Mental Health and Neurosciences Leaders Away Day

Royal College of Psychiatrists, 21 Prescot Street London E1 8BB
Wednesday 26th June 2019
8.30am-5.30pm

Agenda

8.30am: *Registration and Refreshments*

9am: Welcome and introduction

9.10am: Morning presentations

11.10am: *Refreshment break*

11.40am: Morning presentations cont…

1.35pm: *Lunch*

2.30pm: Workforce panel discussion

3.25pm: *Comfort break*

3.35pm: Condition specific pathway breakout sessions.

16.35pm: Afternoon presentations

5pm: *Close*

Lived Experience of Huntington's Disease Care

Ben Walters

Ben and Megan were married in 2000. In 2008 Meg was diagnosed with Huntington's Disease. For the next seven years the couple battled with HD and bought up their two daughters, Flo and Ellie, now 16 & 14. Since Meg's passing Ben has given this talk to several audiences and is passionate about sharing their experiences in order address the incredibly difficult challenges patients, family members and the carers of those with neurological conditions face.

Ben Walters June 2019

Thoughts from those who cared for Meg

“Psychiatric services often struggle to get help from other specialities including general practice and neurology, I’m sure it’s the same in the other direction”

“Patients with complex problems need support from integrated services.”

“The patients with the most complex problems often get the most fragmented service”

“There is a real gap in the provision of neuropsychiatric services particularly in the neurodegenerative disorders areas such as Huntington’s disease, Parkinson’s disease, frontotemperal dementia. Loads of others too.”

Dr Ray Vieweg

Consultant Psychiatrist and Clinical Service Director

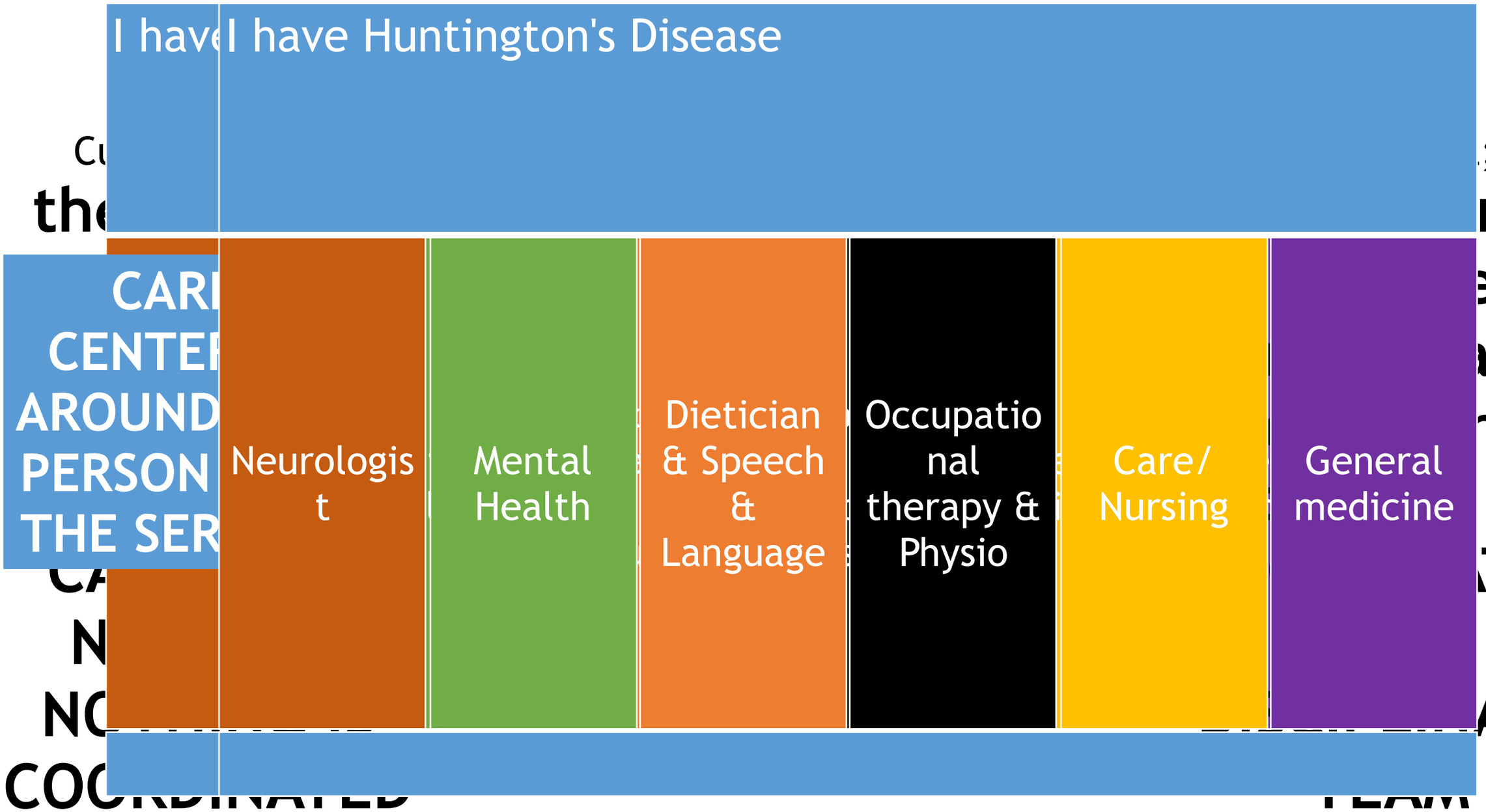
East AMH Southern Health Foundation Trust

If I could only say three things about HD…

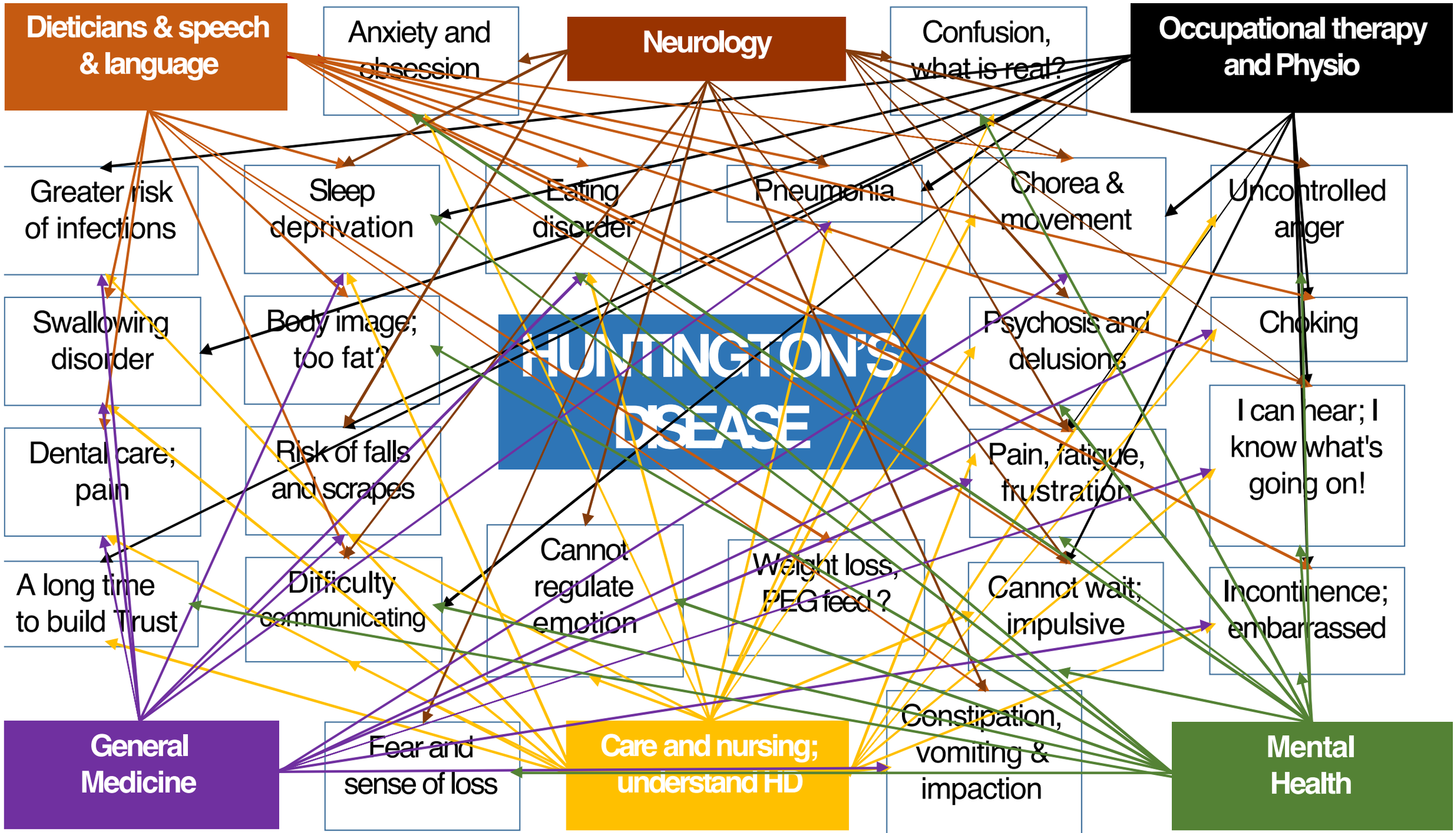
1. The interaction of symptoms is unique for each sufferer

2. Listen to the carer and accept advice from HD expert

3. Only a Multi-disciplinary team approach is effective;
   - Clinical specialists, combined with quality care in the right setting,
   - bound together by experience in the disease,
   - improves & prolongs quality of life,
   - and ultimately saves resources



Ben Walters June 2019



Ben Walters June 2019

State of the Nation: Mental Health

Professor Tim Kendall
National Clinical Director for Mental Health, NHS England and NHS Improvement

26 June 2019, Mental Health and Neurosciences Leaders Away Day
Royal College of Psychiatrists

Mental Health Five Year Forward View: priorities for 2020/21

70,000 more children will access evidence based mental health care interventions.

Intensive home treatment will be available in every part of England as an alternative to hospital. Older People

No acute hospital is without all-age mental health liaison services, and at least 50% are meeting the 'core 24' service standard. Older People

At least 30,000 more women each year can access evidence-based specialist perinatal mental health care.

10% reduction in suicide and all areas to have multi-agency suicide prevention plans in place by 2017. Older People

Increase access to evidence-based psychological therapies to reach 25% of need, helping 600,000 more people per year. Older People

The number of people with SMI who can access evidence based Individual Placement and Support (IPS) will have doubled.

280,000 people with SMI will have access to evidence based physical health checks and interventions. Older People

60% people experiencing a first episode of psychosis will access NICE concordant care within 2 weeks including children.

Inappropriate out of area placements (OAPs) will have been eliminated for adult acute mental health care.

New models of care for tertiary MH will deliver quality care close to home reduced inpatient spend, increased community provision including for children and young people.

There will be the right number of CAMHS T4 beds in the right place reducing the number of inappropriate out of area placements for children and young people.

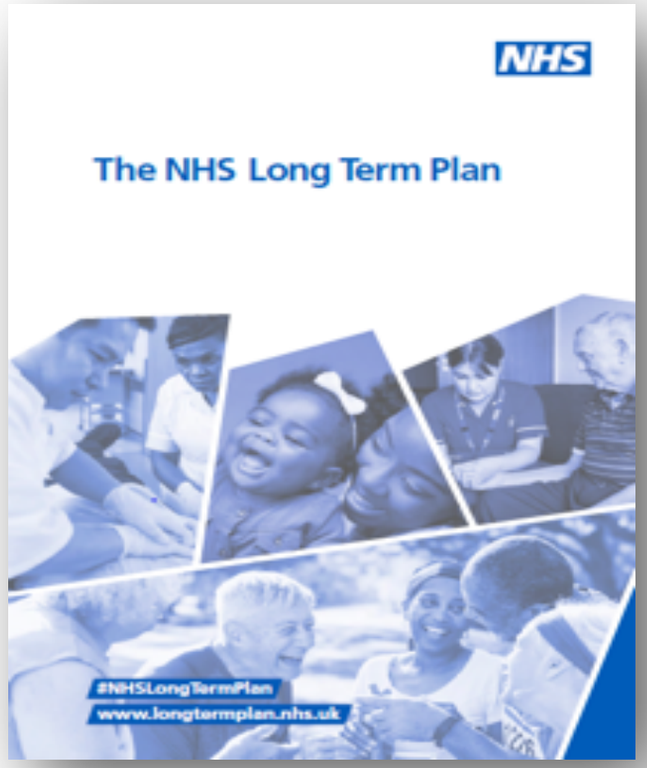
The NHS Long Term Plan

- 18 June 2018, the Prime Minister announced NHS funding will grow at an average of **3.4 per cent** a year real-terms increase from 2019/20 to 2023/24, equating to £20.5 billion in real term over the next five years.

- In return, the NHS was asked to prepare its Long Term plan, setting out ambitions for improvement over the next decade, and plans to meet them over the five years of the funding settlement.

- The NHS Long Term Plan published on 7 January 2019 commits to grow investment in mental health services faster than the overall NHS budget.

- This creates a new **ringfenced local investment** fund worth at least £2.3 billion a year by 2023/24.



www.england.nhs.uk

Long Term Plan Key ambitions at a glance

NHS England

345,000 more CYP will access help via NHS funded mental health services and school or college-based Mental Health Support Teams

Provide better community mental health support to 370,000 people with SMI via new and integrated models of primary and community care

24,000 additional women will access specialist perinatal mental health services. The period of care will be extended from 12 months to 24 months post-birth

Anyone experiencing mental health crisis will be able to call NHS 111 and have 24/7 access to the mental health support they need

380,000 more people will access NICE-approved IAPT services each year

Reduced length of stay in units with a long length of stay to the national average of 32 days

Ensure that the parts of England most affected by rough sleeping will have better access to specialist homelessness NHS mental health support

Expand geographical coverage of NHS services for people with serious gambling problems

Expand the existing suicide reduction programme to all STPs in the country

Integrated primary and community care

By 2023/24, 370,000 adults and older adults supported to live well in their communities via new and integrated models of primary and community care.

- **Test four-week waiting times** for adult and older adult community mental health teams.
- **Greater choice** and **control over** care, and **support** to live well in their communities.
- This includes maintaining and developing **new services** for people who have the most complex needs including EIP, ‘personality disorder’, rehabilitation and adult eating disorders

An opportunity for a new model…

Place-based, neighbourhood based networks

- **Place based, neighbourhood based,** with specialist services arrangements to contribute to variation in population size

- Care built around **local needs, local geography** with care organised around local communities, built around **clusters of GP practices**
- **Primary care enabled** to provide a broader range of services in the community that integrate primary, community, social and acute care services, and bring together physical and mental health
- Creates **multidisciplinary** team, with **strong links** with crisis teams and other services such as inpatient care, residential and liaison mental health services in emergency departments
- Networks will have **common pathways** for specific needs or problems, **agreed protocols** for the delivery of care, **shared protocols** for the management of specific problems, and **reduction in multiple points of access**

Local community:
- population size ~ **50,000**

Wider community:
- population size **250,000 +**
- Several local communities

Long Term Plan : crisis and acute mental health

NHS England

Ensure that anyone experiencing mental health crisis can call NHS 111 and access 24/,7 age-appropriate mental health community support.

Introducing mental health professionals in 111/999 control rooms

Continue ambition to ensure that all adult community crisis resolution and home treatment services are resourced and operating with high fidelity by 20/21

Ensure that by 2023/24, 70% of Mental Health Liaison services in acute hospitals meet the 'core 24' standard for adults, working towards 100% coverage thereafter

Increase provision of non-medical alternatives to A&E such as crisis cafes and sanctuaries that can better meet needs for many people experiencing crisis

Increase alternatives to inpatient admission in acute mental health pathways, such as crisis houses and acute day services.

Improve ambulance responses to mental health crisis by introducing mental health transport vehicles, introducing mental health professional in ambulance control rooms; and building the mental health competency of ambulance staff.

Children and Young People MH Green Paper

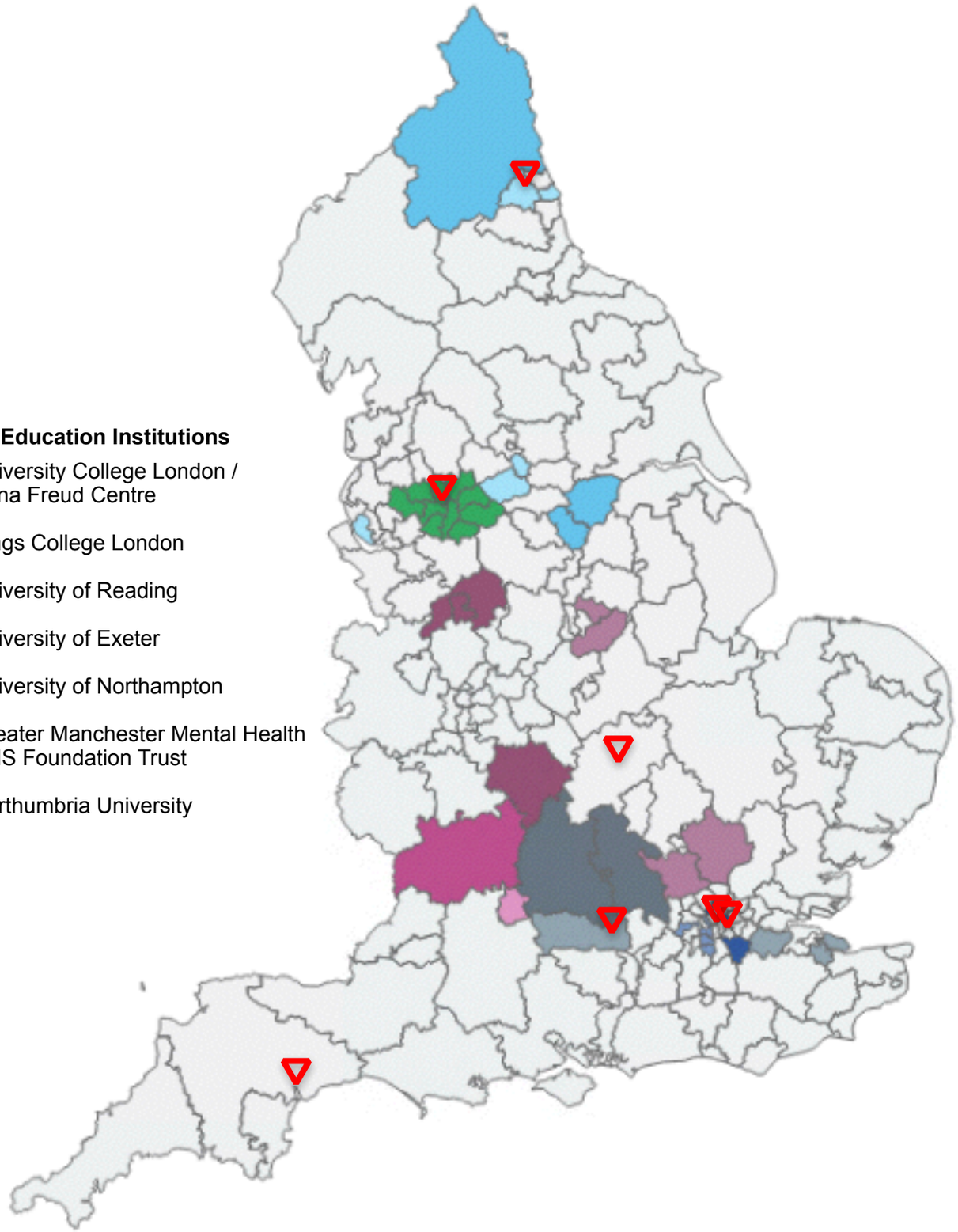
The CYPMH Green Paper commits to three core deliverables:

1. **DfE lead:** Schools and colleges to identify a **Senior Mental Health Lead** to oversee the approach to MH and wellbeing. All NHS CYPMH services identify a link for schools and colleges.
2. **NHS lead: Mental Health Support Teams**, supervised by NHS CYPMH staff, to provide extra capacity for early intervention. Their work will be managed jointly by schools, colleges and the NHS.
3. **NHS lead**: **Trial a four week waiting time** in a limited number of areas for access to NHS secondary CYPMHS.

Progress to date:

- Successful **launch of 25 Wave One sites** (12 of which are 4WW pilots)
- Over **200 new staff in training** in seven Universities.
- Over **1000 schools and colleges covered** by new teams from the 18/19 trailblazers
- STPs/CCGs have targeted schools and colleges with higher need
- Teams will be fully operational by December 2019
- Process underway to identify the next wave of 19/20 MH Support Team sites
- Health Education England are **commissioning up to seven more Universities** to provide additional training capacity from January 2020

Distribution of Wave 1 Sites



Higher Education Institutions

- University College London / Anna Freud Centre
- Kings College London
- University of Reading
- University of Exeter
- University of Northampton
- Greater Manchester Mental Health NHS Foundation Trust
- Northumbria University

MHST Pilot CCGs

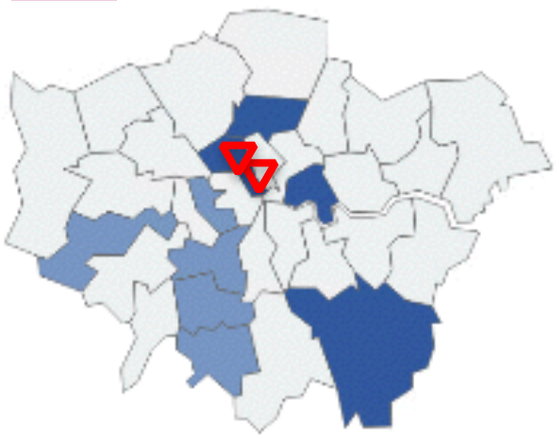
London:
- NHS Hounslow CCG
- NHS Merton CCG
- NHS Sutton CCG
- NHS Wandsworth CCG
- NHS West London CCG

Midlands and East of England:
- NHS East and North Hertfordshire CCG
- NHS Herts Valleys CCG
- NHS Nottingham North and East CCG
- NHS Rushcliffe CCG

North of England
- NHS Greater Huddersfield CCG
- NHS Liverpool CCG
- NHS Newcastle Gateshead CCG
- NHS North Kirklees CCG
- NHS South Tyneside CCG

South East
- NHS Berkshire West CCG
- NHS Dartford, Gravesham and Swanley CCG
- NHS Swale CCG

South West
- NHS Swindon CCG



NHS England

MHST and 4 Week Wait Pilot CCGs

London:
- NHS Bromley CCG
- NHS Camden CCG
- NHS Haringey CCG
- NHS Tower Hamlets CCG

Midlands and East of England:
- NHS North Staffordshire CCG
- NHS South Warwickshire CCG
- NHS Stoke on Trent CCG

North of England
- NHS Doncaster CCG
- NHS Rotherham CCG
- NHS Northumberland CCG

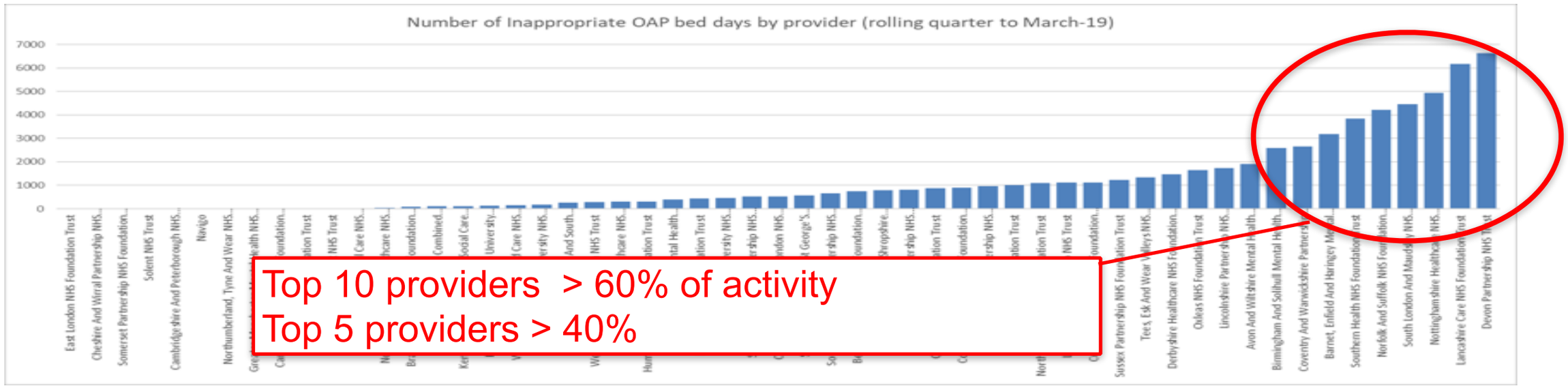
Greater Manchester
- NHS Bolton CCG
- NHS Bury CCG
- NHS Heywood, Middleton and Rochdale CCG
- NHS Oldham CCG
- NHS Salford CCG
- NHS Stockport CCG
- NHS Tameside and Glossop CCG
- NHS Trafford CCG
- NHS Wigan Borough CCG
- NHS Manchester CCG

South East
- NHS Buckinghamshire CCG
- NHS Oxfordshire CCG

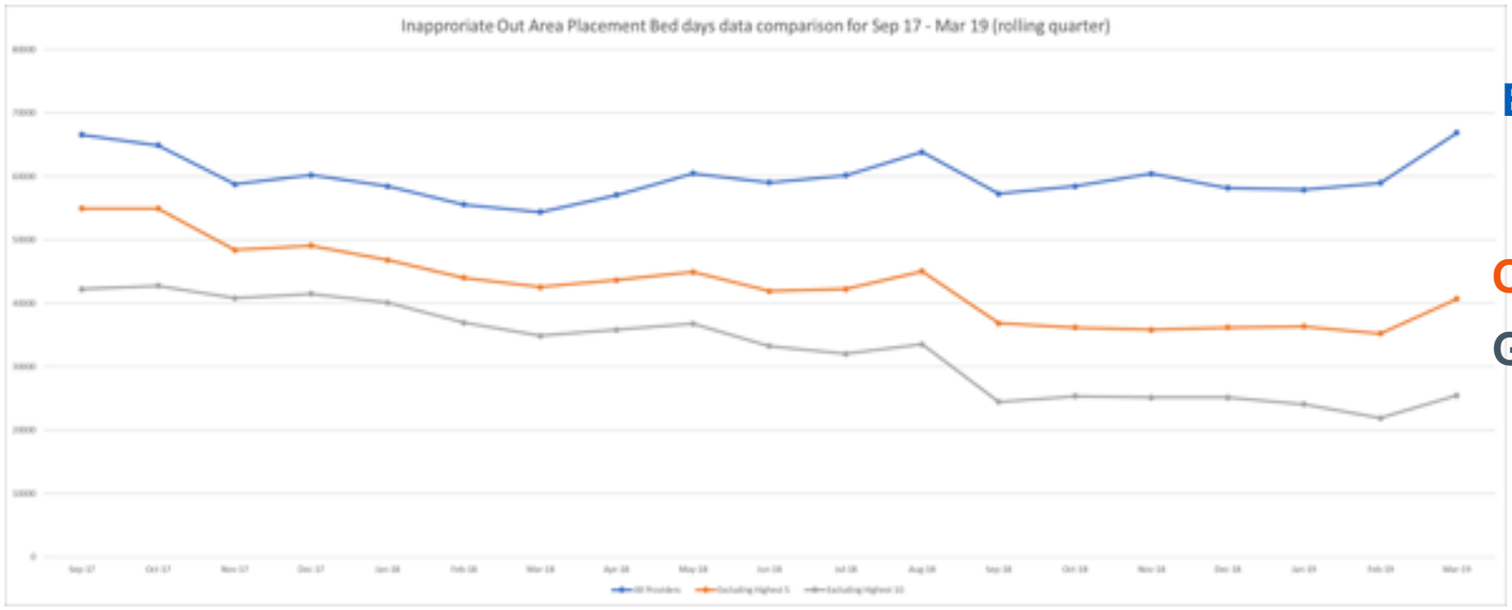
South West
- NHS Gloucestershire CCG

Reducing Out of Area Placements - Activity

Illustration of polarisation between providers:



OAPs activity trend over the last year (by rolling quarter):



Blue line is the rolling national total

Orange line removes the top 5 trusts

Grey line removes the top 10.

Reducing Out of Area Placements - Action

Assurance of Outliers

- Local visits organised for a number of STPs with Tim Kendall, National Clinical Director Mental Health and Mike Hunter, Associate NCD
- Letters to Regional Directors formally communicating the requirement for the OAPs outliers to:
  1. **submit a OAPs Recovery Plan**
  2. **share OAPs data on a monthly basis with regional and national teams**
- These are preconditions which must be met, before these STPs can access the crisis care funding.

New actions for regional leads

- Regional leads to explore the reasons for the increase in reported OAPs within non-outlier providers and share findings by 1st July.
- Regional leads to share OAPs Recovery Plans and data with national colleagues – timescales for receiving and approving plans will impact when funding can be accessed.
- Regional leads to consider if areas beyond the current top 10 require individualised attention

Mental Health Safety Improvement Programme (MHSIP) – the background

- Oct 2017: former Secretary of State (Sof), **Jeremy Hunt** asked NHS I and CQC to:
  - deliver **Mental Health Safety Improvement Programme**
  - compile **Mental Health Safety Support List** (11 MH Trusts having greatest difficulty with safety)
  - accompany SoS on a national programme of visits to MH trusts, to raise awareness of safety in mental health

- Cross Arms Length Bodies programme: **Reducing Restrictive Practice**
  - response to concerns raised by CQC
  - co-ordinated by NHS England

- **Sexual Safety Programme** National improvement collaborative to support NHS mental health providers to improve sexual safety on their wards

Reducing Restrictive Practice
Strategic Oversight Group

Department of Health & Social Care

CareQuality Commission

NHS Digital

NHS Improvement

NHS Health Education England

NHS England

NHS England

Cross ALB strategic oversight group

NHSE, NHS I, CQC, DH, HEE, NHS Digital

Cross ALB Delivery Group

Expert Reference Group

3 x work streams

1) Definitions & Reporting

2) Training & Accreditation

3) Provider Improvement Programme

GIRFT (Getting It Right First Time)

GIRFT will identify unwarranted variations in care whilst considering the lack of a defined urgent care pathway and multiple projects resulting in a wealth of information but no commonly understood best operational or clinical best practice

We don't know what best or good looks like but we do know what better looks like. To get to knowing what is best or good we need to start routinely reporting and acting on outcome data.

GIRFT in Mental Health

1. **GIRFT Acute and Crisis Pathway**
2. **GIRFT Rehabilitation**
3. **GIRFT CAMHS (Children and Young People MH Services) Tier 4**

GETTING IT RIGHT FIRST TIME

Suicide Prevention and Postvention Bereavement

- **MH5YFV: 10% reduction in suicide rates by 2020/21 (backed by £25m investment)**
- **Secretary of State 2018 – zero suicide ambition for mental health patients**
- **LTP– full coverage of existing suicide reduction programme and roll out of postvention bereavement services across the country; implementation of a MHSIP focussed on suicide prevention**

In 2018/19, we have:

- Supported MH trusts in developing and getting assurance from STPs for Zero Suicide Plans
- Identified and allocated resources to STPs with high rates of suicide.
- Designed and commissioned a National Quality Improvement offer delivered by *National Confidential Inquiry into Suicide and Safety in Mental Health* (NCISH) & RCPsych.
- Allocated funding to regions for joint NHS England–Public Health England regional suicide prevention leads, and to support for STPs not in receipt of priority funding.
- Commenced a 3 year evaluation of wave 1 sites

In 2019/20, we plan to:

- Continue to support MH trusts with Zero Suicide Plans
- Give additional funding to more STPs with high rates of suicide, trailblazers (sites of good practice and innovation) and postvention bereavement services (including central hub of resources).
- Continue with National Quality Improvement offer and Regional Support offer.
- Commission postvention bereavement implementation support.

Thankyou

NHS
Midlands Partnership
NHS Foundation Trust
A Keele University Teaching Trust

An Integrated Pathway in Practice

Dr Sarah Watts, Clinical Lead and Consultant Clinical Psychologist MPFT South Staffordshire Wellbeing (IAPT) teams

MPFT

mpftnhs

@mpftn


"MOST OF THE IMPORTANT THINGS IN THE WORLD HAVE BEEN ACCOMPLISHED BY PEOPLE WHO HAVE KEPT ON TRYING WHEN THERE SEEMED TO BE NO HOPE AT ALL."
DALE CARNEGIE

IAPT-LTC Project

- Aims:
- To implement integrated psychological therapies at scale – improving care and outcomes for people with mental health problems and long term physical health problems, and distressing and persistent medically unexplained symptoms.
- To build the return on investment case for integrated psychological therapies – demonstrating savings in physical health care.
- To build capacity in the IAPT workforce, starting the expansion of the workforce needed to meet 25% prevalence by 2020/21.

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Potential barriers to neurology patients accessing IAPT

- Most services have started their LTC work with diabetes, respiratory care and/or cardiac care
- Recovery model in IAPT need not be a barrier if staff properly trained
- Staff anxieties in all services that patients with neurological issues need ‘something different’
- Rigidity of some IAPT services re session length/ episode duration/delivery methods

How does this work in South Staffs for neurology patients?

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- Close links with Neuropsychology colle
- Top up training for therapists
- Self referral system
- Adapted sessions as required
- Clinical Lead who has worked in neuropsychology – in house consultation, supervision and training

Case study - Julie

- Diagnosis of epilepsy
- Depression resulting from >5 seizures per day
- Telephone assessment
- Difficulties in face to face sessions
- Computerised CBT with telephone sessions
- Partner as co-therapist
- Discharged in recovery

Case study - Bill

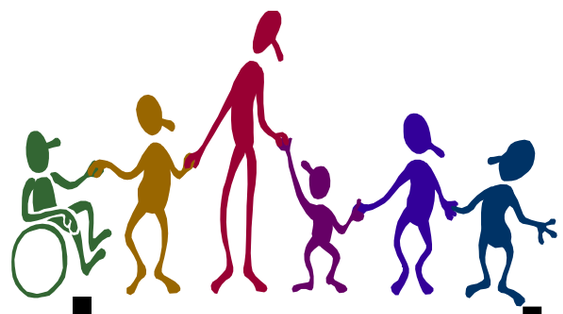
- Diagnosis of Parkinson's Disease
- Relationship issues and anxiety
- Face to face assessment
- Seen 1-1 by CBT therapist and supervised by neuropsychologist
- More sessions needed and slower pace
- Discharged in recovery with strategies in place

Midlands Partnership
NHS Foundation Trust
A Keele University Teaching Trust

Thanks for listening

n.watts@mpft.nhs.uk

YHANO



Neurology training for IAPT staff

Yorkshire and Humber Association of Neurological Organisations (YHANO)

It was broke …

- Previous education events didn't attract the crowds, but a good model
- We know that mental health support is poor
- But we didn't know what was available beyond limited neuro psychology
- Tried to engage at STP level, where mental health is a priority, but to no avail
- So start smaller

Somewhere …

- Started by conversation with Calderdale social care team and Airedale MS nurse …
- So approached IAPT services – as it's where most people will start
- Two way – we learn about services and they learn about neurological conditions
- 15 services across Yorkshire and the Humber
- Four completed, four planned, seven to go

Positive feedback

- Really positive feedback
- Hull – 40+ people delivering services many of whom were working or had worked with people with neuro conditions. But also going to talk to groups, offering sessions
- Bradford – clinical team: lots of questions and learning on both sides. They have definitely used information in improving practice.
- Calderdale and Kirklees – positive impact seen already. Awareness session was ‘invaluable’

Great for us too

- “It has been a pleasure to be involved with Let's talk Hull, and has resulted already in some of our members benefiting from their service. The fact that they have some insight into Parkinson’s gives us more confidence when referring people to their service.”
- The local MS Society group has already organised for someone from Let’s Talk Hull to visit the group. The plan is to encourage people to go to Let’s Talk Hull, not the group’s counselling service and use the freed funding for other priorities.

And more…

- “We know that the impact of the diagnosis and progression is colossal for people affected by MND, and yet anecdotally, people do not generally access mental health services. Meeting the teams and being able to pass on an outline of latest thinking in the condition, as well as outlining the resources and support we can offer, was invaluable. Meeting clinicians working in this area was very valuable, I felt they valued our information and experience and it felt a positive interaction for people affected by neurological conditions more widely”.

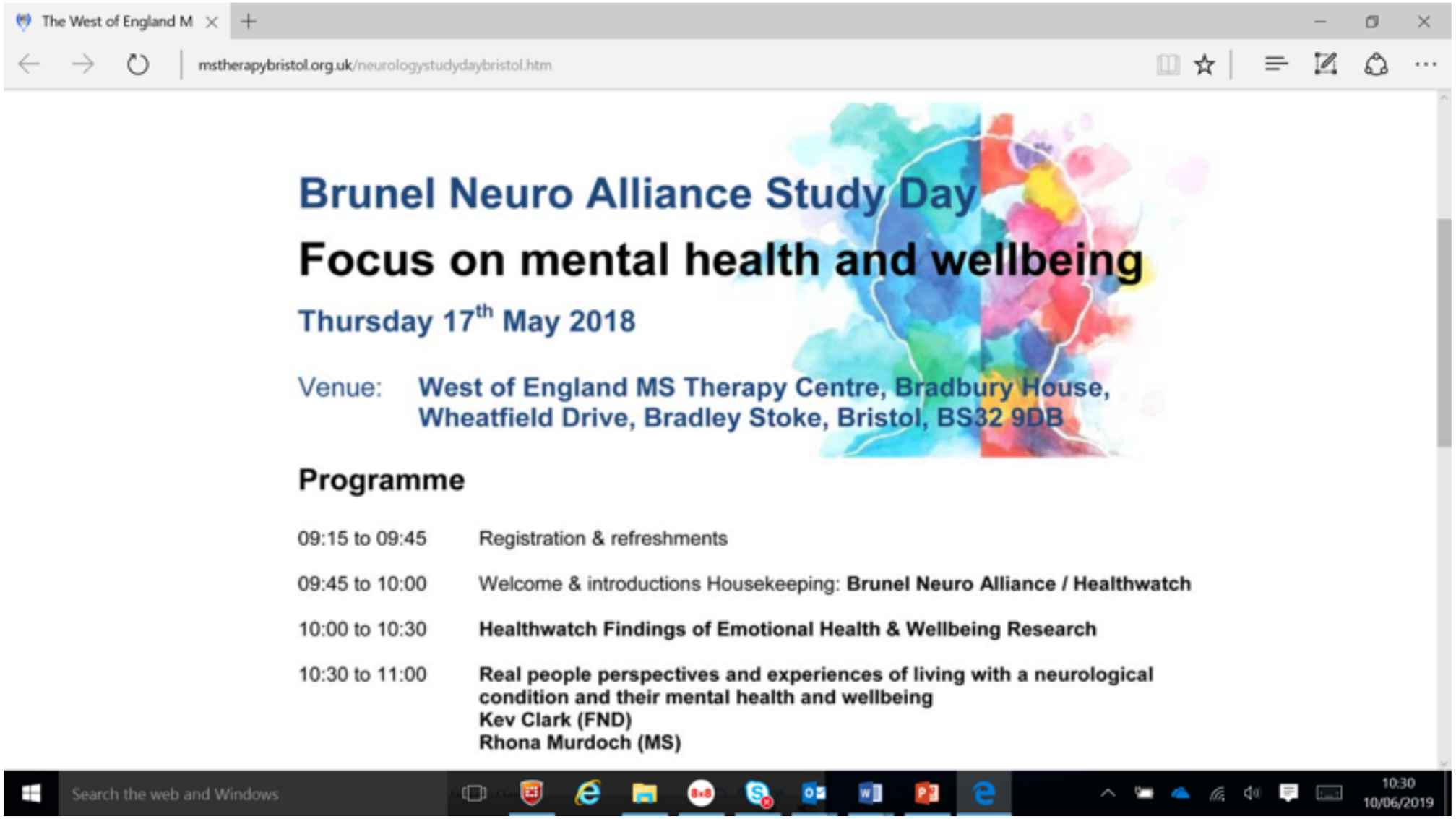
And more …

- “There has been really good feedback in all the areas that I cover about the sessions. There are more appropriate referrals and more understanding of why people are like they are as well as the condition (Huntington’s). Other services have fed back that the sessions have helped with people that they have linked with too. Really worth while and makes a big difference. I have learned a lot from the sessions too.”

Summary

- Approach has worked well for all involved.
- Starting at the beginning where people can self refer – makes sense.
- Can take time to find the right contact, but it is worth persevering.
- Not ignoring the bigger picture – still asking for action at the STP level, but at least something positive is happening.

And it’s not just in Yorkshire…..



An integrated pathway in specialised neurorehabilitation

Mike Dilley, Neuropsychiatrist & Clinical Director, Neurosciences ODN South
Colette Griffin, Neurologist

St George's University Hospitals NHS
NHS Foundation Trust

What is Integrated Care?

- Integrated care provides a **continuum** of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care that is coordinated across different levels and locations of care
- It needs to include physical, mental health and social care and be provided in an **interdisciplinary** way
- Traditional models of rehabilitation have *multidisiciplinary* interventions but less commonly have integrated mental health diagnosis and treatment as part of the team
- Consultation-Liaison mental health models run in parallel and are often in different Trusts and locations

“I wanted to be a Neurologist: that seemed to be the most difficult, most intriguing and most important aspect of medicine. It has links to psychology, aggression, behaviour and human affairs.“

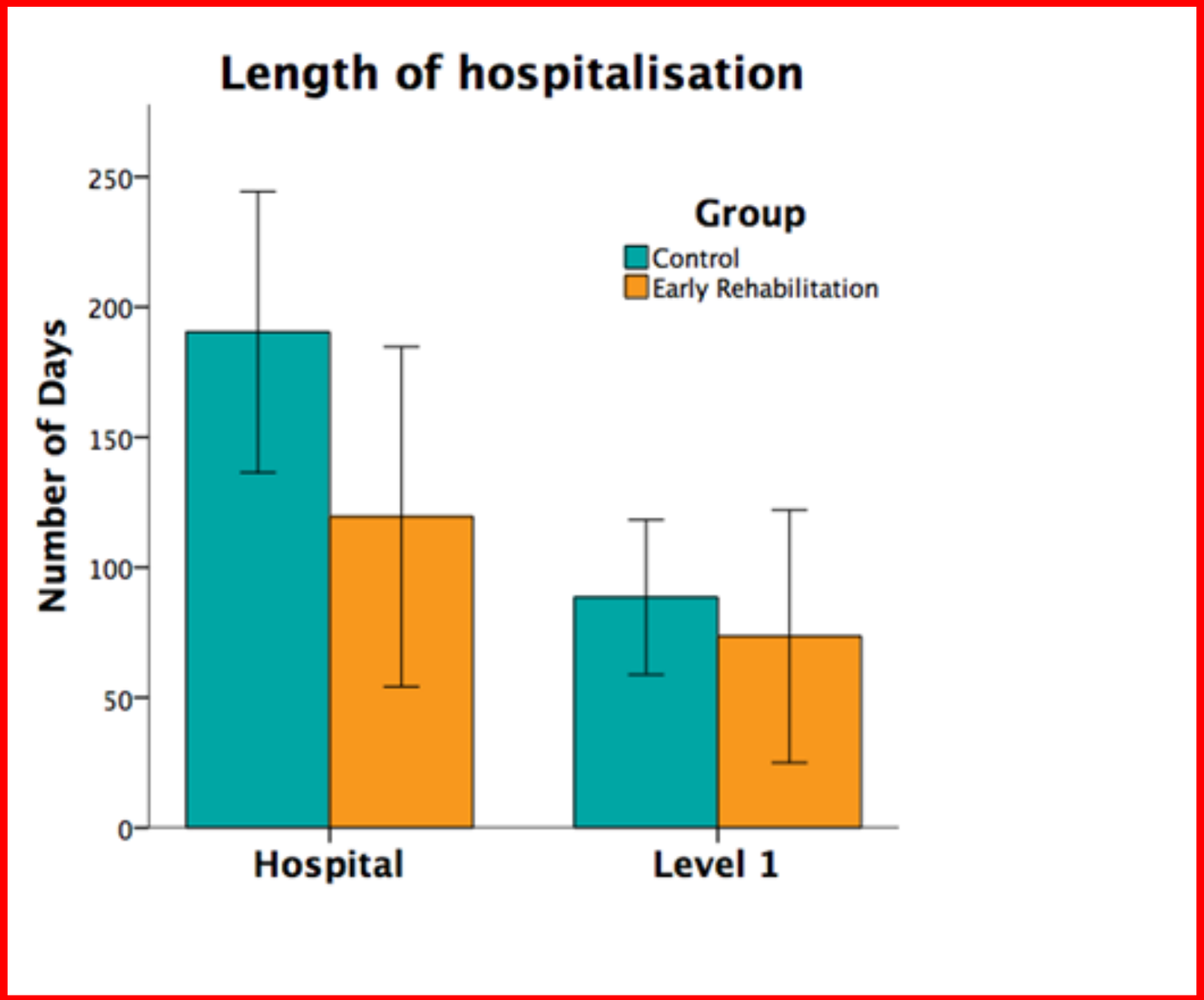
Diagnosis, diagnosis, diagnosis

Agitation – A Wide Range of differentials

- Neurological
  - e.g. Seizures; paroxysmal sympathetic hyperactivity
- Medical
  - Infections, pain, hypoglycaemia, hypoxia, withdrawal from substances and alcohol, prescribed drug effects
- Psychiatric
  - Psychosis, mood and anxiety disorders
- Post Traumatic Seizures
  Vespa 2005
  - 20% in moderate – severe injury
  - 60% non-convulsive
- Medications *Silver 2006*
  - Opiates
  - Hypnotics
  - Typical antipsychotics
  - Tricyclic antidepressants
  - Anticonvulsants e.g. LEV

Pilot of Acute TBI, Early, Integrated Rehabilitation

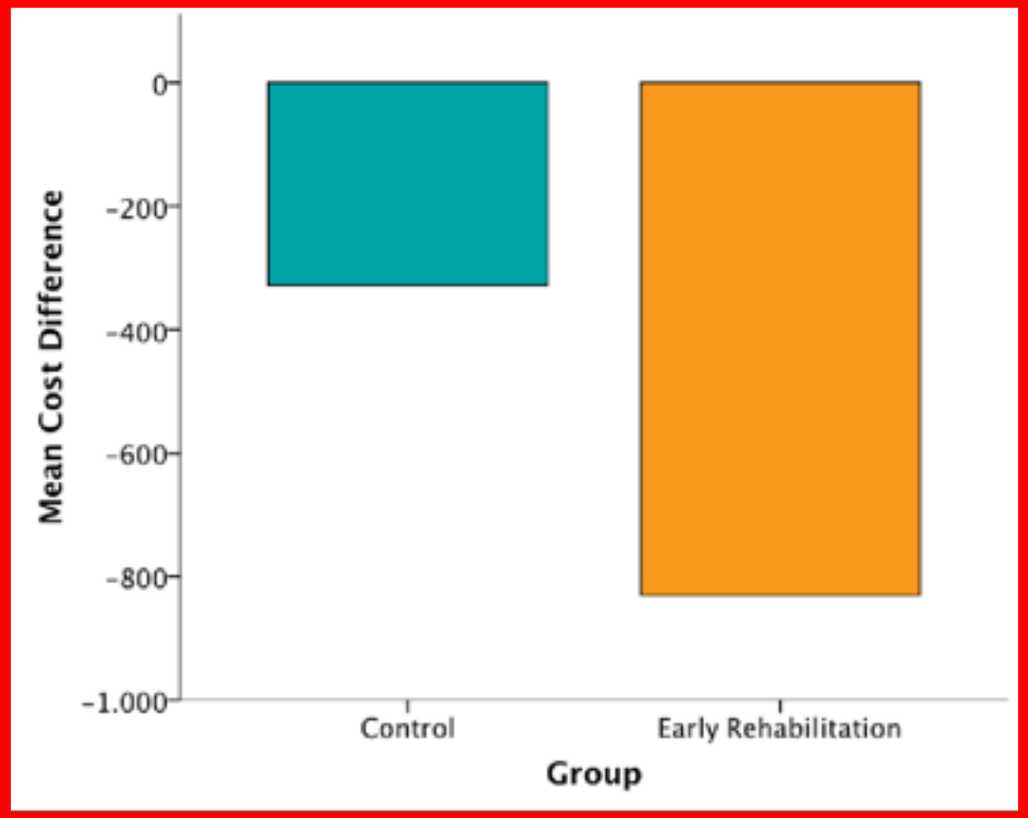
- Aim of the pilot study was to examine the effects of early access to integrated neurorehabilitation on the recovery of patients with TBI
- In November 2017 , a commissioned change was implemented in the way neurorehabilitation services were delivered
- Two groups of patients with matched demographic and clinical profiles received tertiary specialised neurorehabilitation either 50 or 100 days post injury



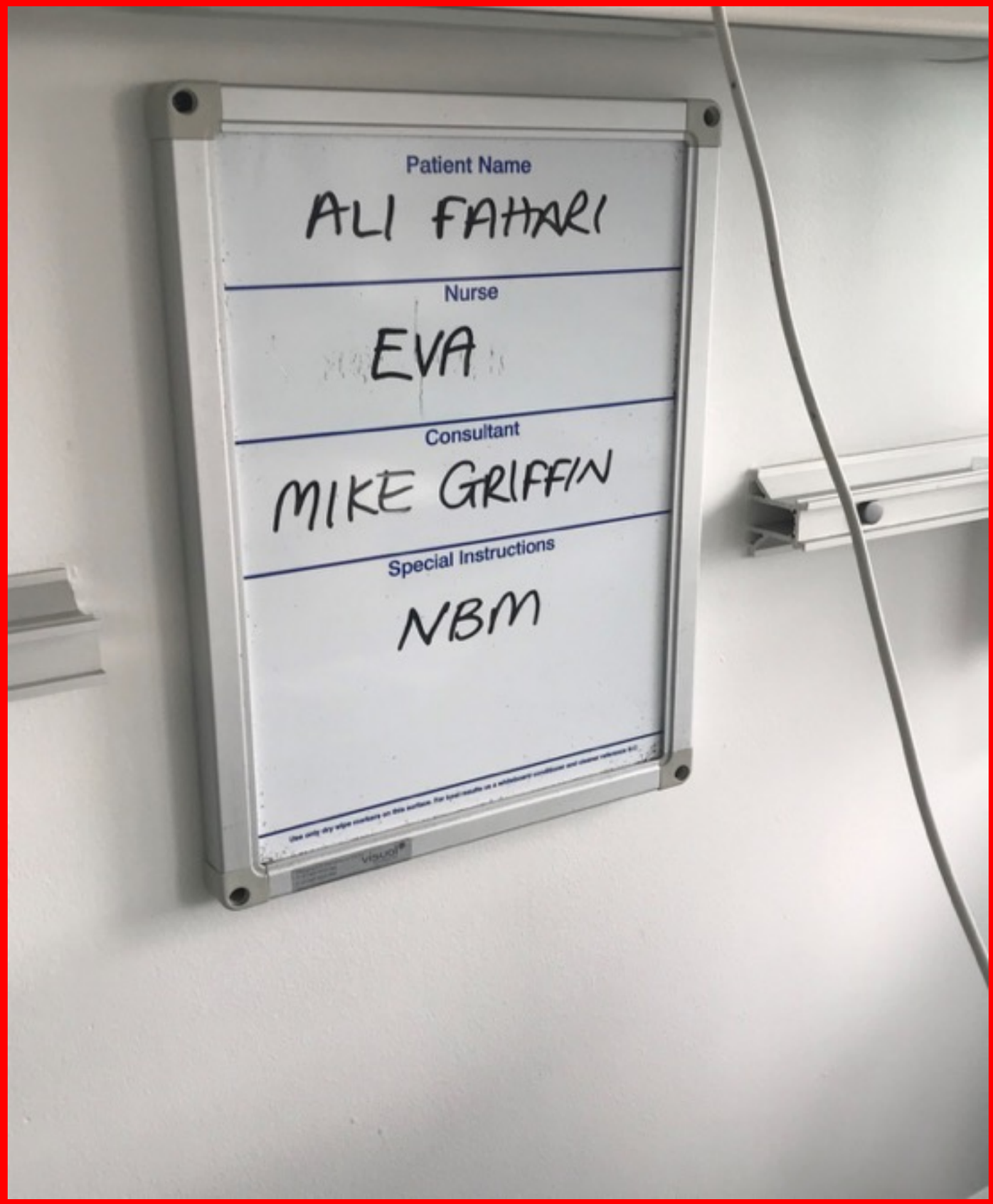
Mean number of days in hospital and mean number of days receiving Level 1 rehabilitation for control and early rehabilitation patients. Error bars= ±1SD .

Care costs

- Mean care cost difference between admission and discharge was -£327.62 (SD = 696.25) for the control group, and -£830.50 (SD = 634.31) for the early rehabilitation group i.e.£500 per patient/week – 61% decrease



Amalgamation, merger, union, blend, mixture, mingling, fusion, alloy, marriage, weave, coalescence, coalition, pooling, conjunction, incorporation, synthesis, composite, concoction, cooperation, collaboration, concert, synergy, association, alliance, partnership, league, mix


Patient Name
ALI FAHARI
Nurse
EVA
Consultant
MIKE GRIFFIN
Special Instructions
NBM

The Association of British Neurologists Perspective

David J Burn
President

A Major Health Burden

- Estimated *14.7 million neurological cases* in England
  - equates to 1 in 6 people having a neurological condition
- Prevalence data
  - > 75,000 cases per CCG
  - Rare diseases > 150,000 neurological cases
  - Intermittent = 9.7 million cases
  - Progressive = 2.1 million cases
  - Stable with changing needs = 1.7 million cases
  - Sudden onset = 1.1 million cases

S Vibert, Neurological Alliance, ABN Edinburgh 2019

Members' Survey 2018-19

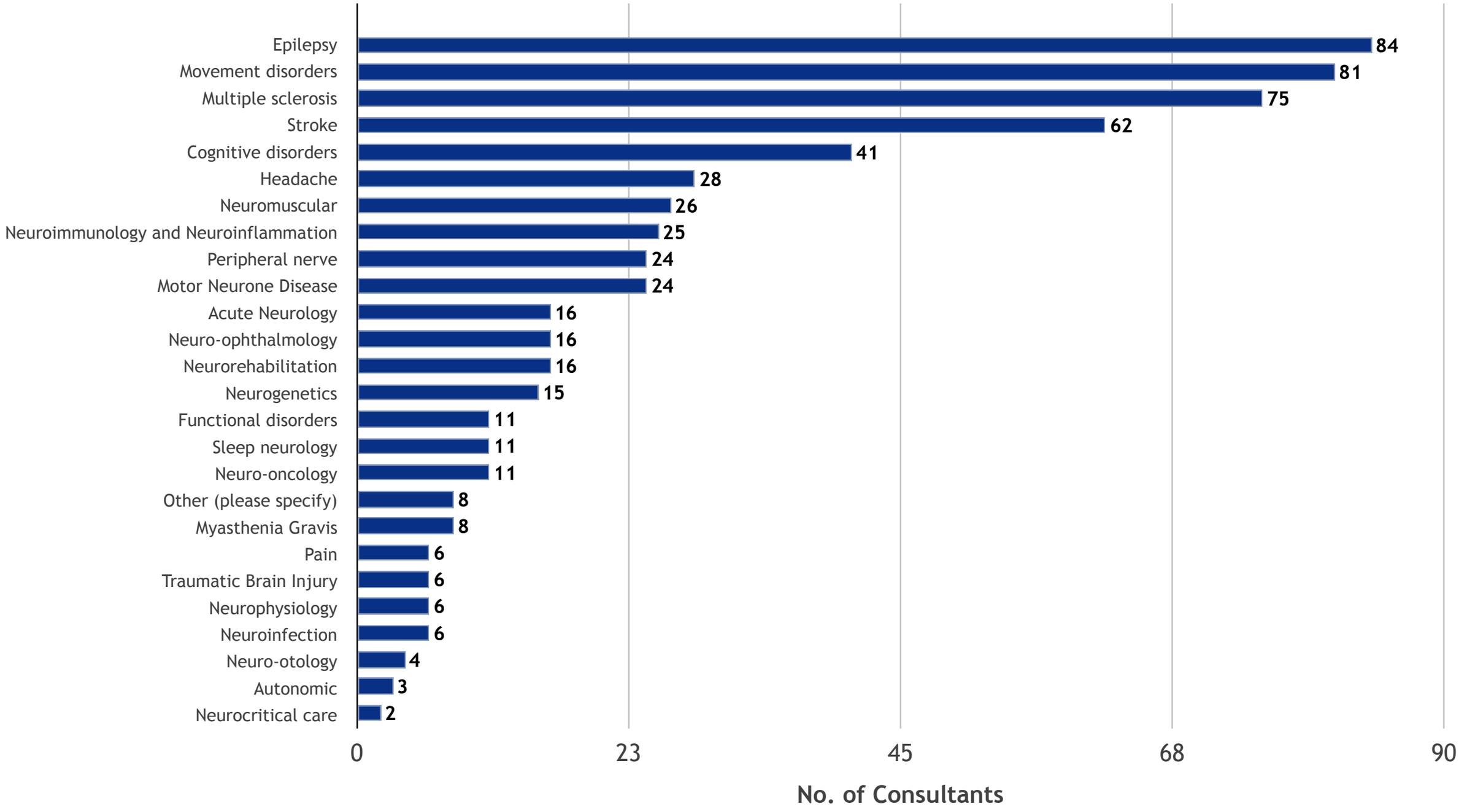
670 respondents of which 500 active consultants

- 2017/18 RCP census* estimates 920 consultant neurologists in UK
- 500 represents a 54% response rate
- Extrapolating on that basis = 657 Clinical FTE

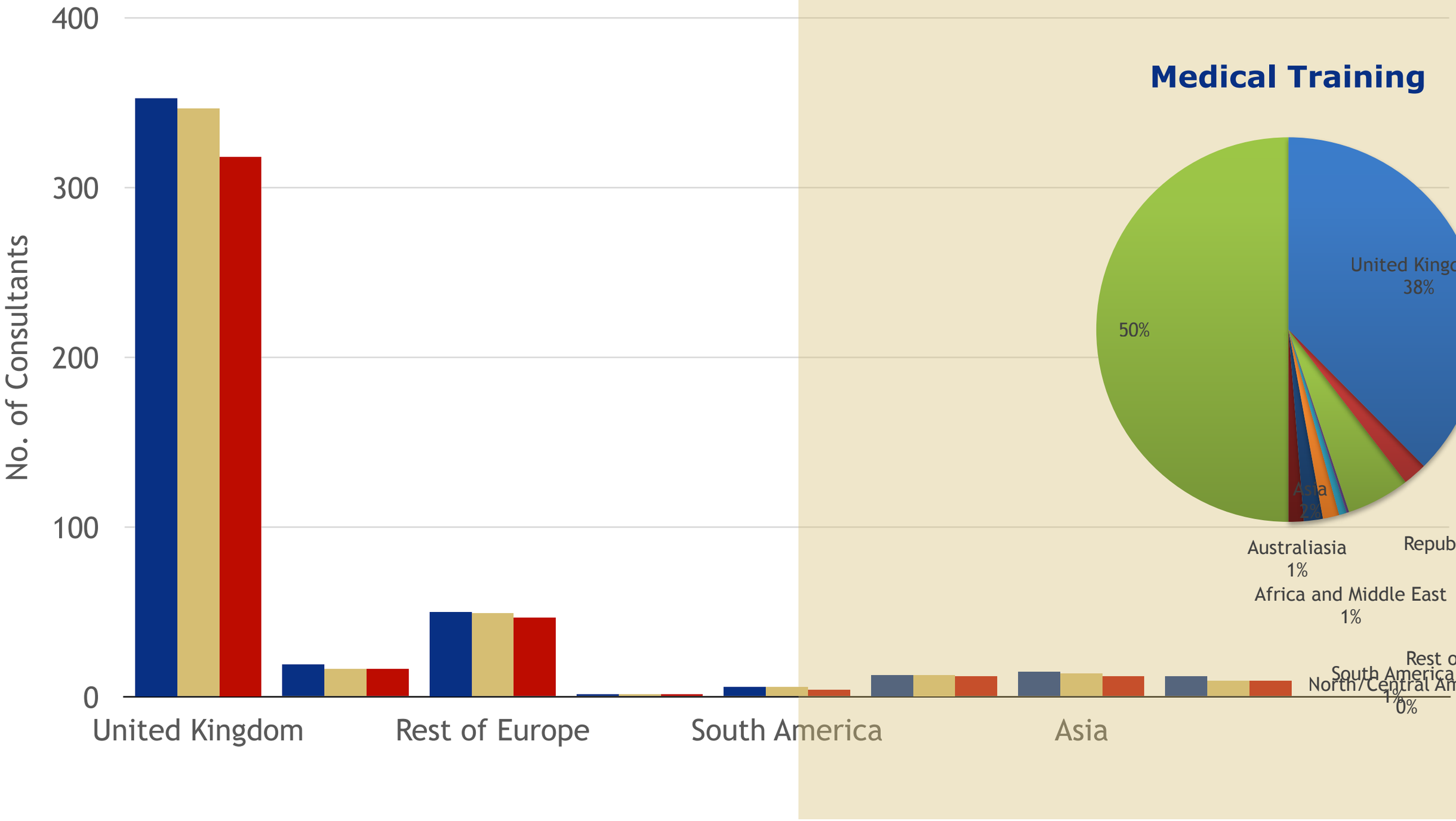
Contract / FTE	Clinical	University	Other
NHS (UK)	605	16	41
University	52	86	4
Total	**657**	**101**	**45**

* The census was conducted by the Royal College of Physicians' (RCP's) Medical Workforce Unit (MWU) on behalf of the Royal College of Physicians of London, the Royal College of Physicians of Edinburgh and the Royal College of Physicians and Surgeons of Glasgow.

Sub-Specialty Interests



Where Neurologists Trained



The Neurologist's Perspective

- Primary neurological conditions with associated mental health manifestations
  - may predate neurological presentation
  - may have dominant effect upon QoL
- Primary mental health disorders with secondary neurological manifestations
  - how many people affected see a neurologist?
- Primary mental health disorders masquerading as neurological conditions

Addressing Gaps

- Improved transition from paediatric to adult care
- Addressing service areas of unmet need (*e.g.* neurodevelopmental disorders)
- Greater exposure to (neuro)psychiatry in neurological training
  - integral part of knowledge of neurological conditions (*e.g.* epilepsy, Parkinson's)
  - more "formal" training in psychiatry

Training: Further Considerations

- In the Neurology section of the Internal Medicine curriculum
  - presentations of relevance include: abnormal behaviour, acute confusion, memory loss & intellectual decline
  - conditions include: dementia, cognitive disorders, delirium & functional illness

- It seems very likely that the final version of the Neurology curriculum will have one (of a total of 8) Capability in Practice that at least includes Neuropsychiatry

- With attention on credentialing & new curricula we should not overlook local opportunities:
  - *e.g.* joint meetings, trainee exchanges, joint training days for SpRs *etc*.

"The Exam Questions"

- What are the main priorities for ensuring the NHS workforce is equipped to meet the needs of people with neurological conditions & co-morbid mental health needs?
- How best should the NHS go about achieving this in the next 10 years?

- Identifying service gaps, training, multi-level integration, networks, research
- Flexibility, funding & a strategic rather than a tactical approach

Professor Eileen Joyce - Royal College of Psychiatrists

Integrated care: The role of neuropsychiatry

Psychiatrists who assess and treat:

- The manifestation of neurological disorders as a mental illness
- The manifestation of a mental illness as a neurological disorder

BUT

- Neuropsychiatry is not a recognised GMC sub-speciality
- There is no training pathway
- Neuropsychiatrists are essentially self-defined

Are we different from a liaison psychiatry?

- Consultation/liaison
- Own referrals and caseloads
- Outpatient clinics and dedicated inpatient beds (some centres)

Ways forward to improve the provision of neuropsychiatry services

1. Increasing service provision to provide the bedrock for training – Mike Dilley
2. Develop a training pathway e.g. credentialing
3. Workforce : Improve trainee recruitment and retention in psychiatry
   Embed neuroscience teaching in the core curriculum to make it more attractive to trainees

Training by Credentialing

GMC regulated 1 year certification pre or post CCT

Two main aims:
To improve patient safety
Address service demands in discrete areas of practice

Approval based on 9 areas:
- Complexity of clinical procedures or context
- Service gaps: more expertise will improve patient outcomes
- Service delivery: e.g multiple sites or hub and spoke
- Breadth of practice: skills over and above standard training
- Outside the NHS with weaker clinical management
- Level of expertise
- Number of future doctors needed
- Number of future patients needing care

Intended commissioned credentials:
- Cosmetic surgery
- Liaison psychiatry
- Mechanical thrombectomy
- Rural and remote health
- Pain medicine

Training by Credentialing

College strategy

Work with the Association of British Neurologists (ABN) and British Neuropsychiatry Association (BNPA)
to develop a training pathway ultimately suitable for a credential

Working groups established: within the Faculty of Neuropsychiatry and between ABN and BNPA

A syllabus of the knowledge required by a neuropsychiatrist has been developed and approved by all 3

The next step is to incorporate this into a full curriculum

GMC have asked all medical disciplines to develop new curricula

Higher training in general psychiatry has just been approved by the COG

We will use this as a template for a neuropsychiatry application

The Workforce

NHS England Regions

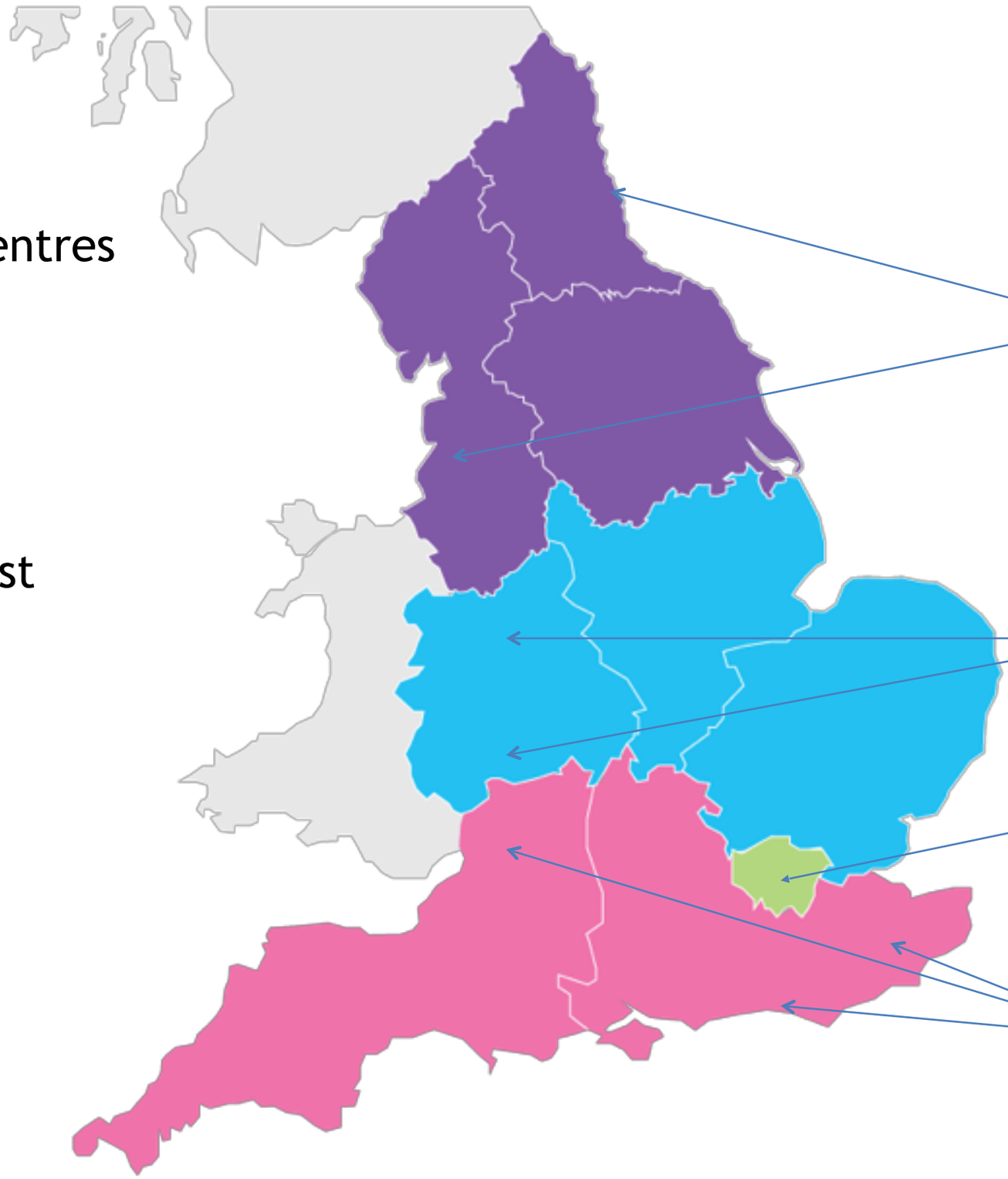
Neuroscience Centres

North
7

Midlands and East
7

London
7

South
4



Neuropsychiatry Services: Consultants

North
10.65 (9.4) wte

Midlands and East
7.5 wte

London
15.8 (11.4) wte

South
4.7 wte

Belfast
1.0 wte

Cardiff
1.3 wte (1.0 brain injury)

Edinburgh 2.0 wte
Glasgow 0.5 wte

NHS Region	Neuroscience Centres	Neuropsychiatry Service	Consultants	Trainees
North	*7*	*Lancashire/Mersey* *Salford* *Liverpool (Walton)* *Newcastle*	*2.8* *2.8* *1.0* *4.0*	*1.0 HT* *0.5 HT* *0* *1.0 HT +1.0 CT*
Midlands and East	*7*	*Birmingham* *N Staffs*	*5.5* *2.0*	*1.0 HT* *1.0 HT*
South	*4*	*N Bristol* *Kent and Medway* *Brighton and Hove* *Oxford*	*2.0* *1.8* *0.4* *0.5*	*1.0 HT* *2.0 HT* *0* *0*
London	*7*	*SLAM* *UCLH* *St Georges/SWL* *The London*	*6.5* *3.8* *5.0* *0.5*	*2.0 HT 2.0 CT* *1.0 HT 1.0 CT* *1.0 HT 0.8 CT*
Scotland		*Edinburgh* *Glasgow*	*2.0* *0.5*	*1.0 HT*
Wales		*Cardiff*	*1.3*	*0*
N. Ireland		*Belfast*	*1.0*	*1.0 HT*

Improving recruitment into psychiatry

The Gatsby/Wellcome Neuroscience Board

Initially 2 years, renewed for further 3 years

Initiative to introduce a modern neuroscience perspective into psychiatrists' clinical work

Funded by The Gatsby Foundation and The Wellcome Trust

Led by Wendy Burn (College President) and Gareth Cuttle

Improving recruitment into psychiatry

‘Choose Psychiatry’

Core training fill rates:

2018: 71%
2019: 86.13% (100% child and adolescent from 83%)

Higher trainee fill rates:

2019: 52% no change

The Gatsby/ Wellcome Neurosciences Project

The psychiatrist of the future ‘will need to know about cortical dynamics, neural networks, and genomic variation. Those entering psychiatry today will need to know how to think about the brain and how to critique brain science.’ Insel 2015

- Trainees will be better prepared for the advances that will be made during their working lives
- Full review of Core Curriculum and MRCPsych syllabus
- Agree the content of the revised, combined Core Curriculum and MRCPsych examination syllabus with particular regard to ensuring that modern neuroscience is included.
- Ensure that all scientific content of the new curriculum reflects the most recent knowledge and that there are systems in place to guarantee that this is updated on a regular basis in the future

Also:

- Annual neuroscience meetings
- Neuroscience ‘bootcamps’ across the country
- Trainees appointed as ‘Neuroscience Champions’ in each region

Commission more services

- Specifications for specialist neuropsychiatry services submitted by College Faculty
- Approved by Clinical Neurosciences Advisory Committee
- Recommends that there is a neuropsychiatry service in every Academic Neuroscience Centre
- NHSE funds multidisciplinary specialised inpatient services
- CCG's and NHSE collaboratively commission specialised outpatient services (essentially epilepsy surgery/DBS and Tourette's)
- CCG's fund outpatient specialist neuropsychiatry services.

- Being considered by ‘Programme of Care Board’
- Requested more evidence about existing neuropsychiatry and neuropsychology provision in England

Limiting the mental health impact:
Co-ordinated care in the community

Dr Neil Bindemann
Executive Director

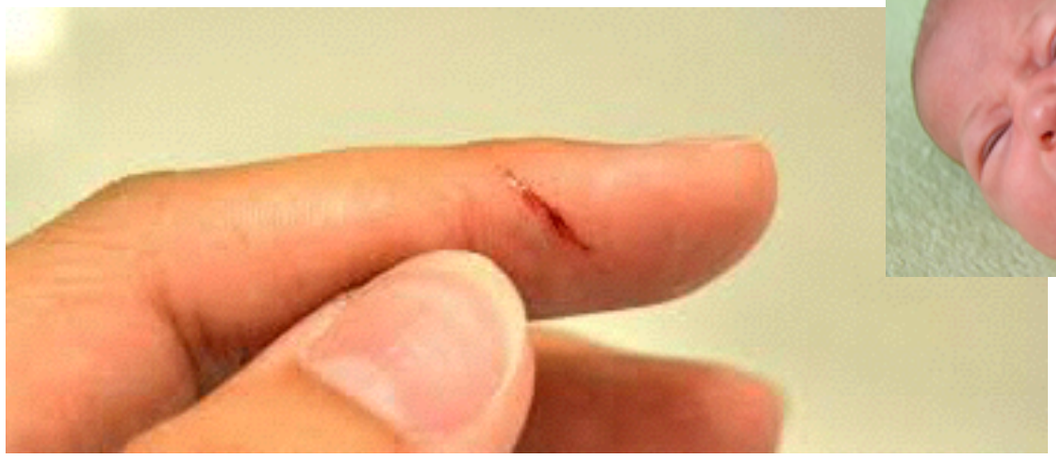
Recognising the need

TRAUMA

A **deeply** distressing or disturbing experience

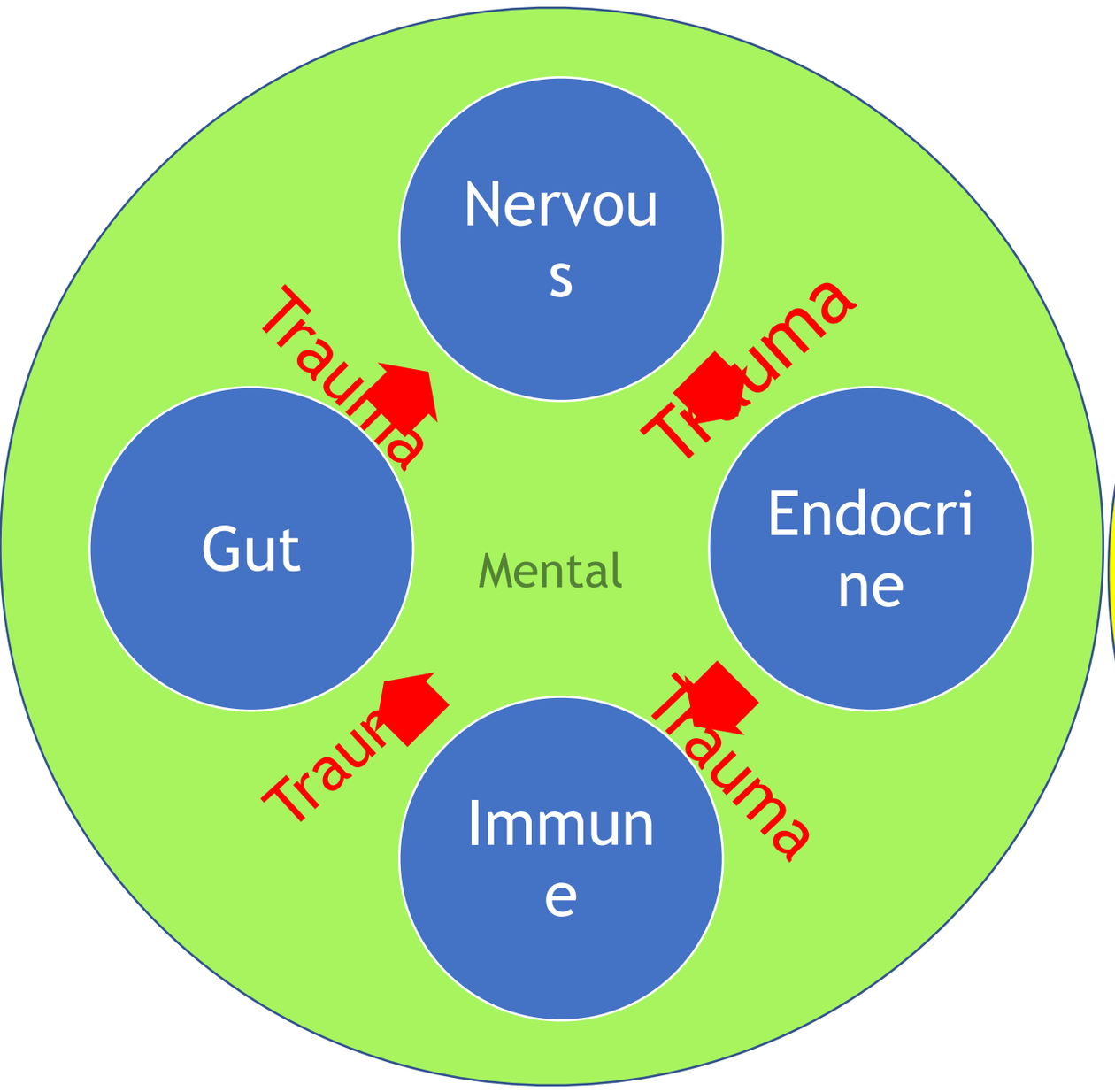
TRAUMA

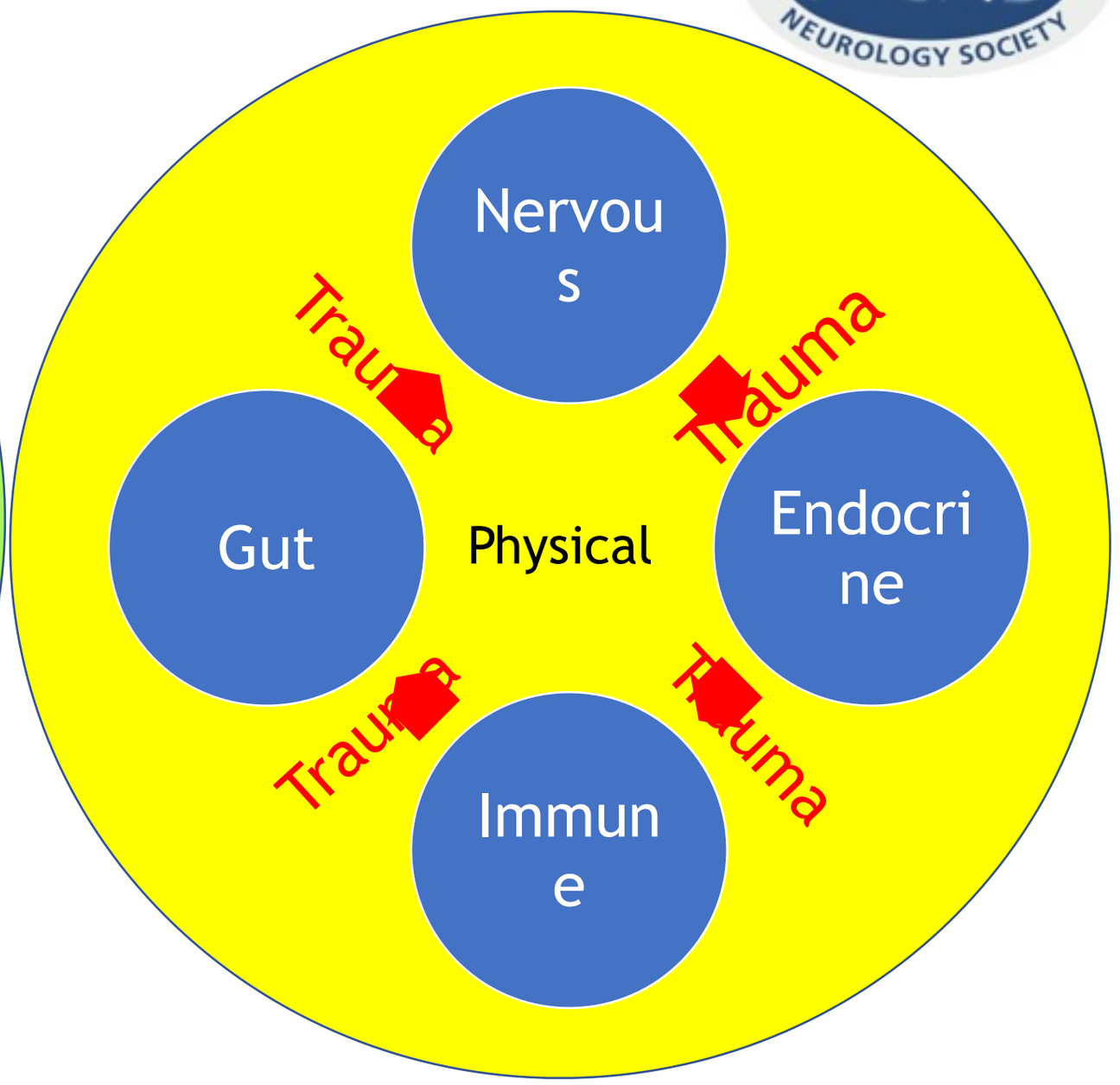
Physical injury



Post TRAUMATIC stress disorder

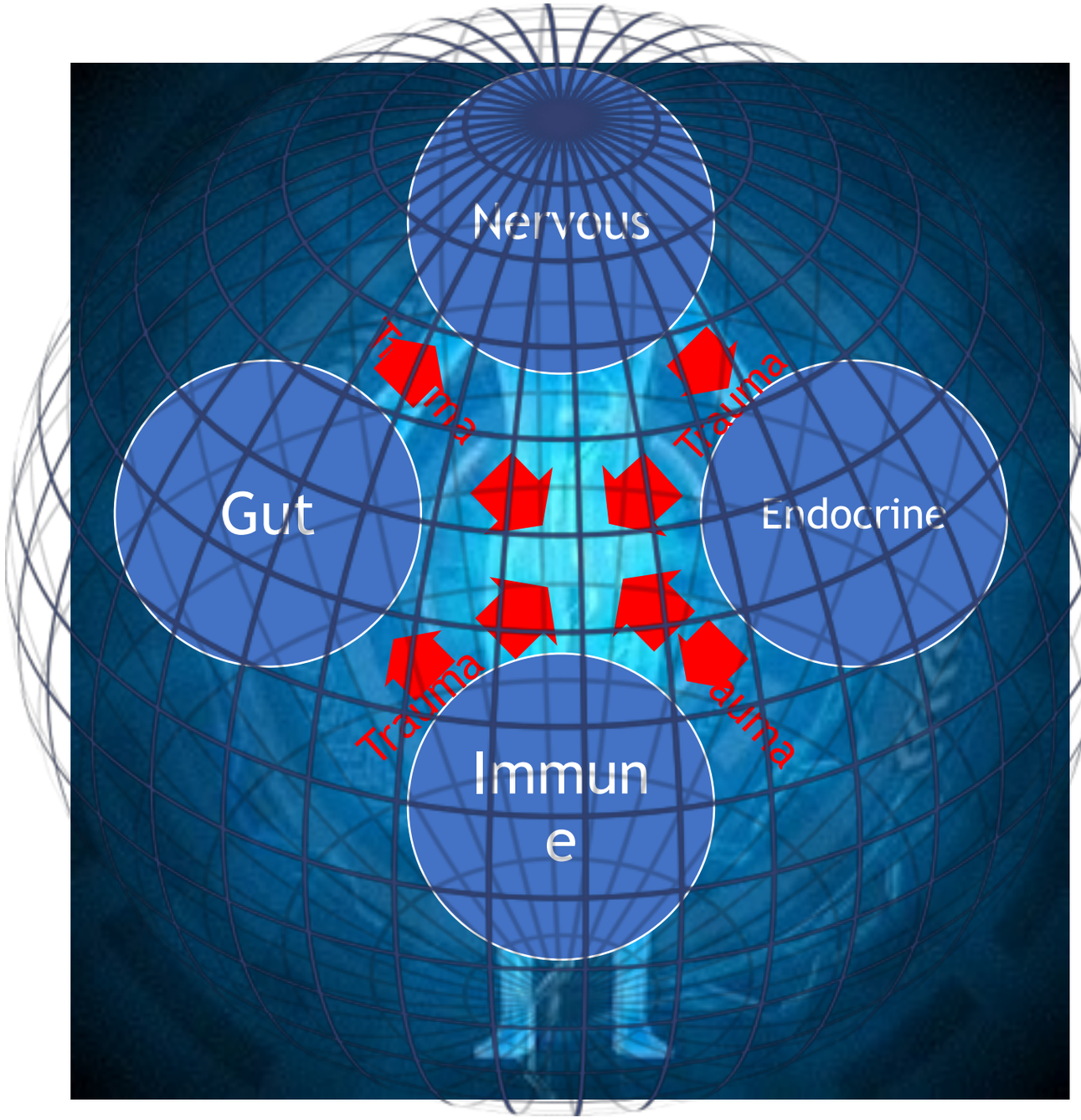
A condition or persistent mental and emotional stress occurring as a result of **injury** or **severe** psychological shock,


Nervous
Trauma
Trauma
Gut
Mental
Endocrine
Trauma
Trauma
Immune


Nervous
Trauma
Trauma
Gut
Physical
Endocrine
Trauma
Trauma
Immune

BODY-MIND IS ONE

Receiving the diagnosis


Nervous
Gut
Endocrine
Immun
e
Trauma
Trauma
Trauma
Trauma

Service issues

Service issues

- Preparation for hospital discharge – expectations
- Communication between hospital discharge team and the primary care team
- Agreement on who is responsible for the ongoing mental health support for the patient and family members
- Contact with patient and family within a agreed time frame once back home
- Information to patient and family on how to access mental health support
- Link to existing community mental health services

NHS Service

or

NHS System

Oxford University Hospitals NHS Trust

Psychological Medicine (Liaison Psychiatry) in Secondary Care for Neuroscience Patients

Dr David Okai MD(Res) MRCPsych DipCBT
Consultant Neuropsychiatrist

Overview

- “What are the main priorities for ensuring that the NHS workforce is equipped to meet the needs of people with neurological conditions and co-morbid mental health needs”.
- How best should the NHS go about achieving this in the next 10 years?”

Brief overview of Oxford Psychological Medicine Se

Oxford University Hospitals NHS Trust

- Oxford University NHS Foundation Trust
- 16 Consultant Psychiatrists, 3 trainees and > 30 Clinical Psychologists.
- (Unusual) employment by Acute Trust
- Highly regarded by physicians and surgeons, winning the Trust's 'Gold Team of the Year award' (2014), RCPsych Psychiatric Team of the Year (2018).
- Celebrated as a beacon of integrated patient-centred care by the CQC, King's Fund, and NHS England.

Psychological Medicine in Neuroscience

Oxford University Hospitals NHS Trust

Psychiatry

- 0.5 WTE (due to increase to 1WTE)
  - Employed by the Acute Trust (not SLA agreement with MH services)
  - 1 OPC/week (specialist funding)
  - 1 joint OPC clinic/month (Neuroimmunology)
  - 4 specialist MDTs per month (PD, Epilepsy Surgery, Cognitive Disorders, Neuroimmunology)

Psychology

- 4 psychologists

  Specialist clinics:

  1. Functional Neurosurgery (Movement Disorders and Pain)
  2. Epilepsy Surgery
  3. Neuro-oncology Awake
  4. Cognitive Disorders Clinic

Psychological Medicine in Neuroscience

Oxford University Hospitals NHS Trust

We are part of a service that helps neuroscience clinicians understand, and manage the complexity of their patients.

This requires a good understanding of the individual from the biological; psychological; and social perspective.

Without this there may be problems with LoS, readmission, and abnormal illness perception.

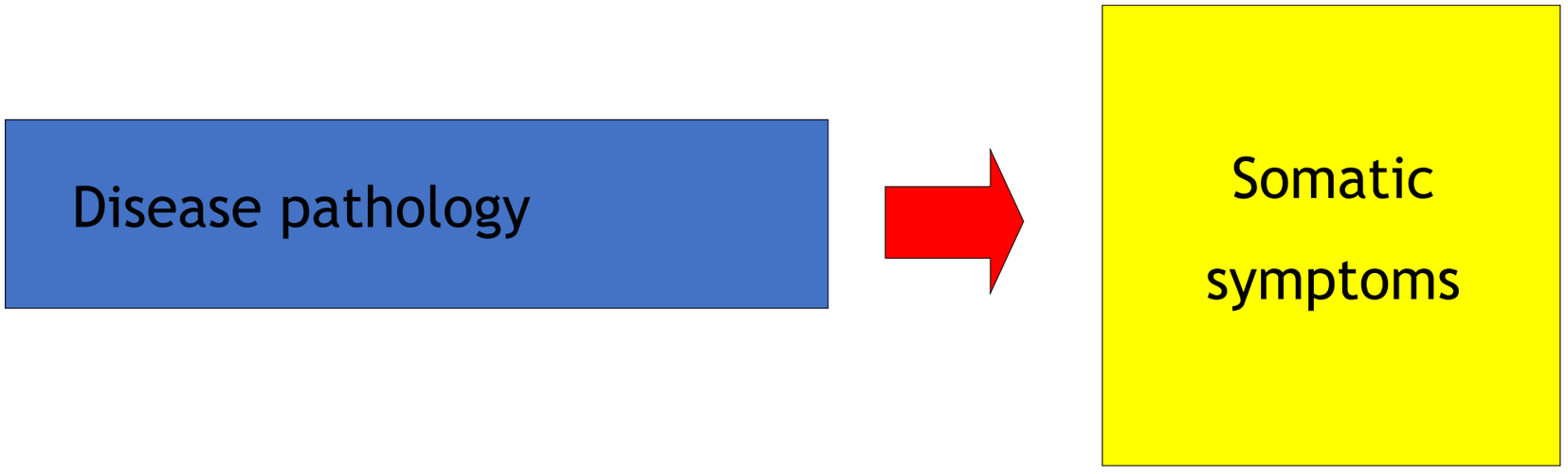
The benefit to patients through quality improvement is central

Oxford University Hospitals NHS Trust

Patient			
Sustainable Services	Innovative Treatment & Care Pathways	Better Outcomes	Improved Effectiveness & Efficiency

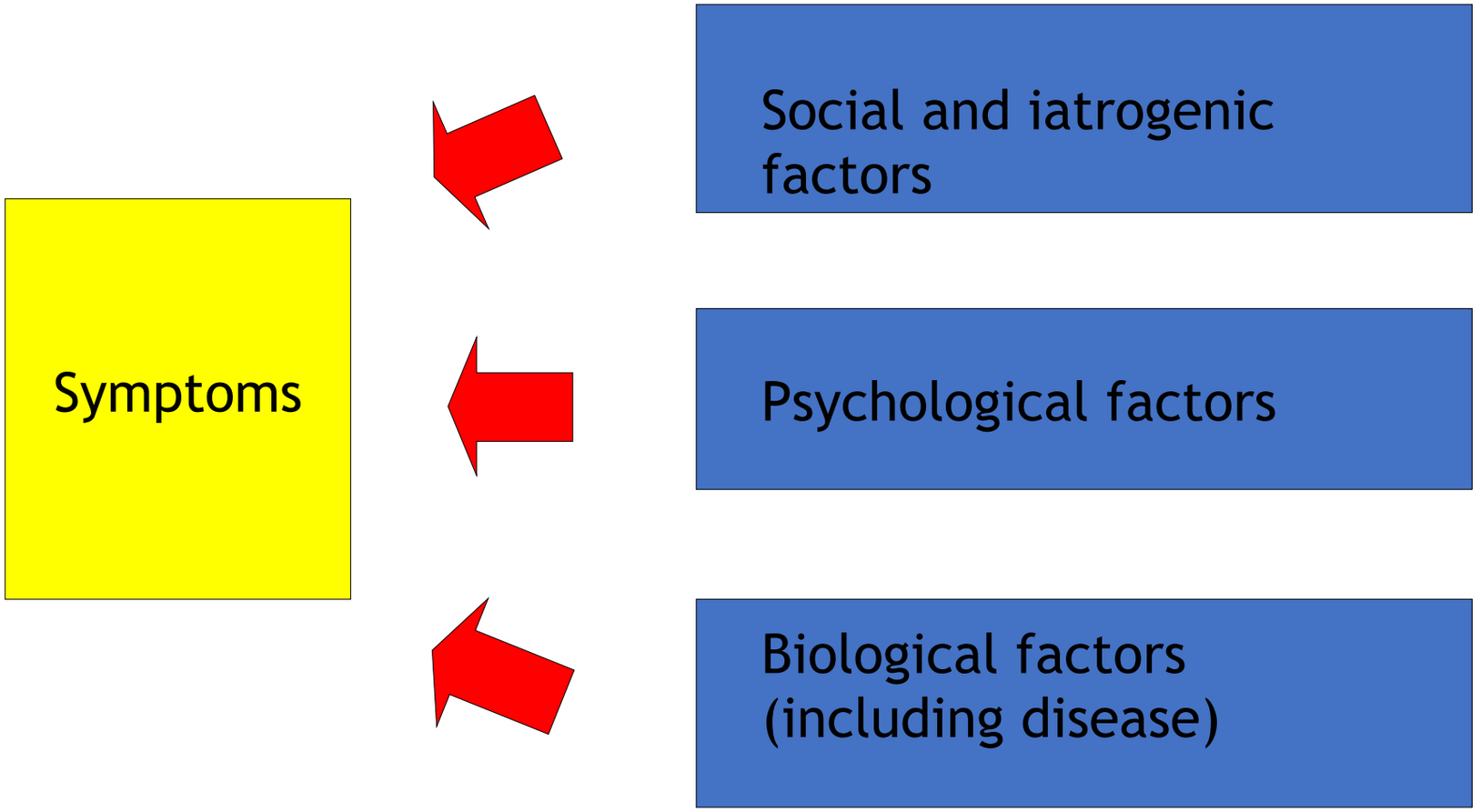
Pathological perspective

Oxford University Hospitals NHS Trust



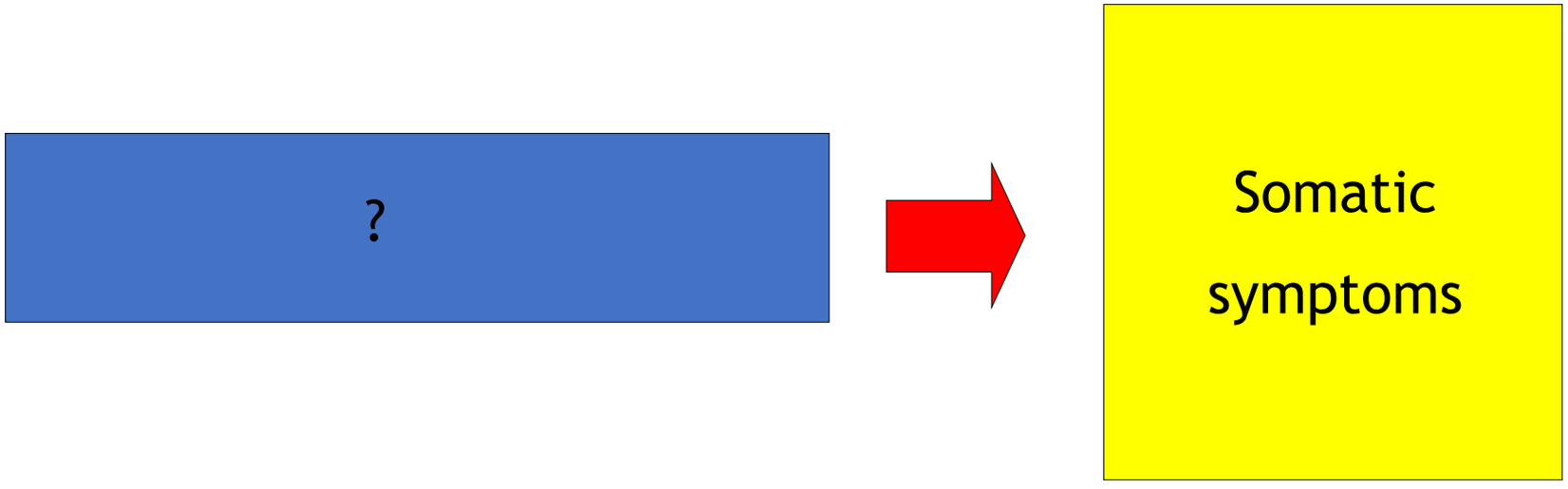
Symptom perspective

Oxford University Hospitals NHS Trust



Symptoms without disease: medically unexplained symptoms (MUS)

Oxford University Hospitals NHS Trust



Social and iatrogenic facto

Oxford University Hospitals NHS Trust

- Commonly held beliefs – ‘all headaches are dangerous’
- Behaviour of other people – ‘you must rest you are ill’
- What doctors do and say – order more tests (psychological iatrogenesis)

Psychological factors

- Personal fears – ‘my brother had a brain tumour – I will ’
- Depression and anxiety (panic) – cause physical symptoms
- Focussing of attention – magnification of symptoms

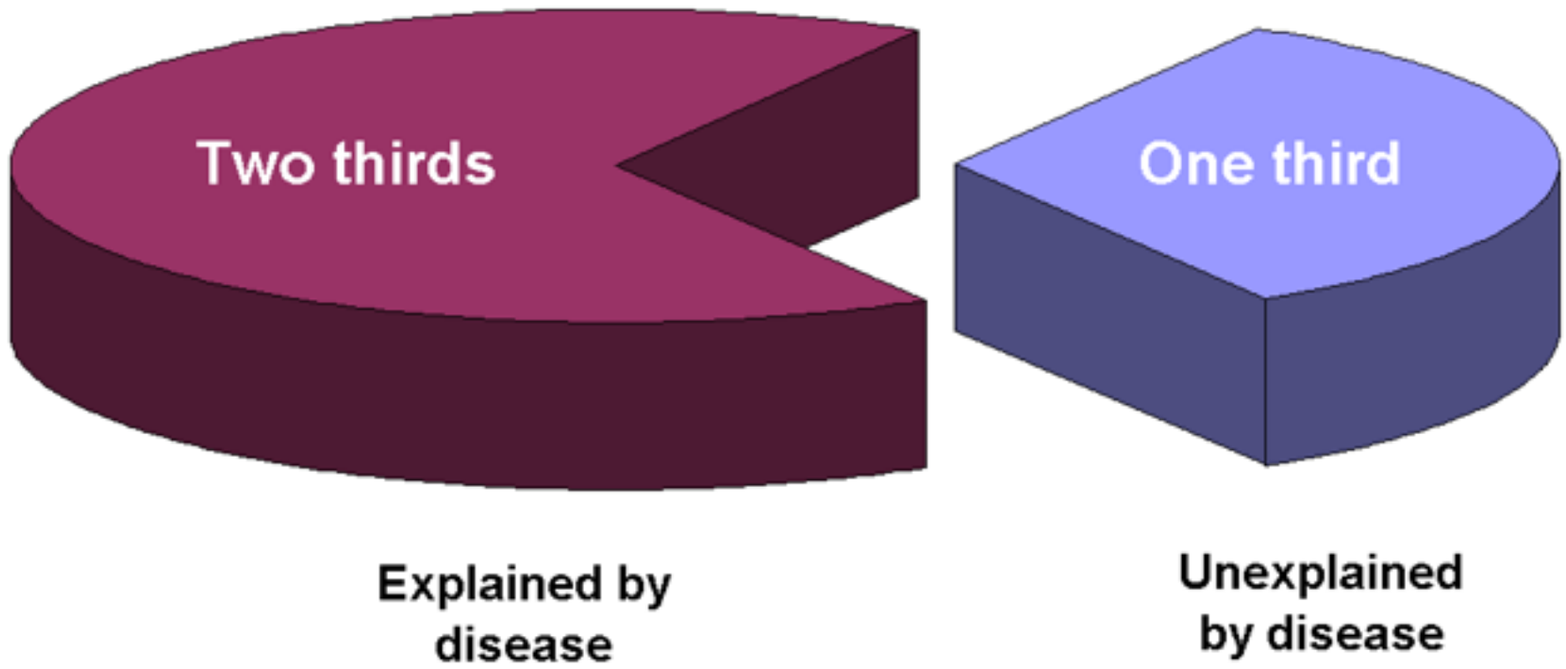
Oxford University Hospitals NHS Trust

‘The good physician treats the disease; the great physician treats the patient who has the disease’

[Sir William Osler 1849-1919]

How common are MUS in secondary care

Oxford University Hospitals NHS Trust



How common are MUS in neurology?

‘To what extent can this patient’s symptoms be explained by organic disease?’

Not at all Somewhat Largely Completely

Oxford University Hospitals NHS Trust

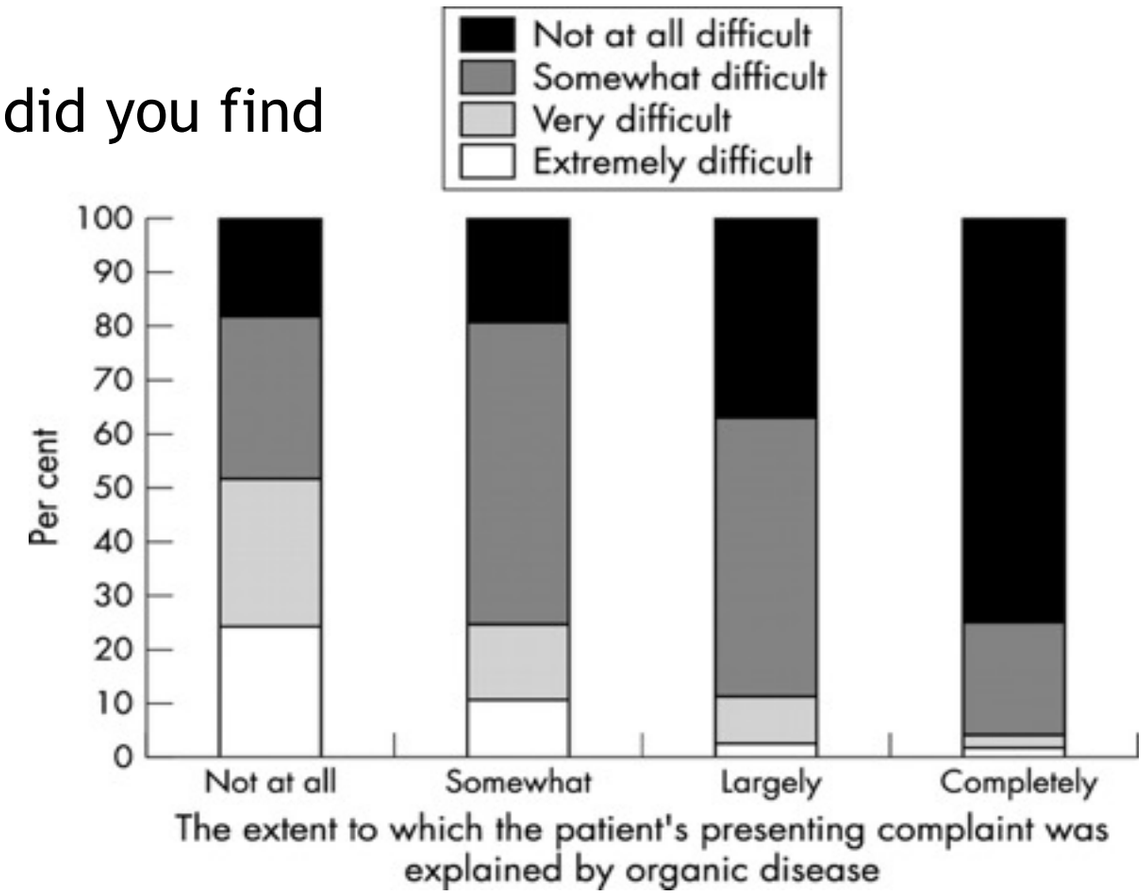
‘To what extent can this patient’s symptoms be explained by organic disease?’

Not at all	Somewhat	Largely	Completely
12%	18%	25%	45%

Do experienced doctors find them easy to manage?

Oxford University Hospitals NHS Trust

How difficult to help did you find this patient?



[Carson et al JNNP 2004]

OUH FND pathway

Oxford University Hospitals NHS Trust

Neuropsychiatry: Assessment and Management
- Neurology:
- Out-/In-patient referral
- Psychology: OUH
- Physiotherapy: Level 1 Neurorehab unit (OCE)

Tertiary referral

Psychology: Mindfulness

- 3 courses per year initially, now 6 courses per year with 2 Psychologists
- c. 15 patients per course complete
- c. 90 patients per year complete
- c. 290 assessment clinic slots per year
- 2/3 of referrals attend, 2/3 complete
- No demographic or diagnostic predictors of completion

Mindfulness: Detert & Douglass (2014)

Group	N	Measure	Pre MT Mean (SD)	Post MT Mean (SD)	Partial Eta Squared	Cohen's d
Functional	16	GSI	1.46 (0.81)	1.26 (0.92)*	0.286	0.2
	16	PSS	2.28 (0.75)	1.30 (0.64)***	0.658	1.41
Neurological non-progressive	30	GSI	1.18 (0.71)	0.77 (0.62)***	0.425	0.62
	30	PSS	2.31 (0.66)	1.15 (0.55)***	0.847	1.91
Neurological progressive	46	GSI	1.37 (0.63)	0.73 (0.49)***	0.681	1.13
	46	PSS	2.38 (0.46)	1.06 (0.43)***	0.889	2.96

Note GSI: Brief Symptom Inventory General Severity Index, PSS: Perceived Stress Scale
** p<0.05*
****p<0.001*

Parkinson's Neuropsychiatry

Oxford University Hospitals NHS Trust

- Specialist commissioning
- OPC/inpatient work in <65 age group
- MDT
- Beacon of excellence (PD UK)
- Neurology, Neuropsychiatry, Neurosurgery, Parkinson's Nurse Specialists, and community psychiatry input.
- Recent invitation to written and oral evidence on this service at All-Party Parliamentary Enquiry as a gold standard of collaborative care to overcome barriers in health care provision.
- Access to GP notes, medications allowing for immediate comprehensive management.

PD Commissioning

- “The board therefore identified a need to increase PD specialist consultants from 1.5 WTE to 3 WTE.”
- It is possible that this increase in WTE would fund itself in opportunity cost savings:
  - Nationally published data demonstrates that an integrated psychological medicine service reduces length of stay from between 2-5 days (Parsonage et al., 2012).
  - An estimated cost of an excess bed day is £346 (Department of Health, 2018).
  - If 30% of the 580 NELs had neuropsychiatric input sufficient to reduce length of stay by 2 days, this would generate sufficient **opportunity cost savings of £120,400** – sufficient to pay for 1.0 WTE neuropsychiatrist plus some in reserve to go towards other consultant PD specialist increase. (Note, however, as this is a reduction in length of stay, it is an opportunity cost saving, rather than reduction in hospital cost).

Neuropsychiatry in Neuroimmun

Oxford University Hospitals NHS Trust

- Local/National patients
- NDCN run a National diagnostic service for autoantibodies
- Outpatient clinic (joint psychiatry/neurology)
- Inpatient work (protracted stays):
- Rare high burden patients (NMDA, LGI-1, CASPR-2 encephalitidies).
- E.g. average stay for NMDA
  - 4-5 months
  - Low numbers (2-3 per year)
  - Significant proportion in ITU
  - 100% full recover over last 5 years
  - OUH also offers

Overview

- “What are the main priorities for ensuring that the NHS workforce is equipped to meet the needs of people with neurological conditions and co-morbid mental health needs”.
- How best should the NHS go about achieving this in the next 10 years?”

Oxford University Hospitals NHS Trust

What would ‘good’ look like in terms of meeting the emotional, cognitive and mental needs of …… patients

- *Types of treatment, therapies and/or intervention.*
- *Who provides this care?*
- *Who else needs to be involved?*
- *Where “good” care is accessed e.g. online/group setting/hospital based*
- *Factors that are unique to this patient group*

What (if any) are the biggest challenges to achieving (1) and how could they be overcome?

Oxford University Hospitals NHS Trust

- *Access to treatments*
- *Workforce considerations*
- *Health professional training and education*
- *Guidelines*
- *Aids and adaptations*
- *Digital technology*
- *Commissioning arrangements*

Transforming Children and Young People's Mental Health

Professor Prathiba Chitsabesan

Associate National Clinical Director

Children and Young People's Mental Health

NHS England

26th June 2019

NHS England and NHS Improvement

“It is easier to build strong children than to repair broken men.”

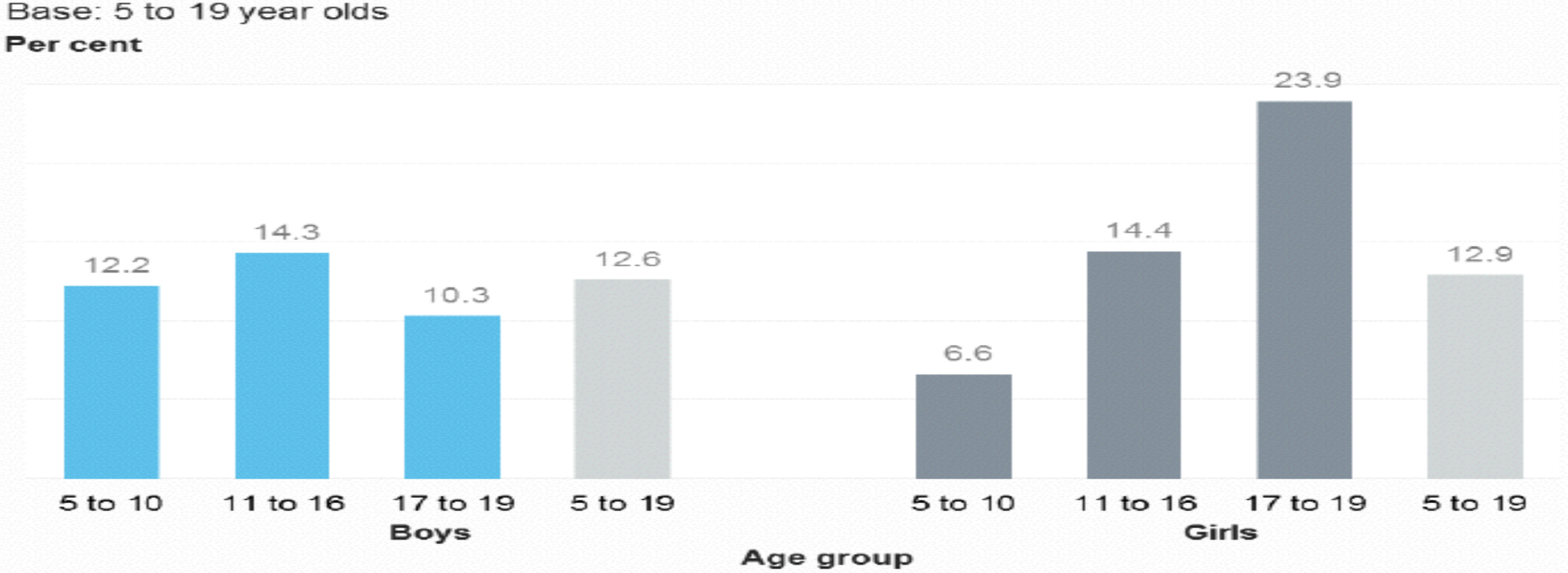
- Frederick Douglass, 1818 - 1895

NHS Digital 2018 Prevalence Survey

- One in eight (12.8%) of 5 to 19 year olds had at least one mental disorder when assessed in 2017.
- Emotional disorders were the most prevalent type of disorder experienced by 5 to 19 year olds in 2017 (8.1%).
- Rates of mental disorders increased with age. 5.5% of 2 to 4 year old children experienced a mental disorder, compared to 16.9% of 17 to 19 year olds.

Figure 2: Any disorder by age and sex, 2017

Base: 5 to 19 year olds



Epilepsy and Mental Health

CYP with a central nervous system disorder like epilepsy can have six times the risk of having symptoms of depression and anxiety compared with adolescents in the general population and CYP with complex epilepsy have increased rates of autism and hyperactivity disorders compared with their peers.

The reason for the greater prevalence of mental health in those affected by physical health can be due to:

- Adjusting to a diagnosis
- Living with symptoms
- Dealing with treatments and side effects
- Managing life threatening conditions
- Disrupted educational and social development

Some mental health issues relating specifically to long term conditions in children include:

- Depression or anxiety
- Anxiety about treatments
- Issues around school attendance and education
- Stigma and bullying around their condition
- Parent or sibling affects as a result of their condition
- Lack of independence

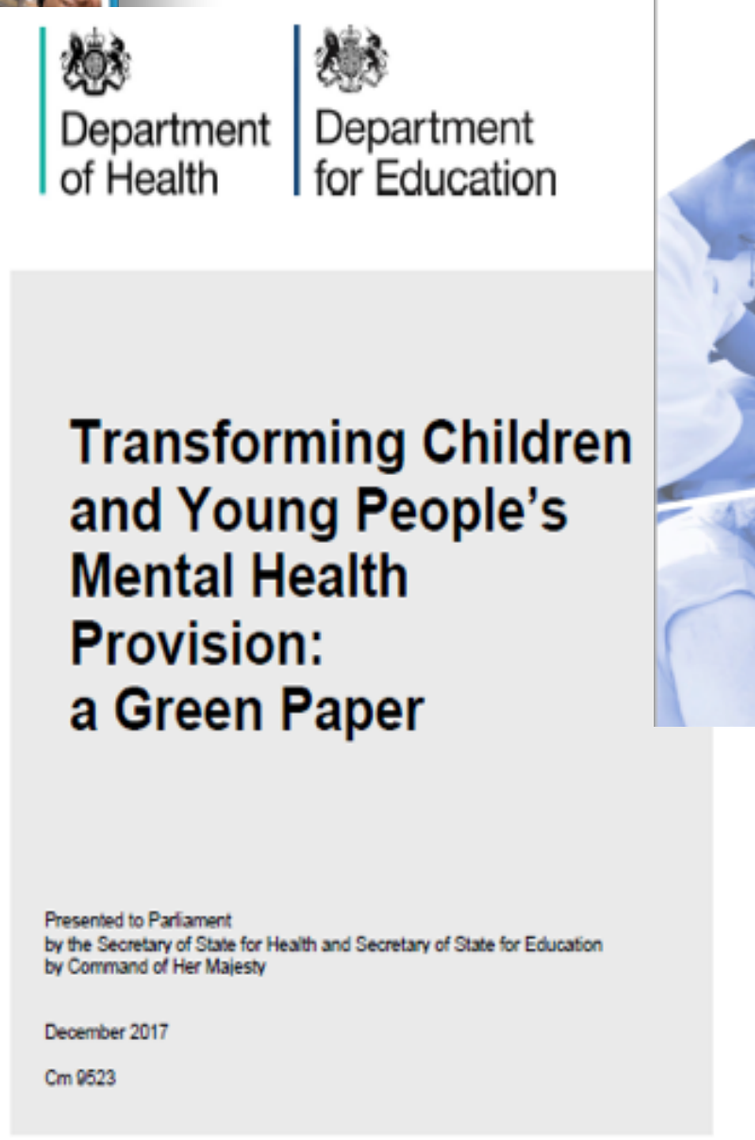
These can impair the social, educational and personal development of the child.

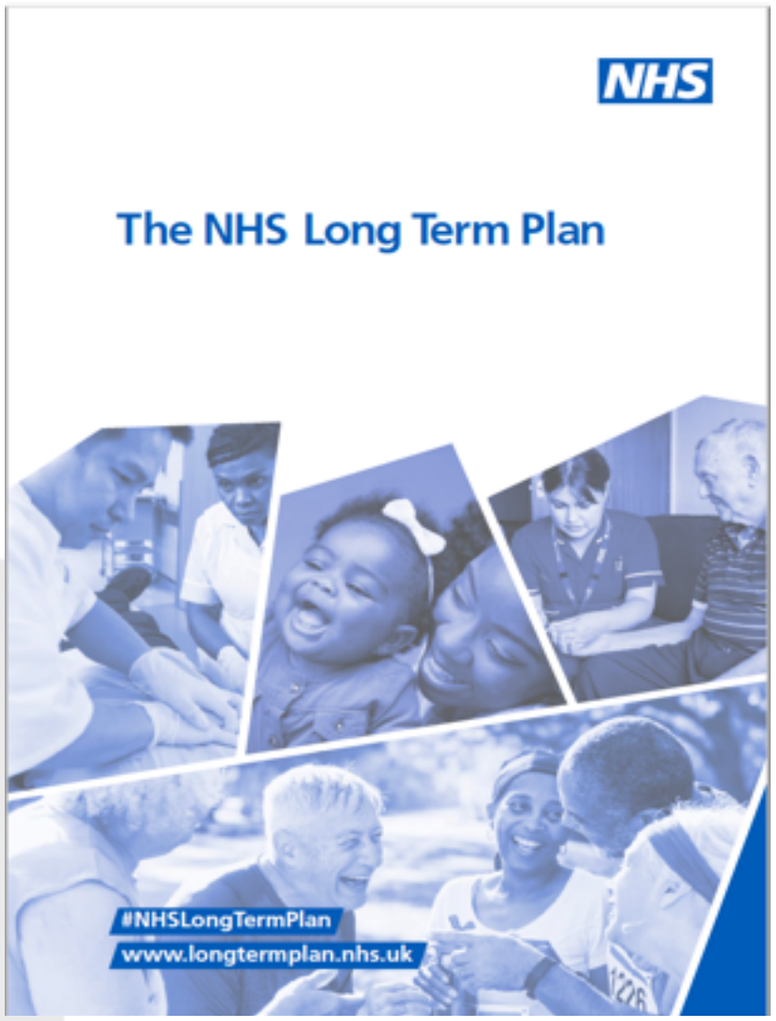
(8) *Better everyday healthcare for children and young people in Lambeth and Southwark (2014)*

(27) British Psychological Society. *Children and young people with physical health needs, how psychological services contribute to the care pathway*

(34) Department of Health (2015) *Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*

Policy Context





CYPMH Transformation – whole system responsibility

NHS England and NHS Improvement

- Planning assurance Direct commissioning
- NHS Provider oversight

Department of Health & Social Care

- Whole health system stewardship

Department for Education

- Schools, parenting, Ofsted

Public Health England

- Prevention, health visitors School nurses JSNA

NHS Health Education England

- Workforce

Home Office

- Policing CSA/E

Ministry of Justice

- Health and Justice

Care Quality Commission

- Quality

NHS Digital

- Data

Communities and Local Government

- Troubled Families, social care, housing and built environment

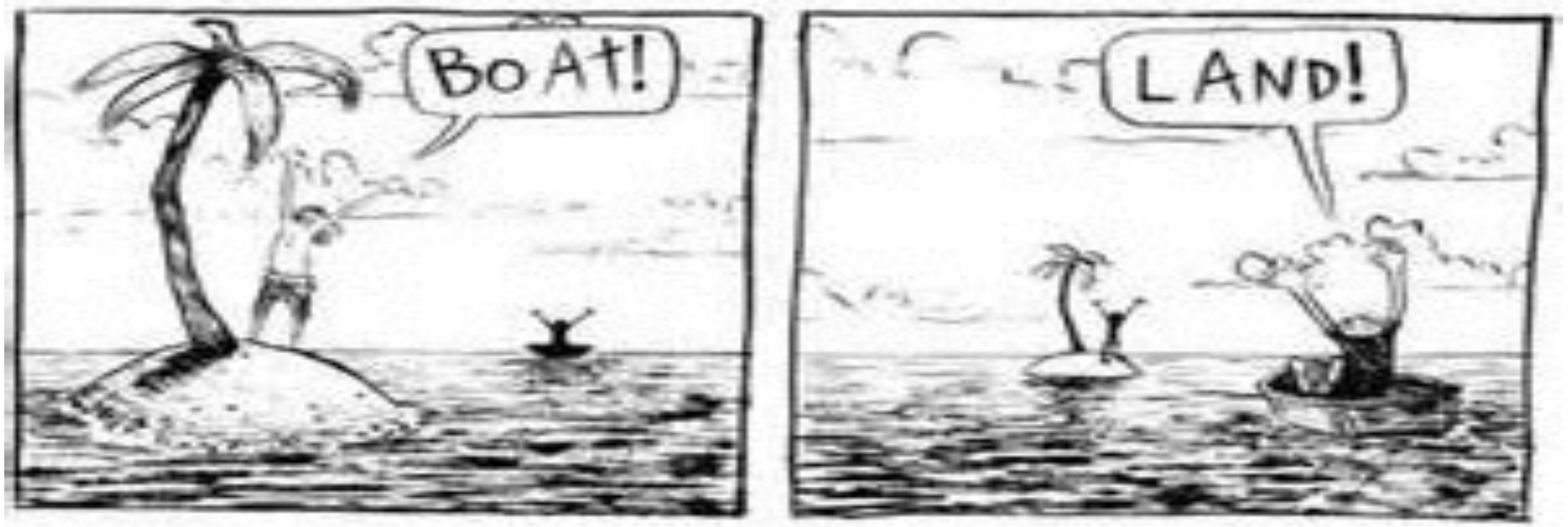
DWP Department for Work and Pensions

- Work, health and parenting

Local Authorities

- Children's Social Care

Challenges: different perspectives across services



Learning from the i-THRIVE Community of Practice

10 **national accelerator sites in October 2015**

74 **CCG areas by July 2018**

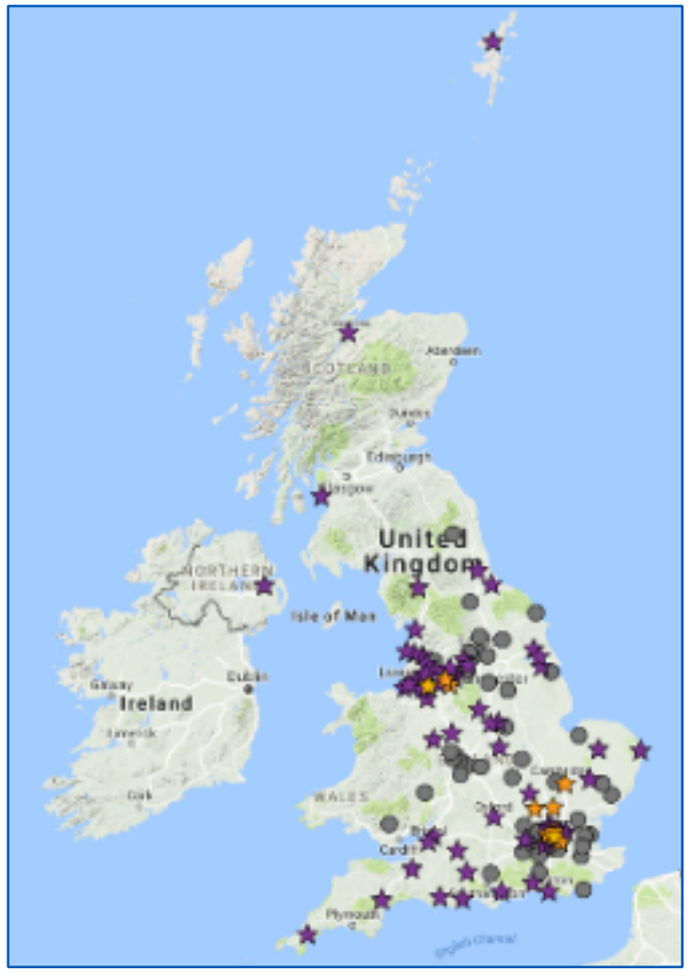
318 individuals in the Community of Practice

20% health commissioner
53% health provider
10% local authority
6% voluntary sector
4% education
7% other

8 **shared learning events held**

attended by over 340

48% **of children and young people within England**



Camden i-THRIVE: Demonstrating the model in practice

Single Point of Access:
All referrals to Camden CAMHS (Open Minded) go through the Joint Intake referral service.

Schools in-reach:
In Camden, CAMHS clinicians are in 100% of secondary schools and 24% of primary schools.

Shared decision making:
Determining needs grouping, modality and interventions. Adapting Option Grids and CollaboRATE for CYP population.

Short evidence-based interventions

Digital enablement:
Digital signposting called WhatsUp supporting schools in-reach.

Shared decision making:
Adapting Option Grids* and CollaboRATE™ for CYP population and adding to digital tools to support SDM e.g. “Include Me”.

Goals Based Approach
CYP and Families set goals with clinicians with regular review.

Shared decision making
- Utilising the complementary SDM training package, Promoting Active Choices Together (PACT).
- Through implementing the SDM approach, the average Camden CAMHS ‘did not attend’ (DNA) rates (2013/14) are 5.4% (cf. 11% national average).
- In on Camden team DNAs were reduced from 25.6% to 7.3% by using Quality Improvement approaches.

i-THRIVE

Aligned with NICE guidance and PbR

Where Risk is the central issue:
Camden brought together health, criminal justice system and local authorities to jointly manage families.

Successfully implemented as the Troubled Families Program organised by Camden Social Services, using the AMBIT model (Fuggle et al., 2015).

Improvement included quicker decisions about care higher rates of reunited families, take up of family interventions and support with education.

Cost savings were realised in the first year.

Shared decision making and Goal Based Approach

Longer evidence-based interventions

Shared decision making:
Adapting Option Grids and CollaboRATE for CYP population

Goal Based Approach

Agreed “THIRVE Plans”

Goal-based approach
- In 2013/14, 99% of children showed improvement in 1 goal and 65% showed improvement in 2 or more goals between assessment and 6 months (or earlier).

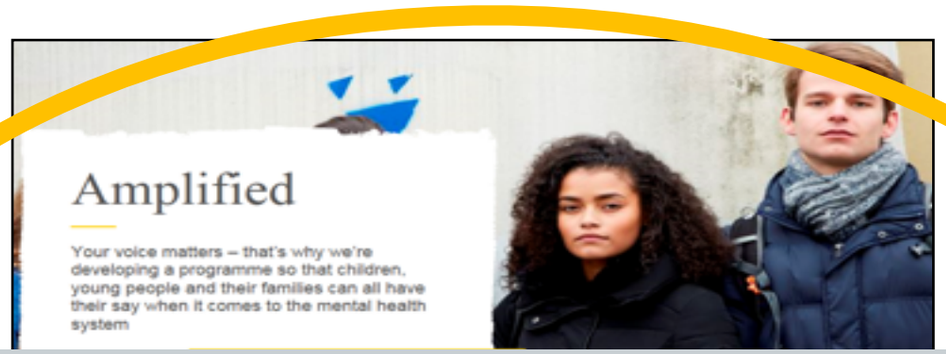
Participation and Co-production

NHS England and NHS Improvement

Meeting Need: CYP and Parent Participation

Involving children, young people and parents in service development and feedback is essential to ensuring services are fit for purpose. The *We Can Talk* programme delivers co produced CYPMH training for acute hospital staff developed at Barts https://wecantalk.online/

Minded www.minded.org.uk provides bite sized e-learning modules for CPD for anyone working with CYP including on self harm



NHS England works with Young Minds to deliver the Amplified programme aiming at increasing CYP and parent participation - supporting local area initiatives, contributing to the development of national policy, strategy, products and commissioner support https://youngminds.org.uk/resources/tools-and-toolkits/

Wendy@rollercoasterfs.co.uk
https://www.facebook.com/rollercoasterparentsupport/?ref=bookmarks
Is a parent created group for parents of CYP experiencing mental health difficulties

NHS England Children and Young People's Mental Health Transformation Programme

NHS England and NHS Improvement

Continue to deliver *Five Year Forward View for Mental Health* commitments by 2020/21

does she not want the how we are doing slide? if possible can we include?

70,000 more children and young people accessing CYP MH services

Reduc

1,700 newly qualified therapists working in CYP MH services

95% o
disorder services seen within 1 week for urgent cases & 4 weeks for routine cases

3,400 existing CYP MH staff trained in evidence based treatments

Improved access to and use of Inpatient Care, having the right number and geographical distribution of beds to match local demand with capacity, and an overall reduction in bed usage

Improved Crisis Care for all ages, including places of safety

Children and Young People's Improving Access to Psychological Therapies Programme (CYP-IAPT)

CYP-IAPT aims to increase access to effective services and evidence-based therapies through system-wide service improvements.

- Commenced in 2011 – now business as usual
- Now forms part of the **workforce development project** within the national Children and Young People's Mental Health (CYPMH) Transformation Programme
- Embeds ways of working in existing services through **5 key principles**

CYP-IAPT Principles

Participation
Ensuring CYP and their families/carers have an active role in treatment and services

Awareness
Increasing public understanding of emotional wellbeing and decreasing stigma and discrimination

5 key principles for CYPMH service improvement

Accountability
Collecting data about outcomes to develop effectiveness of services and interventions

Evidence-Based Practice
Implementing evidence-based therapies and care pathways

Accessibility
Improving access and engagement with services for CYP

Opportunities and Future Developments

NHS England and NHS Improvement

Implementation of Mental Health Support Teams and Four-Week Waiting Time Pilot

NHS England and NHS Improvement

Greater integration with schools and colleges: the Green Paper

The CYP Mental Health Green Paper (Dec 2017) represented major expansion to Children and Young People's Mental Health services. It has three major commitments:

1. Incentivise and support all schools to identify and train a **Senior Mental Health Lead** (**Education lead**)
2. Fund **new Mental Health Support Teams (MHSTs)**. (**Joint Health and Education lead**)
3. **Trialling a four week waiting time** for access to specialist NHS children and young people's mental health services. (**Health lead**)

These commitments are based on evidence on the importance of in-school support for children and young people with mild to moderate MH needs. They build on past and existing initiatives such as the joint **NHS-DfE Schools Link Pilot**, and the **Rapid Schools Pilot in Greater Manchester**.

Alongside this, the Green Paper also sets out steps to:

- tackle the harms that can result from internet use
- better support families
- support the transition period from children's to adult's mental health services
- work with universities around helping those aged 16-25 with mental health issues
- supporting young adults' in the workplace

Children and Young People's Mental Health in the Long Term Plan

NHS England and NHS Improvement

CYPMH in the NHS Long Term Plan

Headlines

Commitment that meeting people's mental health needs is treated as importantly as meeting their physical health needs **(parity of esteem)**

Ringfenced local investment fund worth **£2.3bn** a year by 2023/24

Comprehensive offer for CYP which will extend **up to the age of 25** and aims to identify and treat mental ill health at the earliest possible point

Significantly more CYP will access **timely and appropriate** mental health care

Commitments

More money for CYPMH

Mental Health Support Teams in schools and FE colleges to support early intervention

24/7 access to crisis services

Additional funding to meet eating disorder access and waiting time standards

0-25 services and improved transitions

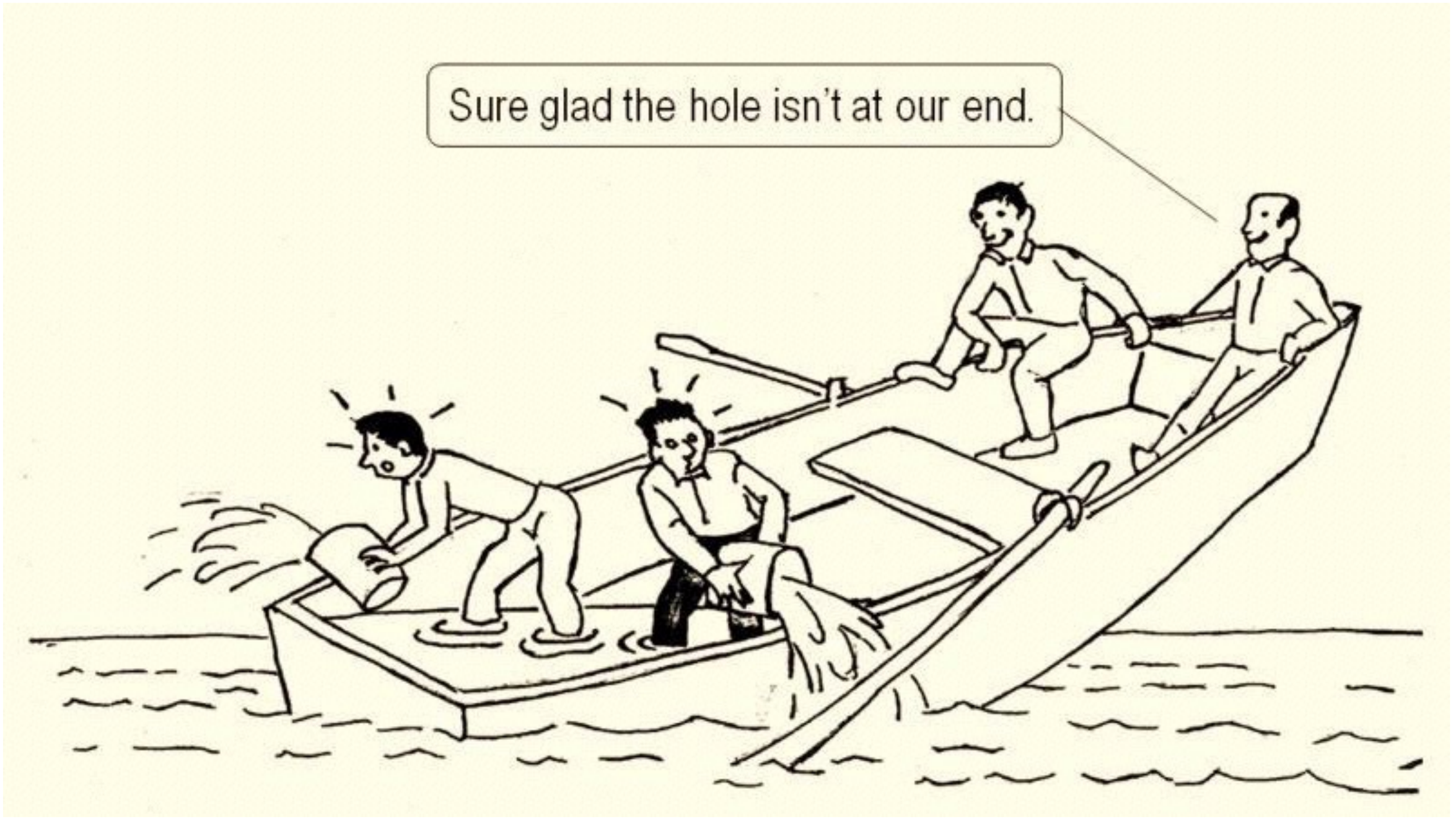
Testing and rolling out new waiting time standards

345,000 more CYP to access services by 2023/24

Integrated Care

- Services need to be designed and delivered to break down barriers across:
  - **Primary / community care and acute services**
  - **Health care and social care and education**
  - **Mental and physical health**
  - **CYP and adult care**
- Networks will be established for the Long Term Conditions including **Asthma, Epilepsy and Diabetes**

Needs collaborative working…



Thank you!

Death and other Data in Neurological Illness; Where Are We Now?

PAUL MORRISH

CLINICAL NEUROLOGIST AND ADVISOR TO PHE

Statistics and Tragedies

Deaths associated with neurological conditions in England 2001 to 2014

ONS, PHE Annual Mortality Extract; usually resident in England, aged 20+
During the most recent period 2012 to 2014: time trends from 2001

Purpose:

- Demographic characteristics of people that have died with a neurological condition
- Other conditions people with neurological conditions have at time of death
- Where people with neurological conditions die

https://www.gov.uk/government/publications/deaths-associated-with-neurological-conditions

Ian Curtis 1956-1980

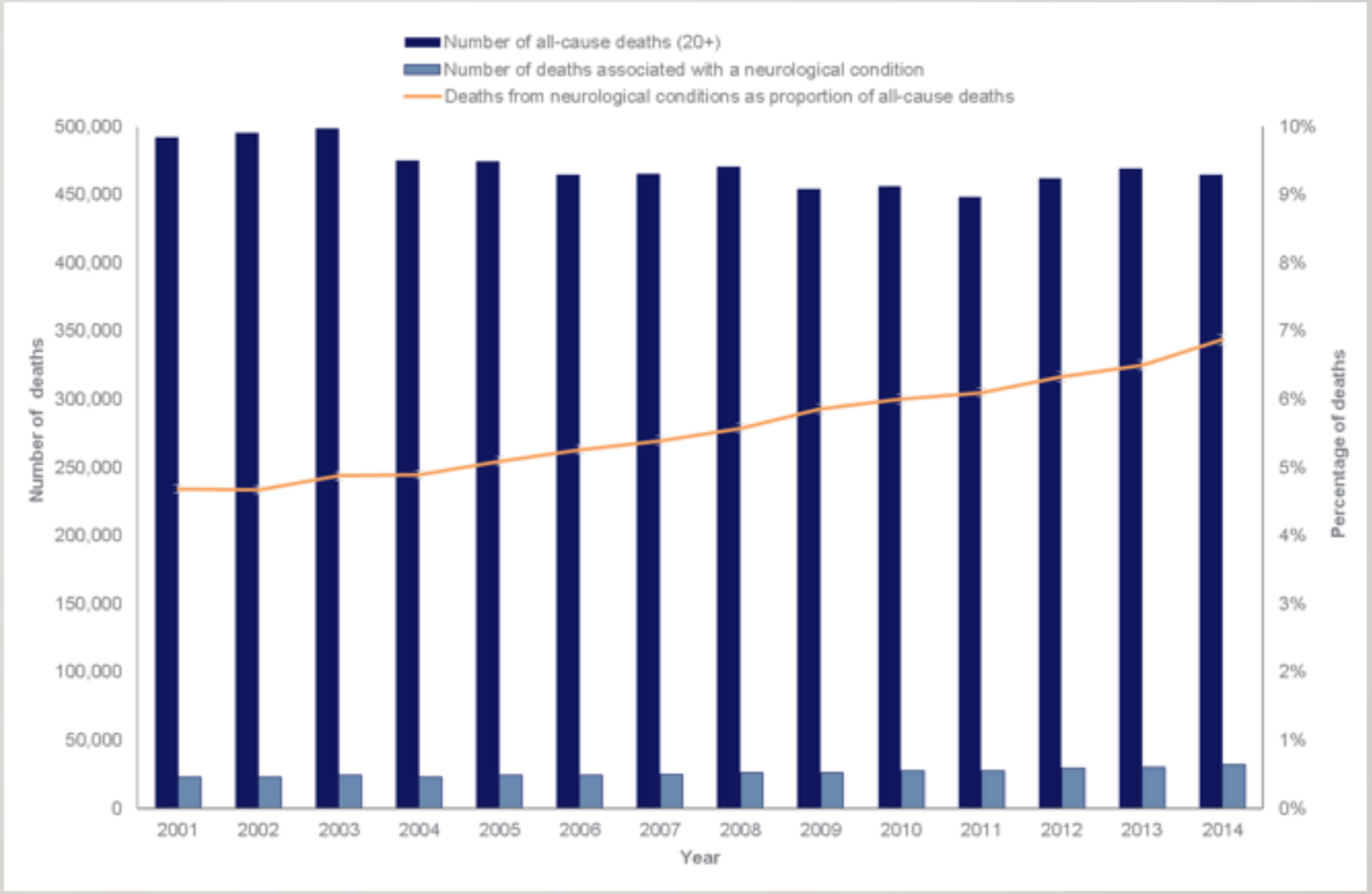
Diagnosed with epilepsy Dec 1978. Treated with Phenobarbitone, Phenytoin, Carbamazepine, Valproate. Died by suicide May 1980.

Deaths in England, 2001-14

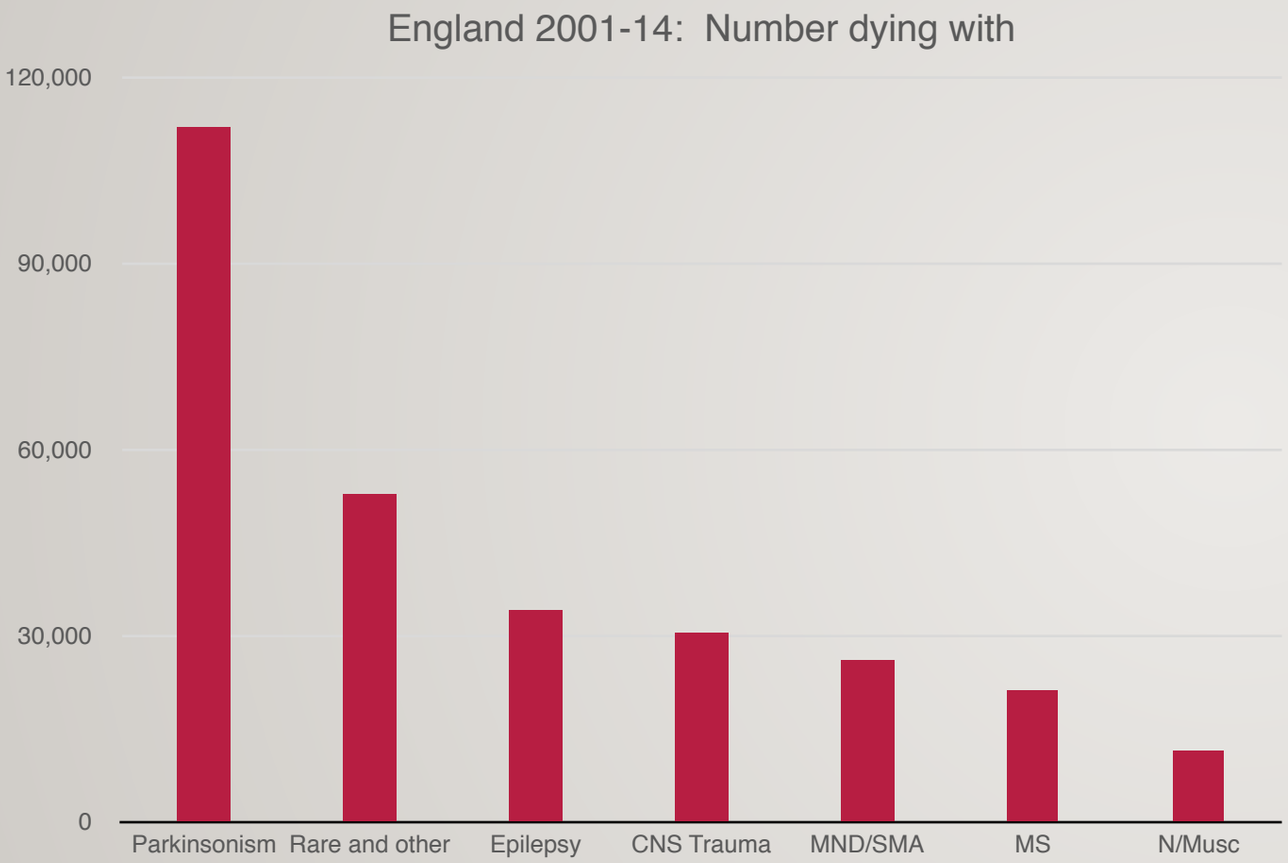
6,590,453 deaths in England, **366,728** were associated with neurological conditions.

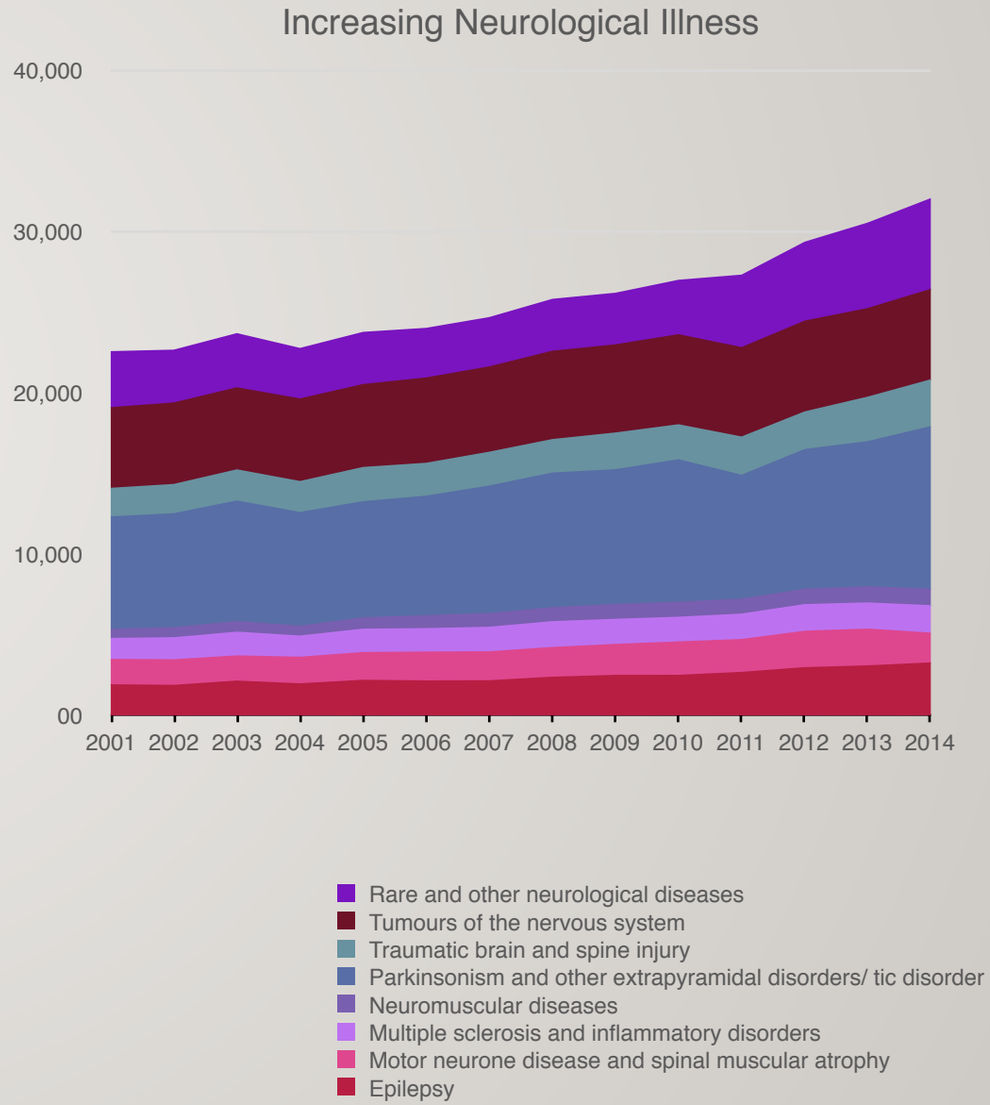
Annual number all-cause deaths decreased by **6%.**

Death with neurological illness increased by **39%** over this period (ie 3% rise pa).



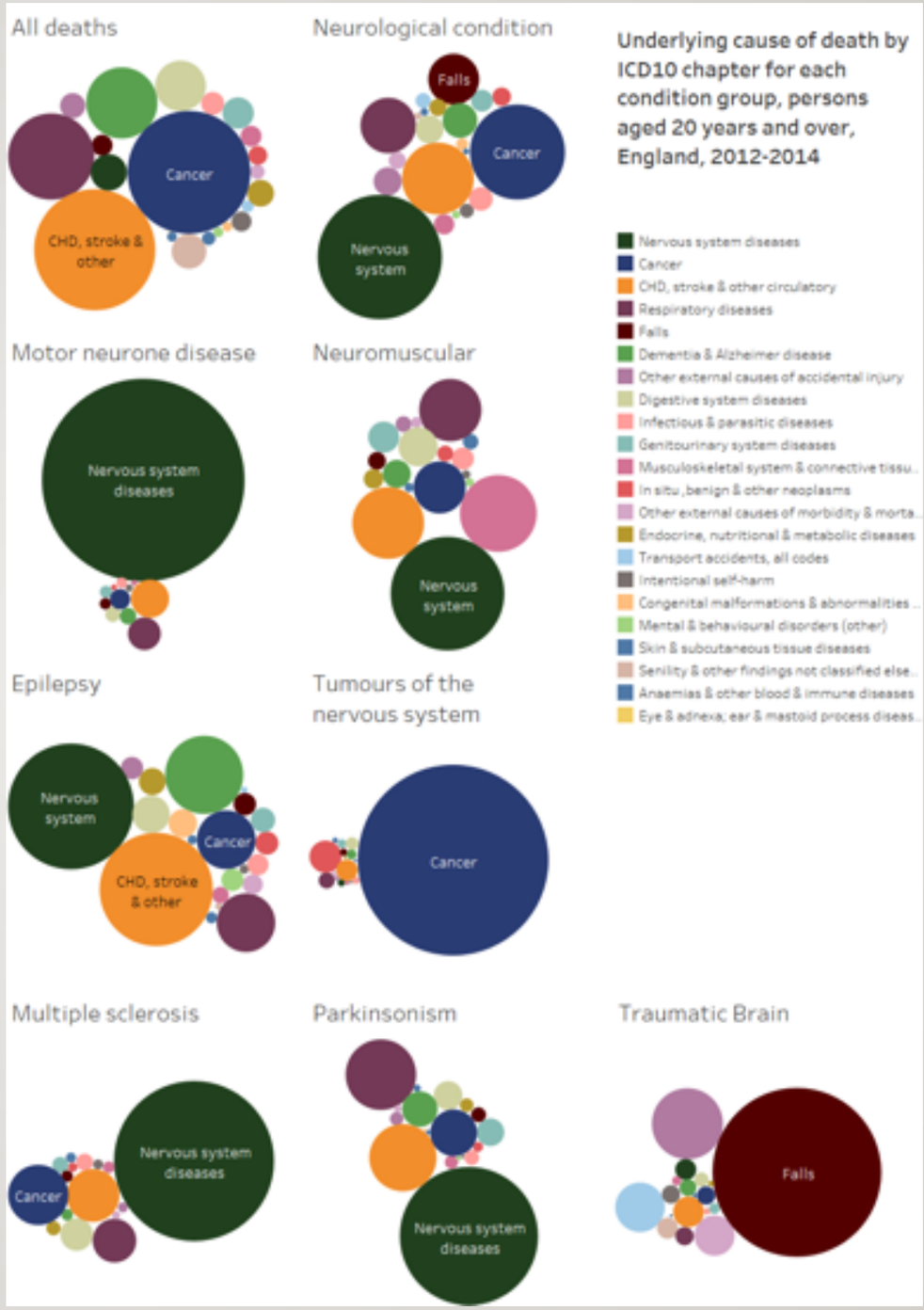
Neurological Patients (excl. stroke and dementia) Dying With:



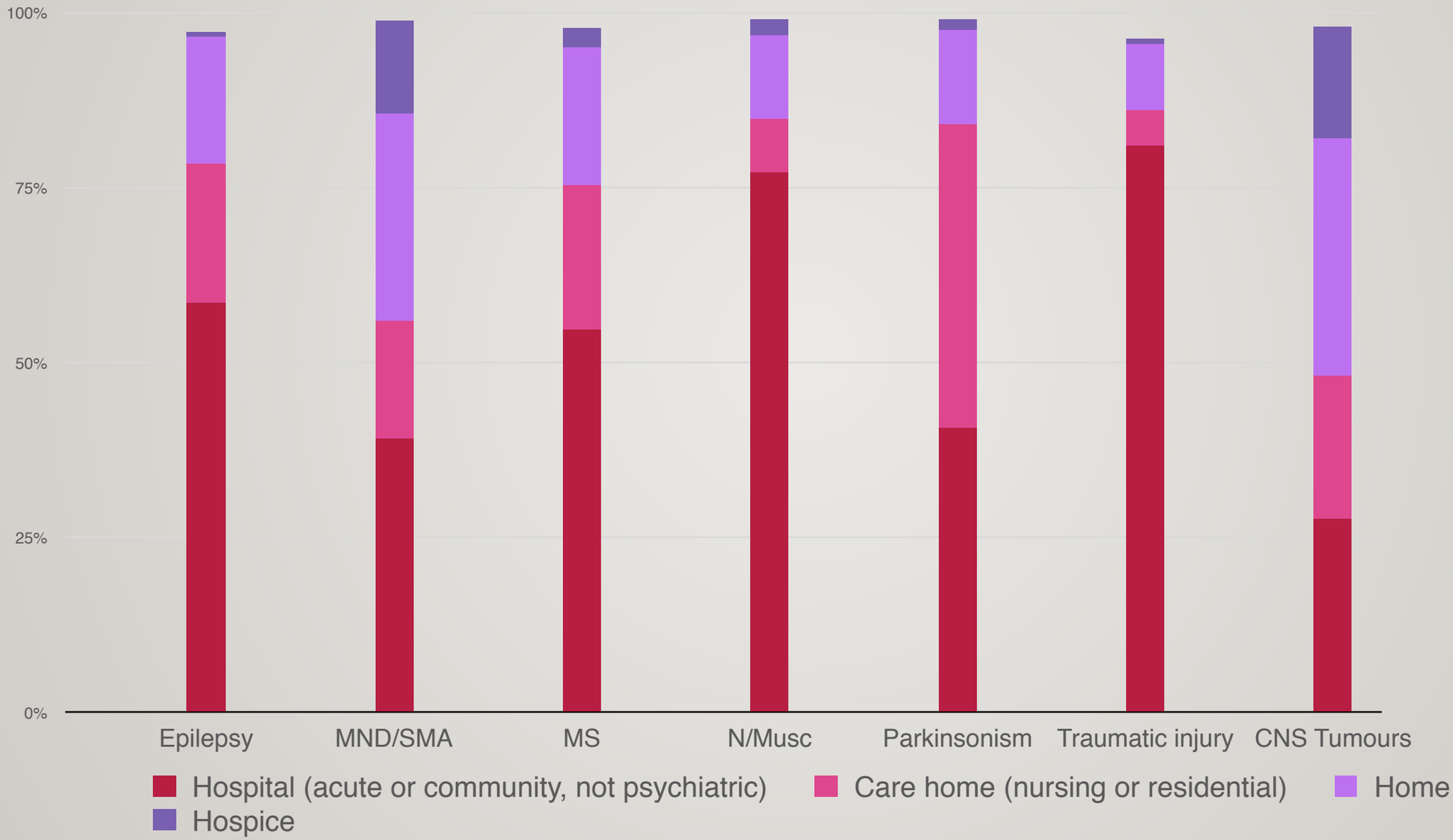


1 Dying of?

- Diseases of the nervous system (**37%)** of cancer (**22%**), CHD, stroke and other diseases of the circulatory system (**12%**) and respiratory diseases (**7%**).
- For deaths associated with epilepsy diseases of the circulatory system (**26%**), dementia and Alzheimer's disease (**13%**).



Dying Where?


100%
75%
50%
25%
0%
Epilepsy
MND/SMA
MS
N/Musc
Parkinsonism
Traumatic injury
CNS Tumours
Hospital (acute or community, not psychiatric)
Care home (nursing or residential)
Home
Hospice

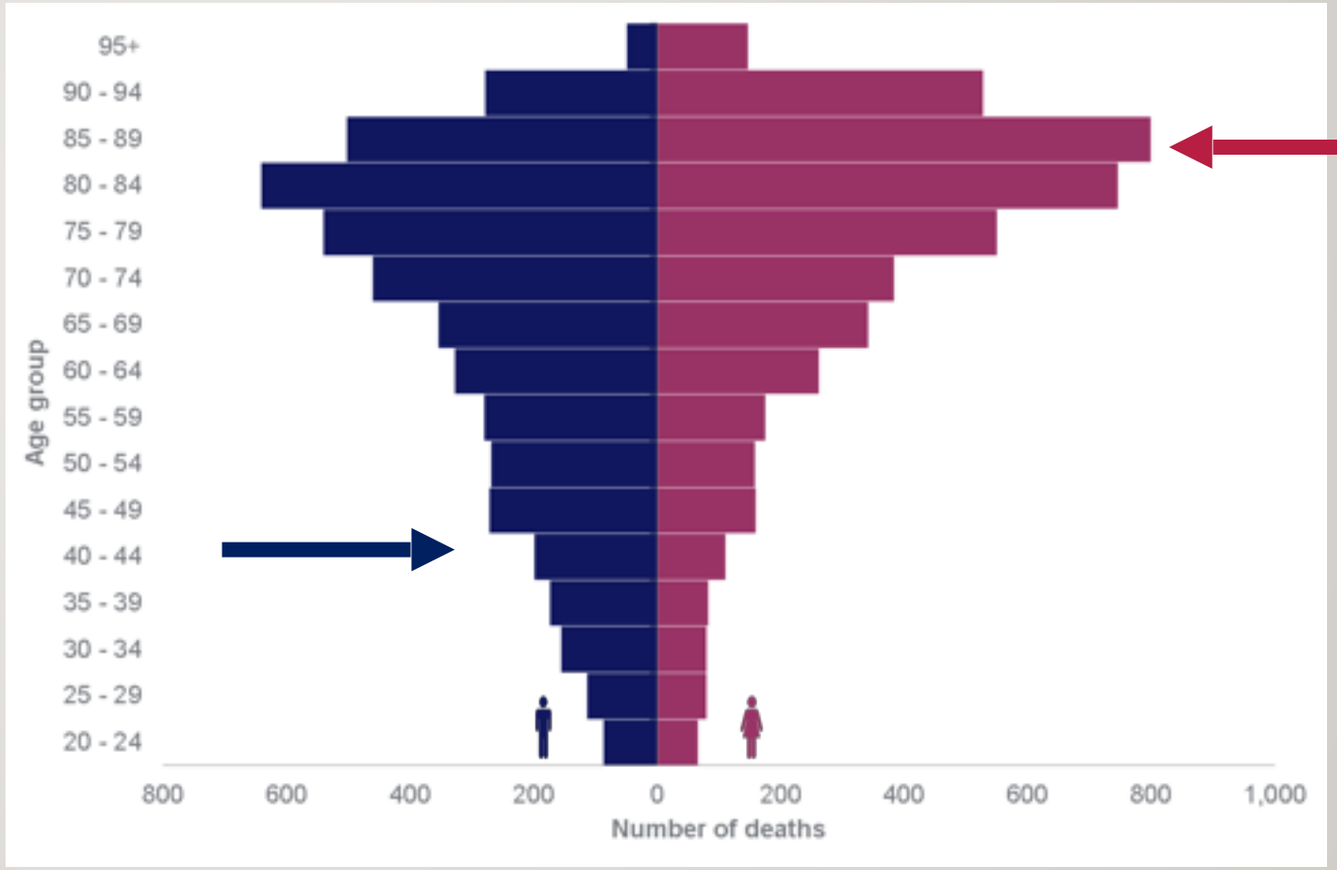
Epilepsy Deaths: Gender And Age

Equal number of deaths in men and women with a epilepsy but women died later in life.

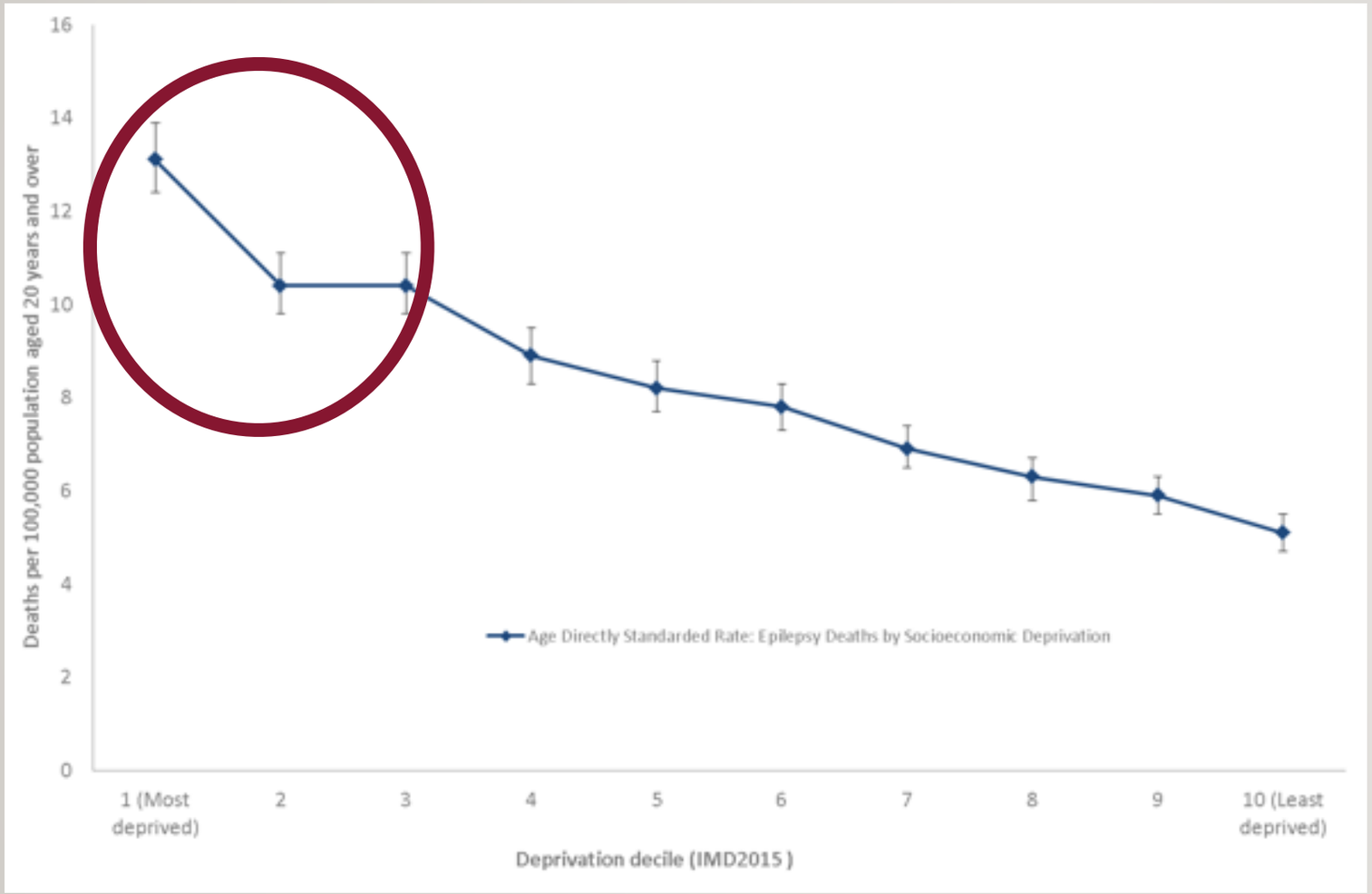
21% men and **12%** women with epilepsy died under age of 50.

Lots of elderly people living with epilepsy

Number of deaths with epilepsy by age group and gender, England, 2012 to 2014



Epilepsy Deaths: The Relationship To Deprivation



13.1 deaths (per 100,000 population) in most deprived decile,
5.1 in least.

Most deprived Deprivation Index
Least deprived

One Cause: Sudden Death in Epilepsy (SUDEP)

SEDS 2009-2016, 16+
10% epilepsy deaths SUDEP

- Mean age 41 (range 16-80)
- 64% male
- 94% on an AED
- 61% had no previous hospital admission with seizures or epilepsy
- 60% from Scotland's two most deprived SIMD quintiles

Cornwall 2004-2012,
48 /93 epilepsy deaths

- Mean age 42.5 (range 2- 82)
- 69% male
- 91% Tonic Clonic Seizures
- 91% Deterioration seizure control prev 6m
- 19% had < 12m contact with Specialist
- 51% had < 12m contact with GP
- 55 % Adherence problems
- Alcohol problems (46%), depression (27%)

Epilepsy Deaths Register 2019
349 SUDEP deaths

- 58% male
- 48% aged 19-30
- 46% employed
- 24% not under specialist care
- 41% recent medication change

PHE: Young adults (≤ 44y) 62% deaths NOT SUDEP.

Scottish Epilepsy Deaths Study < 55 yrs: 69% deaths NOT SUDEP

Unnatural Mortality in People With Epilepsy*

Population-based cohort study matching 58,729 PWE to 1,170,794 comparators.

People with epilepsy more likely to die:

1. Of any unnatural cause (HR, 2.77)
2. Of unintentional injury or poisoning (HR, 2.97)
3. Of suicide (HR, 2.15)

Large risk increase in the epilepsy cohorts for

unintentional medication poisoning (HR, 4.99)

intentional self-poisoning with medication (HR, 3.55)

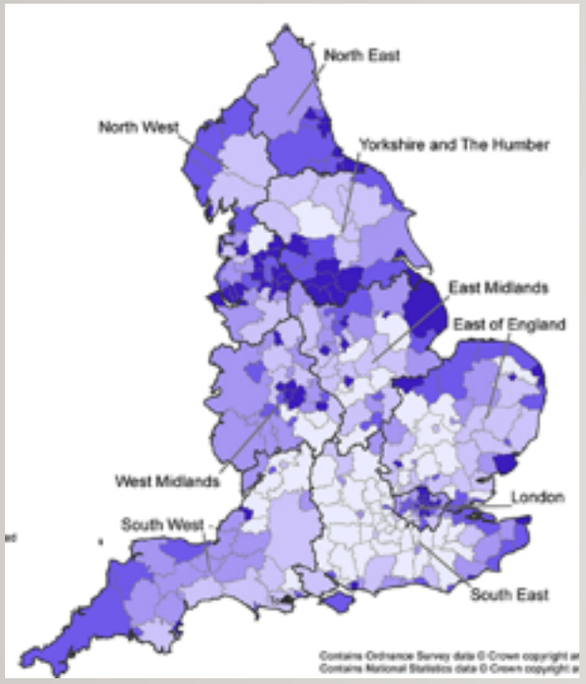
Opioids (56.5%) and psychotropic medication (32.3%) more commonly involved than antiepileptic drugs (9.7%) in poisoning deaths in people with epilepsy.

	CPRD		SAIL	
	Epilepsy	Control	Epilepsy	Control
Previous diagnoses, No. (%)				
Alcohol misuse[a]	2682 (6.0)	12 056 (1.4)	936 (6.7)	5823 (2.1)
Anxiety[a]	7195 (16.1)	104 532 (11.7)	2452 (17.5)	34 486 (12.3)
Bipolar disorder[a]	465 (1.0)	3293 (0.4)	143 (1.0)	1066 (0.4)
Depression[a]	9096 (20.4)	123 989 (13.9)	2930 (20.9)	39 953 (14.3)
Eating disorder[a]	548 (1.2)	5849 (0.7)	183 (1.3)	2025 (0.7)
Migraine[a]	3081 (6.9)	46 150 (5.2)	1058 (7.5)	14 299 (5.1)
Neuropathic pain	1578 (3.5)	30 763 (3.5)	961 (6.8)	18 253 (6.5)
Personality disorder[a]	836 (1.9)	3675 (0.4)	307 (2.2)	1996 (0.7)
Schizophrenia[a]	1273 (2.9)	6711 (0.8)	377 (2.7)	2584 (0.9)
Self-harm[a]	3563 (8.0)	23 248 (2.6)	1050 (7.5)	9140 (3.3)
Substance misuse[a]	2972 (6.7)	11 923 (1.3)	1122 (8.0)	6661 (2.4)
Prior prescription at baseline, No. (%)				
Antidepressant[a]	11 175 (25.0)	171 866 (19.3)	4043 (28.8)	27 104 (20.4)
Antipsychotic[a]	6823 (15.3)	88 433 (9.9)	1843 (13.1)	19 655 (7.0)
Anxiolytic or hypnotic[a]	14 562 (32.6)	124 898 (14.0)	4938 (35.1)	42 137 (15.1)
Lithium carbonate or lithium citrate[a]	162 (0.4)	1982 (0.2)	61 (0.4)	642 (0.2)
Opioid[a,b]	14 355 (32.1)	252 308 (28.3)	6603 (47.0)	100 331 (35.9)
Follow-up time, median (IQR), y[a]	4.0 (1.4-8.4)	5.1 (2.1-9.3)	6.9 (2.9-10.3)	7.7 (3.6-10.9)

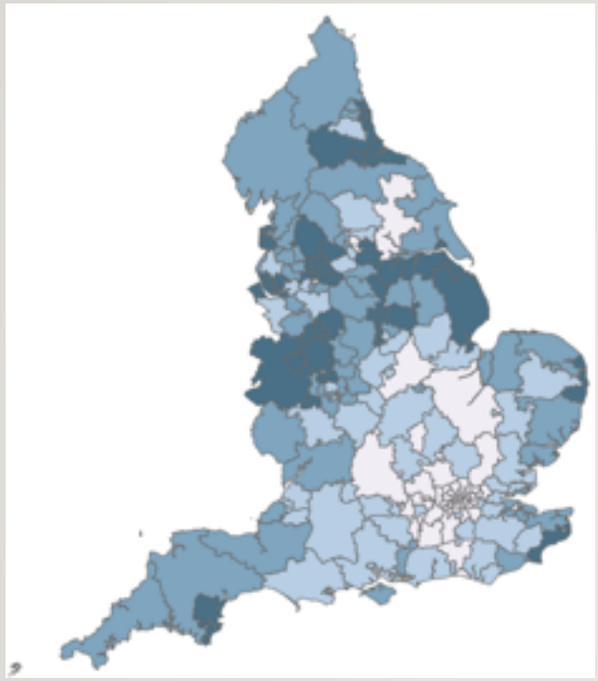
*Gorton et al. JAMA Neurology 20

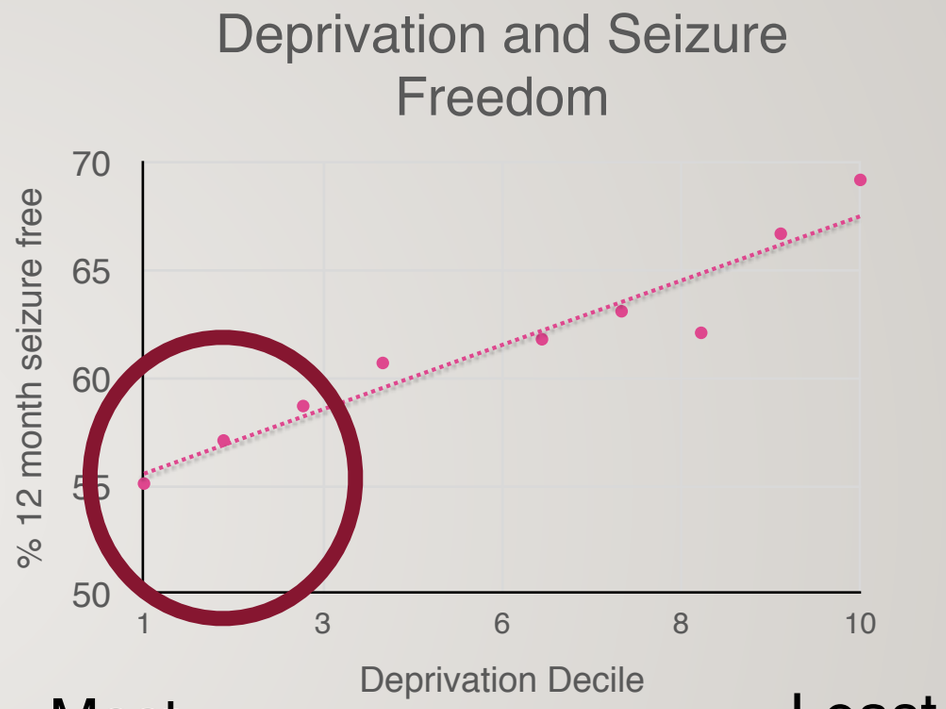
Deprivation and Seizure Freedom

Deprivation



Prevalence

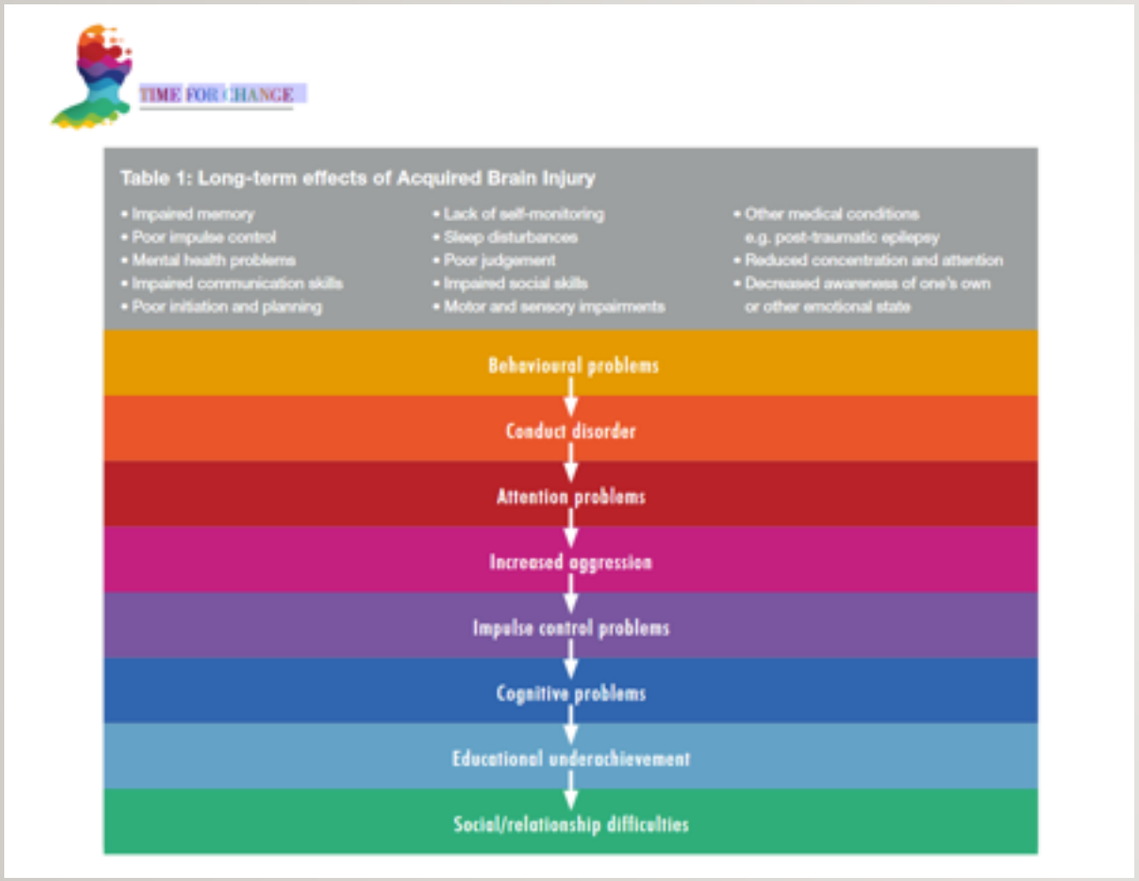




Cause and/or effect

? Deprivation leads to epilepsy
? Epilepsy leads to deprivation
? Poor medical care
? Less good at self-care

Traumatic Brain Injury



Brain Injury and Psychiatric Illness:

25-50% risk of major depression 7 years after TBI. Increased risk of major psychoses, with 65% increased risk of schizophrenia, 59% increased risk of depression and 28% increased risk of bipolar disorder. 28% in Forensic units.

Brain Injury and Prisons:

Mild TBI- 2X risk of suicide

30% young offenders report TBI with LOC. HHI in 25% prisoners, 18% of matched controls.

Brain Injury and Epilepsy: Incidence of 25–30 % after severe TBI and 5–10 % after mild to moderate injury

Traumatic Brain Injury

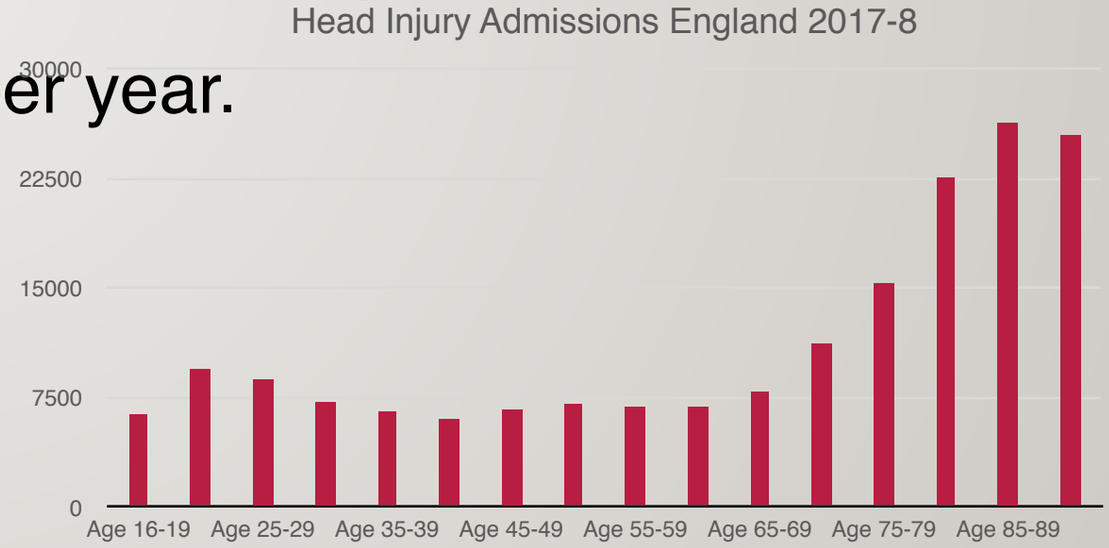
HES England (2017-8):

444000 attendances in A&E, 177000 adult admissions. 10th most common primary diagnosis.

More males in the young and more females in the elderly.

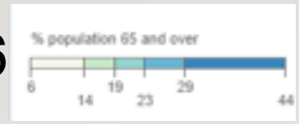
Problems at	Mild	Mod	Severe
Physical	***58%***	***66%***	***82***
Cognitive	***43%***	***49%***	***76%***
Mood	***47%***	***48%***	***76%***

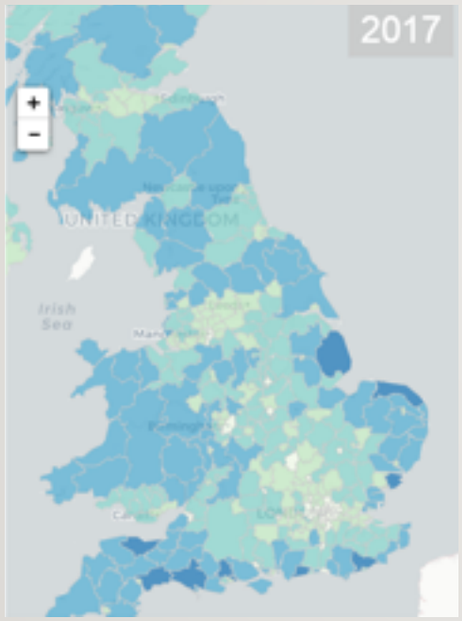
per year.

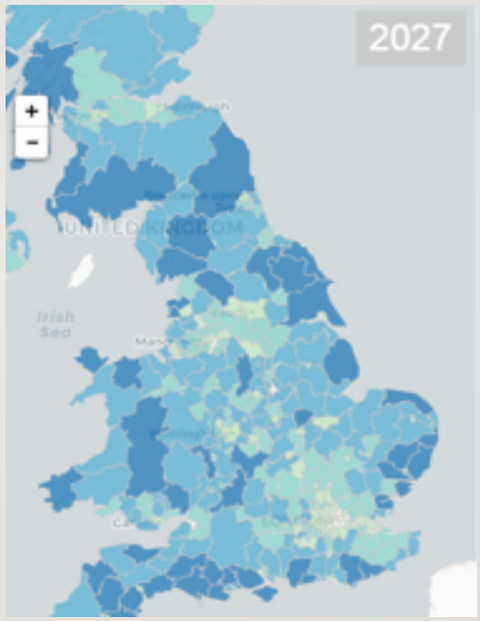


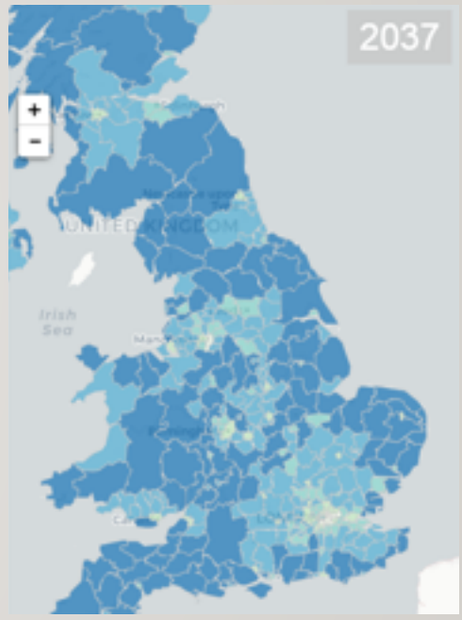
We Must Talk About The Elderly

- Dark blue = >29% population over 6



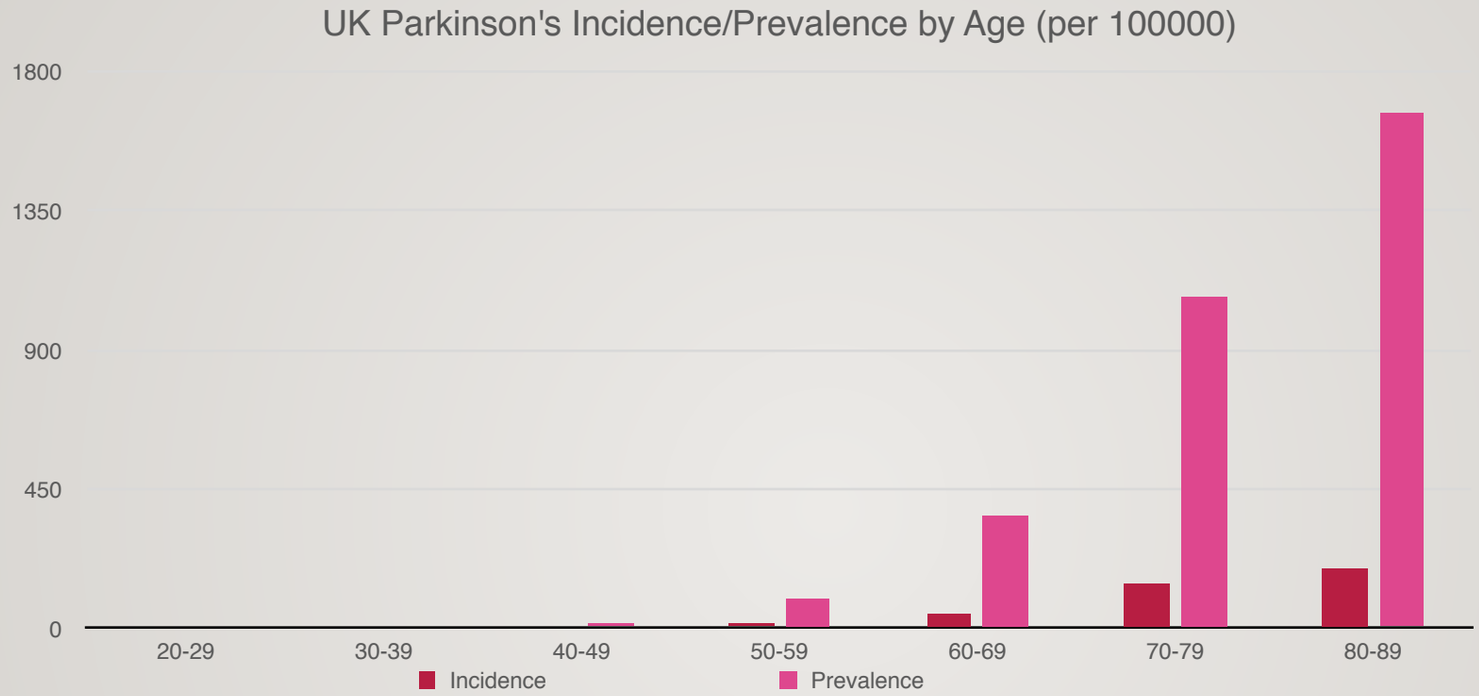






Epilepsy: Age-dependent disparity in referral to specialist services.
68% of under-60s with suspected first seizure are referred to a neurologist, but only 34% of under-60s.

Parkinsonisms



Depression: 17-?% of PwP
Impulse control disorders
Dopamine agonist withdrawal syndrome

Suicide: Few good studies. Meta-analysis/Review of 116 publications. Shepard et al JNNP 2019
Dearth of good quality studies. No useful studies on medication and suicide.

Conclusions

- More people are living and dying with a neurological condition. The future is; more elderly, more neurological illness, more complex problems and more multidisciplinary care.
- Epilepsy is an illness of deprivation. Young men are dying disproportionately. Many deaths may be avoidable. How many are “deaths of despair”?
- Traumatic brain injury is common, avoidable and increasing. Physical, psychological and social sequelae. A public health issue.
- How do we manage the increasing incidence, prevalence and complexity of neurological illness?

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MND & End of Life Care

Chris James
Director of External Affairs

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Quality of life

- 19% of pwMND rate their quality if life as “very poor” or poor”
- 22% of pwMND are not able to access support or social groups
- 49% of pwMND have negative feelings such as low mood, despair, anxiety, depression at least “quite often”
- 24% of pwMND were not able to access psychological support

Quality of life

- “Fatigue, motivation and lack of confidence/consciousness of appearance make it difficult to go out and do any activities for enjoyment.”
- “I have had my chair for a month. It is the first time I've been able to go out for a walk with my wife & children in FIVE YEARS. I got a puncture. I couldn't fix it. The fear of poverty and having our home repossessed & leaving my family with nothing but debt is as worrying as the disease.”
- “I rely heavily on my wife who does most things for me.”

End of Life

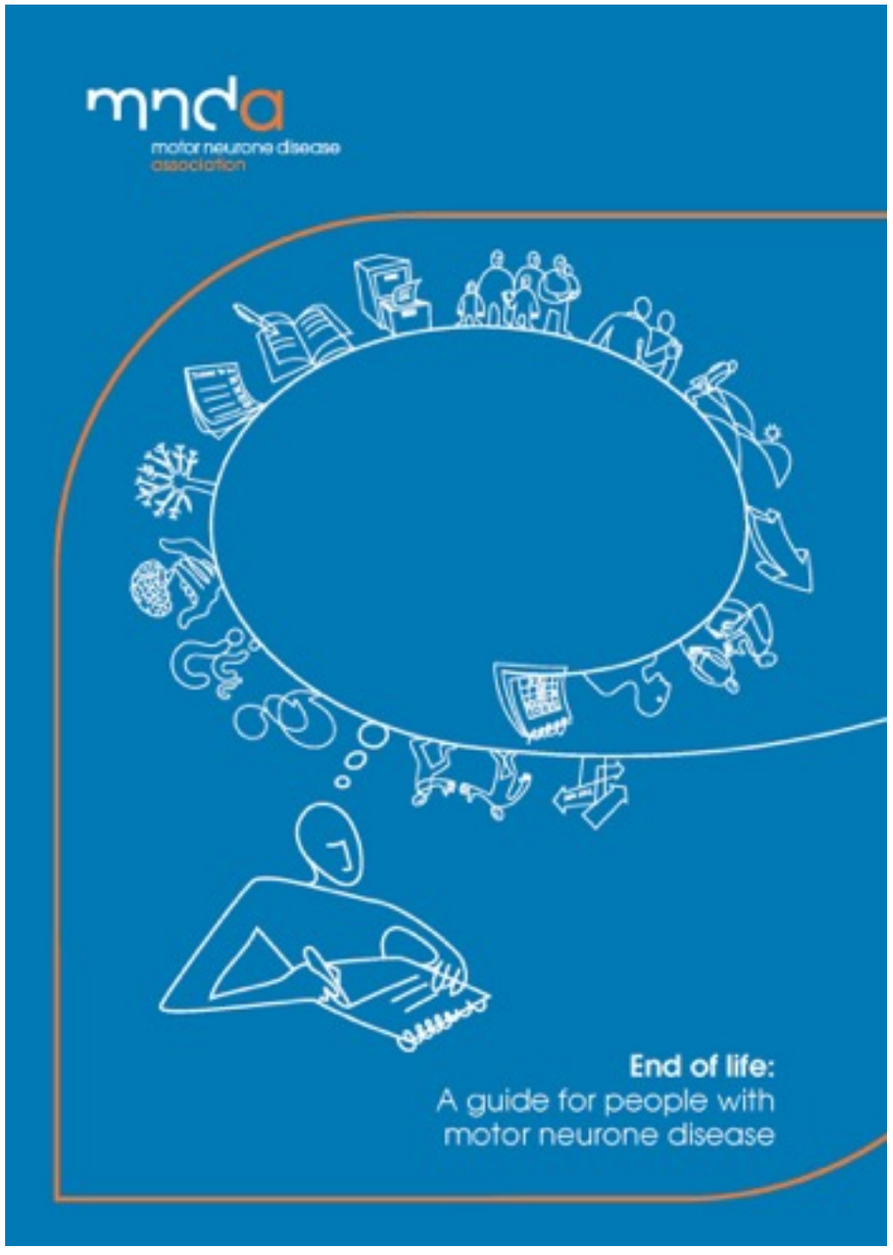
- 48% of respondents have been given the opportunity to discuss end of life with health professionals
- 36% have been offered an Advance Care Plan
- 36% have been offered an Advance Decision to Refuse Treatment

End of life

- “I was satisfied and although it was sobering I was pleased to talk about it.”
- “Myself, my family and Hospice doctor have discussed the end of life care and my niec3e and myself are currently setting it all written down so it can be distributed to everyone involved in my care to ensure my wishes are respected.”
- “Discussed end of life planning at the Hospice - felt it was very sensitively handled.”
- “The care professionals were very understanding.”

End of life

- “Very honest but sensitive. My daughter was involved each time.”
- “upsetting to discuss but I want to be sure everyone understands my wishes”
- “The palliative care team onboarded early in disease progression to help with pain relief. They were frank, informative and supportive”
- “Professionals are open with outcome but abide by my personal advice”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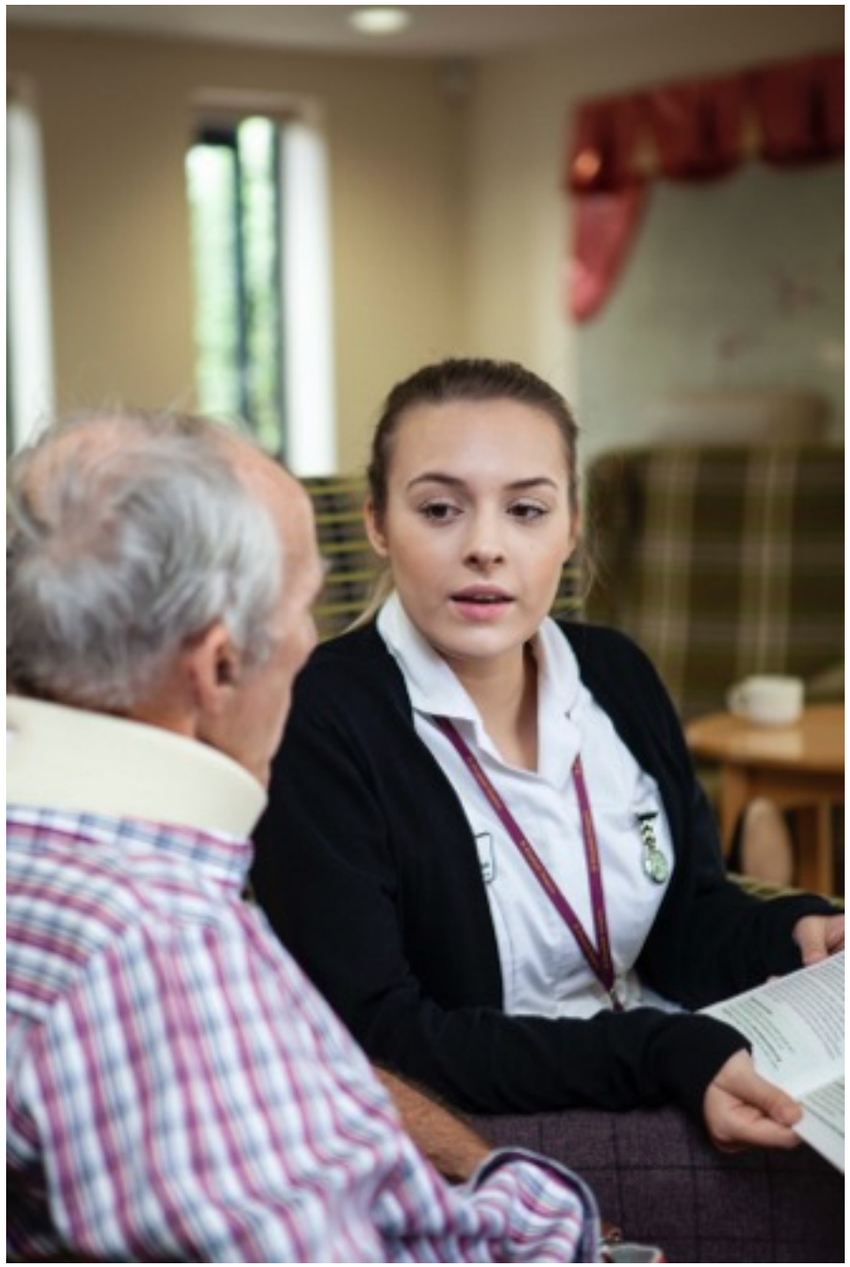
End of life:
A guide for people with
motor neurone disease



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Guidance

- Clinical psychology & neuropsychology
- Accepting & coping with diagnosis & prognosis
- Adjusting to changes & their perception of self
- Involvement in decision-making
- Concerns about family members/carers

Planning for end of life

- Opportunity to discuss preferences and concerns about care at the end of life at key trigger points
- Be prepared to discuss end of life issues whenever people wish to do so
- Provide support and advice on advance care planning for end of life
- Provide earlier opportunities if you expect their communication ability, cognitive status or mental capacity to get worse
- Additional social or nursing care to enable informal carers and family to reduce their carer responsibilities and spend time with the person with MND
- Towards the end of life, ensure there is prompt access to equipment

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Thank you

Equipping the NHS workforce for a future of integration

Panel Discussion:

“What are the main priorities for ensuring that the NHS workforce is equipped to meet the needs of people with neurological conditions and co-morbid mental health needs. How best should the NHS go about achieving this in the next 10 years?”

Condition specific pathways

Breakout sessions:

45 minutes to consider:

1) What would ‘good’ look like in terms of meeting the emotional, cognitive and mental needs of people with XXX

2) What (if any) are the biggest challenges to achieving 1) and how could they be overcome?

Group 1. Functional Neurological Disorders

Group 2. Epilepsy and learning disabilities

Group 3. Headache and Migraine

Group 4. Dementia