a Patient and Family Support Service within the Major Trauma Pathway based at St Mary's Hospital Trauma Centre.

(catchment from Watford and the whole West London area)

- develop links with other ABI services in the sector.
- signpost to other services
- produce a "Yellow Pages" of these resources
- record and evaluate activity using a database

Resource: One Linkworker - two days per week on site at St Mary's.

With support from Headway West London committee



The service has grown organically

- September 2015: weekly attending St Mary's Neuro Surgery outpatients (4 hours per week)
- End October 2015: weekly attendance at the St Mary's Traumatic Brain Injury clinic – one stop shop of cognitive testing, neurology, neuro psychiatry and endocrinology. (5 hours per week) and Neuro Surgery Clinic
- January 2016: Above clinics plus 1) regular visits to Major Trauma Centre when requested by the Major Trauma/Neuro Therapy Team and 2) Referrals from St Mary's Neuro outliers
- September 2016: 2nd part-time Linkworker in post.

Excellent cooperation with Imperial College Healthcare staff as well as Statutory and Voluntary sector colleagues



As at end of August 2016

- Recorded contact made with over 330 brain injury survivors
 - plus over 100 family/carers who accompanied patient to appointments
 - 506 individual meetings/contacts
- 12 months of data produced monitoring achievements and progress against desired outcomes
- “Yellow Pages” of useful contacts developed and regularly updated



Unmet needs identified

- Carer support
- 18-29 age group
- Different language groups
- Employability

How do we meet these needs?

- Family Support Focus group
- Developing educational talks for family and individuals
- Coffee meetings
- Increased social events
- Exploring self-management/activity group
- Building relationships



**Being based in outpatients' clinics
has proved effective**

The clinicians are able to concentrate on the person's neurological and physical health;

The Linkworker is able to focus on other aspects of concern to the person and offer:

- 1:1 emotional support and encouragement to cope with ongoing difficulties and trying to encourage working towards self management goals
- Carer support and guidance
- Referrals to local Headway support and other agencies such as ATTEND, Citizens Advice, Shelter, IAPT counselling services
- Working with TBI team to introduce educational sessions for patients and their supporters



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LINK with Major Trauma/Neuro Therapy has proved effective

- Meeting patients and families in the acute ward at the start of their journey and building relationships as they attend neurosurgery/TBI clinic outpatient appointments.
- Initial advice, guidance and support offered during a deeply traumatic time for patients and their families.
- Opportunity to follow up with more tailored information at outpatients' clinics as it becomes clearer how the person is affected by their brain injury



Raising Awareness

- ❖ Linkworker ensures there is a sustained supply of “All About Headway”/ “Brain Injury Explained” leaflets with linkworker details attached in
 - St Mary’s Major Trauma Ward/Intensive Care Unit.
 - Neuro outlier teams covering other wards
 - St Mary’s PALS.
 - Outpatients waiting rooms

- ❖ Headway West London Linkworker leaflet developed which offers patients and carers contact info and an overview of Headway Information and Support available.

- ❖ Range of factsheets available at outpatients clinics
- ❖ Signposting clinicians to new Headway information/factsheets
- ❖ Visits and liaison with other organisations and sectors



Developing Links

- Visits to neuro rehabilitation units – Northwick Park, Alderbourne and Charing Cross
- Links with local neuro-navigators/community neuro-navigators
- Education: Headway “Viewpoints” seminars
- Encouraging professional visits (such as neuro-navigators) to TBI clinic has helped to increase understanding of the scope of the TBI clinic.



West London

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"The Headway West London Linkworker was immensely helpful to a family with a young son on intensive care following a significant brain injury. They were extremely grateful for her input so early on in their sons journey and the information leaflets she provided helped answer some of their questions." Senior Therapist, Major Trauma Ward

"Lonely" carer

Penny's work in Headway at the TBI clinic is INVALUABLE and I really wish this had been in operation 5 years ago when my son had his accident, the support to us as a family (from a friendly, approachable person!!) would have helped us greatly, as well as helping him too!! parent, May 2016



"I am pleased I met and was able to talk to you for a while at St Marys hospital it is a real boost for me when I am able to get a bit of support and help. Thanks again." Individual at TBI clinic



Challenges

- Keeping in touch with a large number of contacts
- Complex needs of patients
- Wide catchment area
- Capacity of local services and waiting times
- Variability of Headway services in different locations



Case study ABIL Forum

G, an engineer, had a fall from height in April 2016 and seriously injured his spine and head.

The St Mary's Hospital Paddington Major Trauma Ward therapy team referred him to the Headway West London Linkworker after his transfer from the Intensive Care unit.

This was 7 weeks after the accident.



In talking with the couple the Linkworker identified a number of concerns:

- Lack of income due to accident –
 - likely inability of husband to be able to work for some time;
 - restrictions of spouse visa;
 - wife unable to attend to job due to need to care for husband;
- Housing – unsuitability of current accommodation
- Psychological issues for both husband and wife, lack of understanding about the effects of brain injury.
- Care for young child as her mother needed to be attending her husband at the hospital.



Headway West London Linkworker's actions:

- listened to their concerns
- referred on to their local Headway advice team in East London.
 - wife acted on recommendation to make an appointment with Headway East London
- information leaflets from Headway helped them to understand more about brain injury and how to manage negative effects.
- telephone follow-up by Linkworker whilst waiting for local Headway to make contact.



Outcomes:

- Headway East London group has been able to help with housing needs and access temporary child care.
- Headway East London allocated a case worker to give ongoing support.
- Husband and Wife feel supported in the long journey they are facing – both practically and emotionally.



“Thank you very much Penny. I am so happy you have contacted us and have got through to us the leaflets and other stuff. What East Headway has given is really helpful and good information for now and on coming future.”

Wife of patient.