

# Edinburgh Branch Parkinson's UK: Discussion on ParkinsonNet

*This short report is based on forms circulated for the group discussion section of Patrick Mark's session on ParkinsonNet on 19 February 2014. After feedback from each group, 14 at least partially completed forms were collected in and are summarised here.*

## 1: What are the most important propositions in ParkinsonNet ?

Most stressed the importance of services being **patient-driven or patient-centred**, as well as the **training of specialist staff**:

*Being patient driven; having expert therapists all trained in Parkinson's; joined-up thinking. Communication and the training of specialists are important. The patient is a valued partner. The ParkinsonNet system is open for scrutiny / appraisal and covers all of the country, which lessens the lottery of care. It better utilises specialist knowledge and improves workers' satisfaction.*

**Communication** also figured in most of the comments:

*Communication; awareness of skills or national and local help available; training specialists. Services joined up. All in one building. Extra therapy important. Better communication and co-ordination - free-flowing between PwPs and professionals. Having a network of dedicated practitioners within an overall framework headed up by a Parkinson's expert full time - to facilitate sharing of information between patients. Communication - specifically trained personnel all over country. Communication, shared info and understanding, joined-up thinking.*

Some were particularly anxious to put the ideas into **action**:

*This is more than a multidisciplinary clinic! Advance on day hospital model. It's commonsense - time to stop talking and start acting! Not piecemeal, with involvement of government minister and all budget holders, should be easier in Scotland, a smaller country.*

## 2: Can it improve services for Parkinson's? How?

Responses here were **generally positive** about whether it would improve services, though sometimes **tempered with caution**:

*Yes, as professionals learn from colleagues' experience, and it would provide access to an integrated team. But it will not be easy to make it work, when we are still struggling to provide enough Parkinson's nurses, and there is a need for more joined-up thinking to ensure that information is shared not only when diagnosis is first made, but also as the disease progresses. Yes. Patients have increased choice over route to solutions for their problems and access to integrated team. Yes. Getting immediate and latest info; gaining from other people's experience quickly.*

Yes. Some doubts about translating theory to practice. Advantages for people with internet access.

Others commented on how services might improve:

*Reducing costs - a means of persuading government ministers; better specialist services.*

*Big advantage for health professionals in increased knowledge and retraining.*

*If all services and specialists easier and accessible.*

*Patients can be more easily included / integrated into decisions.*

*Face to face talk.*

*24 hour advice - can go out within your region or to another region.*

*Access to team, one-stop health check, gain info of other professionals, medics and share knowledge, information.*

### **3: Can it improve productivity and reduce costs? How?**

Some responses stressed the **scope to improve productivity**:

*Through ParkinsonNet you get specific information; must cut costs because of reduction / prevention of hospital visits.*

*Use existing buildings; the more information that is available to find appropriate therapists.*

*Overall outcome of the management of Parkinson's would be improved, e.g. unnecessary treatment.*

*Central meeting point.*

*Yes, eliminate unnecessary treatment.*

Others, however, highlighted the **need to know more** about the Dutch system and its funding mechanisms before expressing a view:

*Yes, by eliminating unnecessary or ineffective treatment and it could reduce hospital visits.*

*But our group felt we needed to know more about how the NHS structure compares with the Dutch system, which appeared to be insurance-based.*

*This would be very hard to prove as NHS cost heads are not clear - not attributed to patient or condition, but hospital/ service.*

*Don't feel qualified to say. What was the baseline care in the Netherlands?*

### **4: Can it work for health professionals? Why?**

Some who attended the workshop saw **advantages for professionals**:

*This could build their knowledge / experience / worth through networking.*

*Yes, can deal with more patients in need of serious help.*

*More flexibility in how often you see a specialist - how widely read are these specialists, e.g. how much PD research is being done in Lothian?*

*The more information for the carer helps them to cope. Example: memory dementia as condition progresses, require more information and more help.*

*More personal.*

*Get more information.*

*Networking - for patients depends on access to net.*

Others were more **cautious**:

*It could improve practice through networking, enable professionals to deal with a wide range of patients, and it would be excellent if remote professionals were linked in to the network. But there may also be barriers if the structures of professional careers discourage specialisation in one condition.*

*We need to ask them. MCNS already have similar approach - none in PD in Scotland, but need to soup up the model.*

## **5: Does it fit into NHS Lothian strategy?**

Opinion was divided on this. Two of the responses were negative, and most of the positive responses included some doubts, reservations or concerns about how it would fit with the strategy:

*Yes, in principle, if their recently stated strategy is to be credited, it could be a good fit.*

*Yes, directly - but how can patients self-refer?*

*Yes, restructure.*

*Could do.*

*?funding; data protection.*

*What about private health schemes?*

*Probably.*

*Yes. Bigger question: How does it fit with integration agenda - cutting across at least 5 CHCPs post integration (which will mean at least 10 locality plans).*

## **6: How far will people travel to attend a Top Quality Service (in Edinburgh) rather than an average one? Or what cost?**

Only two responses expressed a figure for **travelling time**, one hour, or two hours round trip. Other comments showed concerns not about travelling time, but about **patient mobility** and problems of **early or multiple appointments**:

*Within Edinburgh and the Lothians, there would be no problem about travelling for most, although those who are less mobile might have difficulty. There would be a need to avoid early morning appointments.*

*Already travelling serious miles - but many people are unable to travel great distances.*

*Most people would go far to get best treatment, depends on income and time of appointment.*

*No problem - bus pass - to see a real expert or therapist. Problem of the mind, not distance or excuse for doing nothing.*

*If services are available, I would travel, but we live in Edinburgh.*

*Any distance if mobile.*

*Need to be mobile. Too often problem of early appointments. Eliminate multiple appointments on different days.*

## **7: Should the Branch promote its concepts? How?**

The responses were unanimous in urging the Branch to promote the concepts, with a variety of suggestions for the way forward:

*Yes, although we are not sure how. Need to target the medics, including GPs as well as neurologists.*

*Yes, through existing NNAG / Neuro Voices / Neurological Improvement Groups. This would assist people with other conditions [such as MS]. Fear that Health and Social Care & GPs will not engage.*

*Excellent presentation from Prof. Bloem - endorse fully the proposals to copy network model. Information source at present for PwP is the voluntary Parkinson's UK Branch, no info from NHS.*

*Yes, communication.*

*Yes. Agitate for PNet lock stock and barrel - run a conference for politicians and high health officials. Scotland is a small country so easier to influence ministers, MEPs etc. NHS funding strategy? 10 locality plans in future? Apply for EU money to introduce PNet before the referendum and we leave the EU.*

*Yes, promote to health authorities, MSPs. What about impact on carer, and as carer ages? Branch could promote further EPAC consultations for PD patients throughout life.*

*Regional Hospital.*

*Yes, target medics.*