

# How We can Improve Parkinson's Services in Lothian?

## **A look at ParkinsonNet**

Edinburgh Branch

Parkinson's UK

*22 February 2014*

# A look at ParkinsonNet

- 10.45 Introduction; overview of Parkinson's services in Lothian
- 11.00 Video presentation (45 minutes) Prof Bloem describes the ParkinsonNet system and its benefits
- 12.00 Discussion – Would the ParkinsonNet approach work in Lothian?
- 12.30 What Next?
- 1.00 Close & lunch

# OUR PRIORITIES

## Parkinson's Services in Lothian

1. Access to Parkinson's services should be clear, structured and easily available to all
2. The Parkinson's Specialist Nurse team should be supported and developed to achieve universal access
3. Services should be provided by multi-disciplinary teams structured to focus on patient needs

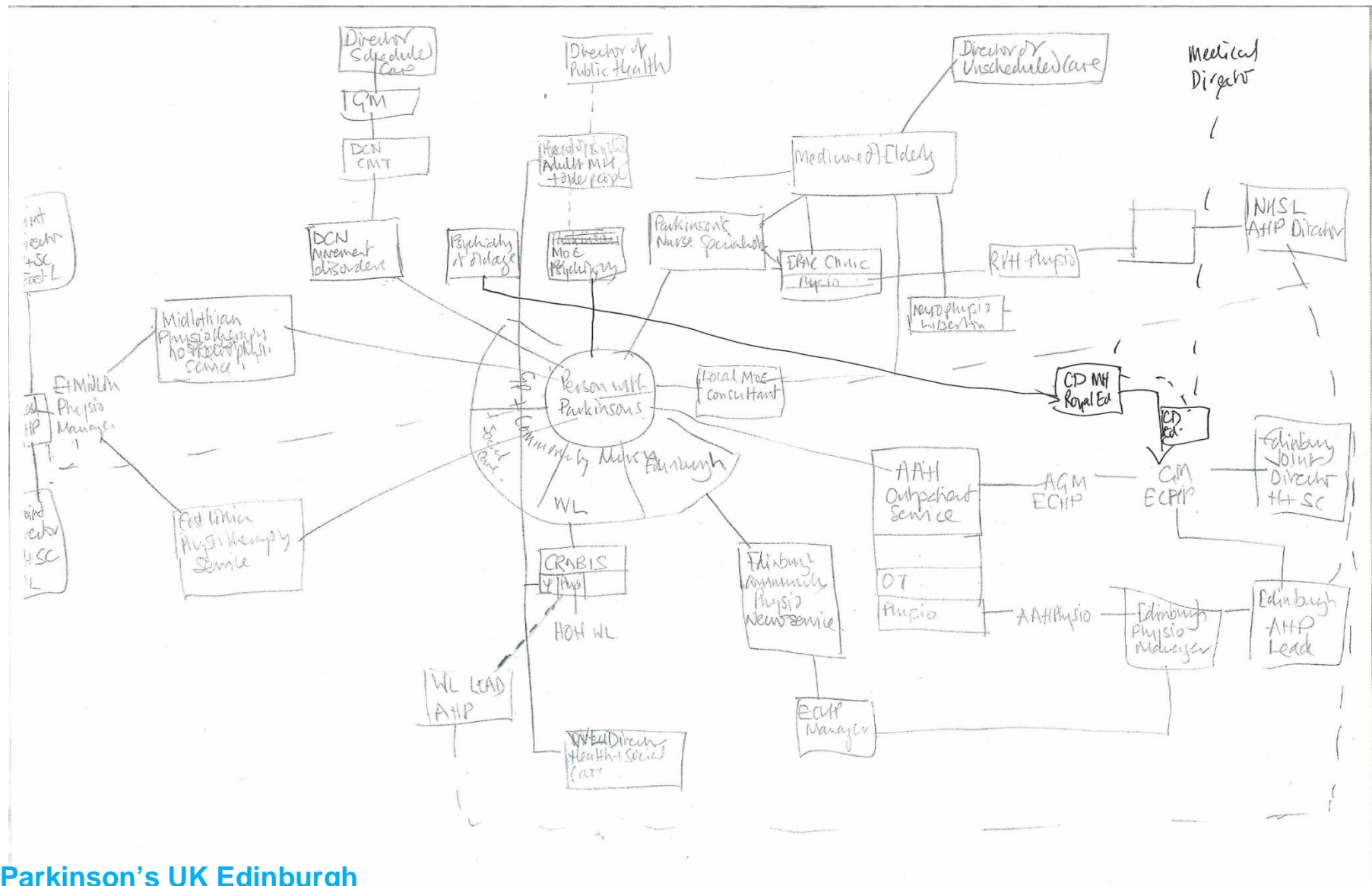
Team members including Physiotherapy, Speech and Language and Occupational Therapy professionals should all have specialist Parkinson's training and experience

*Edinburgh Branch Parkinson's UK - 2010*

# Parkinson's Services in Lothian

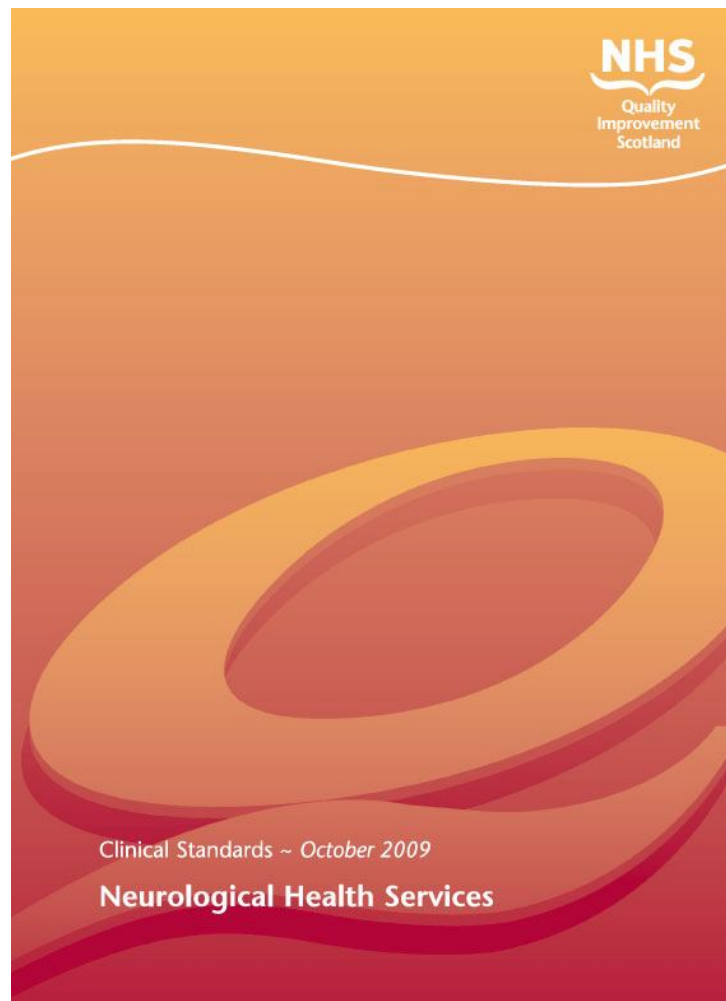
- Good in Parts
- Postcode and age distinctions
- Need to be well informed to get service
- Difficult to find practitioners with proper Parkinson's expertise
- Little co-ordination of activity

# Parkinson's Services in Lothian



# Quality Improvement Scotland Neurological Standards 2009

3 Clinical standards for neurological health services



## Standard 17: Access to specialist Parkinson's disease services

### Standard statement 17

An effective and comprehensive Parkinson's disease service is available and offered across all NHS boards.

#### Rationale

Patients with Parkinson's disease and related conditions receive better quality care when diagnosis and treatment are delivered within a multidisciplinary team in their local NHS board.

An effective Parkinson's disease service also offers their specialist services to patients with conditions related to Parkinson's disease, such as progressive supranuclear palsy (PSP), dementia with Lewy bodies (DLB) and multiple system atrophy (MSA).

**References:** 9, 92, 93, 94, 95, 96, 97, 98, 99, 100, 101, 102, 103

#### Essential criteria

- 17.1 Patients with suspected Parkinson's disease and related conditions are referred to a defined Parkinson's disease service delivered through a multidisciplinary team.
- 17.2 The Parkinson's disease multidisciplinary team consists of, as a minimum: a doctor who specialises in Parkinson's disease, a Parkinson's disease nurse specialist, the patient and carer. Additional input from other healthcare professionals with experience and training in neurological conditions is offered from the following services:
  - physiotherapy
  - occupational therapy
  - speech and language therapy
  - dietetics
  - pharmacy services
  - mental health services.

# Improvement Group Activity

- Lothian Parkinson's Service Advisory Group
- Lothian Neurological Improvement Group
- Lothian Neurological Voices
- Neurological Alliance of Scotland (NNAG &OMG)

# What is Best Practice?

## World Parkinson's Congress 2010

- Prof Nir Giladi (Tel Aviv)
- Dr Robert Iansek (Melbourne)
- Prof Bastiaan Bloem & Dr Marten Munneke  
(Nijmegen NL) **ParkinsonNet**



# Prof Bastiaan Bloem



Parkinson's UK Edinburgh

# Meeting Participants – Sept 2012

## **Prof Bastiaan Bloem**

**Steve Ford** CEO, Parkinson's UK

**Bhanu Ramaswamy**, Physio Consultant, Parkinson's UK

**Robin Elliott** President, Parkinson's Disease Foundation, USA

**Jeff Brodzeller**, Systems Manager ,Wheaton Healthcare, Wisconsin USA

**Amy Rick**, Chief Executive Officer, Parkinson's Action Network, Washington USA

**Anne Thobae** , Executive Director , Houston Parkinson's Society, USA

**Nan Abraham** Cofounder and President, People Living With Parkinson's Inc, USA

**Joyce Gordon** CEO Parkinson's Society Canada

**Barbara Snelgrove** Director Education & Services, Parkinson's Society Canada.

**Vanessa Foran** Vice-President National Programs , Parkinson's Society Canada

**Marjie Zacks** National Director Communications, Parkinson's Society Canada

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# Show Presentation Video

# NHS Lothian– the issues?

- There is not a single Parkinson's Service in Lothian. Services are provided by 5 CHPs, 2 Hospital Trusts and 4 Local Authorities
- 11 different budgets and management structures
- Apart from the PNS no person is entirely focussed on Parkinson's
- How can funding, staffing and management be rearranged to provide a single integrated service structure?
- Who might take responsibility for achieving this?

# ‘OUR STRATEGIC AIMS’

1. Prioritise prevention, reduce inequalities and promote longer healthier lives for all
2. Put in place robust systems to deliver the best model of integrated care for our population – across primary, secondary and social care
3. Ensure that care is evidence-based, incorporates best practice and fosters innovation, and achieves seamless and sustainable care pathways for patients
4. Design our healthcare systems to reliably and efficiently deliver the right care at the right time in the most appropriate setting
5. Involve patients and carers as equal partners, enabling individuals to manage their own health and wellbeing and that of their families
6. Use the resources we have – skilled people, technology, buildings and equipment – efficiently and effectively

# Further Details from Discussion

- Need for 'Anchor Man'
- E1,000,000 over 8 years to set up the project  
E 200,000 to set up a network
- 'Neurologists are the problem – hobby patients'
- Free up full time co-ordinator – wake up/go to sleep
- 3 day training course
- Quality monitoring system
- NL multidisciplinary handbook for patients  
*Multidisciplinaire richtlijn voor de ziekte van Parkinson's*

# ParkinsonNet Questions

- **What are the most important propositions in Pnet?**
- Can it improve Services for Parkinson's? How?
- Can it improve productivity and reduce costs? How?
- Can it work for health professionals? Why?
- Does it fit into NHS Lothian strategy?
- Do you select your own Therapist? – or sign up for the Team?
- How far will people travel to attend a Top Quality Service (in Edinburgh) rather than an average one? Or what cost?
- **Should the Branch should promote its concepts? How?**

# Variation



Number of  
ParkinsonNet Physio's  
per 1000 PwP

- Less than 5
- 5 to 10
- 10 to 15
- 15 to 20
- more than 20



# 2013



	Average ParkinsonNet	Total
Citizens	252.300	16.651.780
PD Patients	851	55.519
ParkinsonNet members	43	2.800
Disciplines	8	19

**66 networks**  
**92 hospitals**  
**>2500 members**

# What patients really want



# What do we want to achieve?

1. Reform Lothian Parkinson's Physio services by Increased specialisation of practitioners
2. Identification of specialist Parkinsons practitioners who will all achieve agreed standards of knowledge and experience. This will follow the establishment of an agreed and certified training structure. PwP will be universally referred to them.
3. Quality standards will be monitored
4. Apply the above principles to other AHPs eg OT and SALT.
5. Use ParkinsonNet principles to set up 'State of the Art' MDTs across Lothian providing the full range of services to all.
6. Achieve a 'Total Parkinsons Service' for Lothian, following ParkinsonNet tools and philosophy.