Delivery of Joint Medical & Social Care for Complex LTC: The UK Parkinson’s Excellence Network

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Outline of Talk

• Parkinson’s: some key facts
• What is the Parkinson’s Excellence Network?
• Measuring improvement
• Using data to inform service improvement
• Challenges & next steps
Parkinson’s: Some Key Facts

• 127,000 people affected in the UK
• Second most common neurodegenerative disease
• Non-motor symptoms are frequent, commonly overlooked & a major determinant of QoL
• Up to 80% of PwP will develop dementia
WHAT THREE THINGS WOULD CHANGE YOUR LIFE WITH PARKINSON’S?

PARKINSON’S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.
Three Themes

Better treatments and a cure

Taking control

Getting the right services
The UK Parkinson’s Excellence Network

A UK-wide Parkinson’s Excellence Network that brings together the passion and expertise of professionals involved in Parkinson’s, the voice of people affected by Parkinson’s and the strategic leadership and resources of Parkinson’s UK.

By working in partnership, together we will drive sustainable improvement in services across the UK.
Why Change?

• National Parkinson’s Audit 2012-13
• Sample = 4079
• Several examples of good practice
• Shortcomings identified:
  – no access to a PD Nurse Specialist
  – no information available in clinics
  – lack of integration with OT & SALT & implementation of best practice
  – lack of training & education for physiotherapists
Network Key Components

- Effective leadership
- Robust quality improvement mechanisms
- Engagement with stakeholders
- "Strategic localism"

Empowerment
Better treatments
Network Characteristics

• High quality
• Equitable
• Inclusive
• Efficient
• Responsive
• Dynamic
• Transparent
• Internationally relevant
Effective Leadership

• National Oversight Structure
  – broad representation
  – multifunctional
    • strategic
    • operational

• Harnessing wide expertise
  – regional
  – thematic
“Strategic Localism”

• 18 regional working groups across UK
• Key units in implementing network strategy
  – encouraged to set own priorities
• Inclusive

• Close linkage with
  – Health Boards
  – Strategic Clinical Networks
  – research delivery via LCRNs & AHSNs
UK PARKINSON’S EXCELLENCE NETWORK STRUCTURE

UK OVERSIGHT GROUP
- Jane**
- David**
- Peter**
- Lynn**

THEME WORKING GROUPS
- Education
  - Peter
  - Lynn
- Research
  - Michelle
  - Nick
- Patient Engagement
  - Ann
  - Linda

REGIONAL WORKING GROUPS
- Sarah
- Donald
- Helen
- Bob
- Andrea
- Biju
- Catalina
- Teddy
- Helen
- David**
- David**
- David**

A DEDICATED TEAM FROM PARKINSON’S UK TO SUPPORT THE EXCELLENCE NETWORK
- Education Programme
- Professional Engagement Programme
- Service Improvement Programme
Themed Group examples - 1

• Service User Involvement
  – reviewing whether regions are involving 'users'
  – impact people involved felt they had & how to support them better deploy their skills and experience (report due Feb)
  – nationwide local network survey of diagnosis experience to inform better practice & provide better support

• Service Development
  – patient focus groups to feedback on what they regard as an ideal clinic
    • TripAdvisor app for people with Parkinson’s to rate their own units
Themed Group examples - 2

• Research
  – scope National Parkinson’s Research database including assessment of Pro-DeNDRoN register and review of JDR dementia database experience
  – scope barriers to research via NIHR regional RDMs and how local PIs may best be supported

• Evidence-Based Practice
  – CAT (Critically Appraised Topics for clinicians and researchers) and KITTENs (for a lay audience)
  – operationalise evidence, produce practical implementation summaries for DaTSCAN, falls and cognitive impairment
Themed Group examples - 3

• Under-served groups
  – survey of care home staff, PDNS & Parkinson’s UK staff about care of people with Parkinson’s in care homes
  – develop a ‘TripAdvisor’ for care homes
  – survey of PDNS regarding challenges in care of ethnic minorities

• Education
  – competency matrix for all professionals to inform “optimum” level of training via website
  – mapping training currently available nationally
Measuring Improvement

• Audit tool
  • evaluate
  • strengthen (e.g. PREM)

• Capacity building

• Increase participation in research
  • Best Research for Best Health
  • engage with NIHR LCRN Clinical Leads
  • NIHR PD-Portfolio Development Group
Measuring Improvement: Why?

- Are people able to access services? Are we meeting need?
- Are we providing a quality service according to best practice?
- Are we achieving the best outcomes for patients?
- Are we delivering value for money?
## 2015 Audit: Submitted data

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Widespread participation in audit
Synergy in Service & Research

Service Excellence

Participation in Research & linkage with CRN

Best Research for Best Health
A new national health research strategy

2006
Using Data to Inform Change

- Patients
- Systems
- Audit & Research
- Population data
- Wearable devices
Baseline PD Health Statistics

Admissions

Over 65s with Parkinson’s in England are 3 TIMES MORE LIKELY to have an unplanned admission to hospital than other over 65s.

People with Parkinson’s were admitted to hospital.

98,195 TIMES IN 2012/13

People with Parkinson’s had 65,293 unplanned or emergency admissions to hospital in 2012/13.

Costs

A person aged 65+ with Parkinson’s costs the NHS 3.5 TIMES MORE in unplanned hospital admissions than someone who doesn’t have Parkinson’s.

The NHS spent more than £212MILLION caring for people with Parkinson’s in England in 2012/13.
MORE THAN £177MILLION was spent on unplanned visits to hospital – that’s 83% OF THE OVERALL COST of admissions for people with Parkinson’s.

People with Parkinson’s in England spend almost three quarters longer in hospital than those of a similar age.

In 2012/13 people with Parkinson’s spent a total of 128,513 extra days in hospital at a cost of more than £20MILLION.
PD Crude Death Rates by Parliamentary Constituency

2010 Crude Death Rates (deaths per 100,000 persons) by Scottish Parliamentary Constituency

2014 Crude Death Rates (deaths per 100,000 persons) by Scottish Parliamentary Constituency

Crude Death Rates are calculated using the mid-year population estimate provided by ONS as the base population
Use of New Technologies

• Technology subgroup
• What’s out there currently?
  – apps, devices, wearables
• Integrated approach
• Sharing best practice
Engaging via a New Website

UK PARKINSON'S EXCELLENCE NETWORK

Are you a health or social care professional working in Parkinson's care? Then the Excellence Network is for you.
Parkinson’s UK Structures

• Major commitment to Network by Parkinson’s UK
  – restructuring centrally & locally to deliver change
• Parkinson’s UK representation on regional & UK-wide Excellence Network structures
• Themed around:
  – education
  – professional engagement
  – service improvement
  – quality
• More “on the ground” service engagement
Challenges to Date

• Changing relationships
• Engaging busy HCPs with no allocation in job plans
• Ensuring a strong patient voice
• Reaching out to primary care & social services
• Internal restructuring at Parkinson’s UK
• Maintaining momentum
Next Steps

• Audit outcomes & report Q1 2016
  – national “top-line” outcomes
  – local service improvement plans
• Online resource for service users
  – diagnosis “offer” & signposting
  – development of research register
• Service improvement grants & awards
  – joint educational events (e.g. BRITMODIS)
Conclusion: Key Messages

• Beholden upon us all to eradicate service inequalities
• The Parkinson’s Excellence Network aims to “raise the bar”
• Momentum building & infrastructure established with exciting regional examples
• This is a process & will take time to evolve

“Discipline is not an end in itself, but a means to an end”

(Robert Fripp)