



Consultation on Independent scrutiny: The independent examination of proposals for major change in NHS services

Response by the Parkinson's Disease Society in Scotland

Introduction

About Parkinson's

About 10,000 people in Scotland are diagnosed with Parkinson's. It is a progressive fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. It is a life-threatening condition that can be managed through specialist care.

Parkinson's affects people from all social and ethnic backgrounds and age groups. Most people are diagnosed over the age of 60. However one in 20 people with Parkinson's are diagnosed before they are 40.

People with Parkinson's typically live for many years with a condition which requires extensive support from NHS services. Many people also have co-morbidities which require treatment during the course of their condition. Because of their close contact with a range of services, people with Parkinson's are very likely to be affected by service change.

About the Parkinson's Disease Society

The Parkinson's Disease Society of the United Kingdom (PDS) provides support, advice and information to people with Parkinson's, their carers, families and friends. It also provides information and professional development opportunities to health and social services professionals involved in their management and care.

This year, the Society is expected to spend nearly £5 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as Parkinson's Disease Nurse Specialists, community

support, and campaigns for changes that will improve the lives of people affected by Parkinson's. The Society is not a service provider.

The Parkinson's Disease Society would be glad to explore any of the details of the consultation response in further depth. Please direct any questions or comments to: Tanith Muller, Parliamentary and Campaigns Officer, email tmuller@parkinsons.org.uk , tel: 0141 423 1518.

Question 1: Do you agree that an expert panel is the most effective way to provide independent scrutiny? If not, what would be your preferred choice?

Yes. An expert panel is the most appropriate way of providing the independent scrutiny remit that the proposal outlines. However, the PDS believes that there is scope to broaden the definition of "expert" and the panel's remit to take account of an analysis of impacts on service users alongside the other evidence listed.

Question 2: Do you agree that the role of the panel should be to assess the safety, sustainability, evidence-base and value for money of NHS Boards' proposals for major changes to local NHS services?

Yes, these are appropriate areas for the panel, but the PDS believes that the panel should also look at the evidence about the impact of Boards' proposals on service users. This should be adopted as a fifth objective.

The PDS recognises the need for the scrutiny process to be based on evidence-based principles. However, it is important that the patient focus of service change is not lost in an analytic process that concentrates solely on the analysis of empirical data.

The evidence of the impact of proposed changes on service users may be hard to gather, and more difficult to interpret, but it is extremely important that some attempt is made to interrogate this as part of the scrutiny process. It is certainly important enough to be considered as an explicit objective.

The discussion document makes reference to the panel encouraging community and patient groups to submit “evidence-based perspectives” for consideration. This is problematic because many community and patient groups do not have the training or resources to produce professional-standard reports. The impact of this is that contributions from service users are less likely to be considered by the panel than those produced by the Board, professionals and umbrella organisations.

The proposal to place the secretariat within the Scottish Health Council provides opportunities to use existing expertise to develop appropriate models to analyse evidence from patient groups and wider service user impacts without sacrificing rigour.

The terms chosen for the panel to investigate must be clearly defined in guidelines, so that they are transparent.

Question 3: Do you agree that the chair should be a lay person appointed by Scottish Ministers?

Yes.

Question 4: Do you agree that the panel should have a lay majority among its members?

Yes. However, this should be underpinned by extensive training and support for lay members.

The PDS is concerned that if lay members are recruited solely by nomination, panels are unlikely to be representative of Scottish society. Ideally, panels would include representatives from hard to reach and underrepresented groups, and particularly individuals who use services themselves. The recruitment methods should enable recruitment from these groups, with meaningful support to allow them to participate fully in the panel.

Question 5: Do you agree that the panel should assess the evidence and options during the process of public engagement prior to consultation,

and provide a commentary on these that would be available to the Board and to Ministers in reaching decisions?

Although the rationale for the panel providing scrutiny at this time is clear, the PDS is concerned that the timing could result in a perception that the public consultation has been presented with a *fait accompli*.

Despite the efforts of the Scottish Health Council, patient representatives and groups do not always feel that Boards are meeting their PFPI commitments properly. There is still a perception that Boards see public involvement as a “tick box” or rubber stamping exercise, rather than a meaningful dialogue. In this context, there is a real risk that a panel that reports before the public consultation stage, and without taking any account of patient issues, it will be widely perceived to be too late for the public to have any influence over decisions.

Question 6. Do you have any other comments on how independent scrutiny should be carried out, or on the guidance on “Informing, engaging and consulting the public in developing health and community care services” at Annex 3?

The Decision Conference model (Option 1) is the best model for encouraging and facilitating participation by service users and the public. PDS accepts that this does not constitute independent or rigorous scrutiny. However, this is a strong model for service development and options appraisal, and Boards should be strongly encouraged to use similar techniques when they consult – including on proposals that do not meet the criteria for “major service change” being drawn up by the Scottish Health Council.

Question 7 Do you have any other comments on either the consultation process or your preferred choice?

No.