



Consultation on the proposed Local Healthcare Bill 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 often highly motivated to engage with NHS.

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 does not provide care services.

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 think the current proposals for independent scrutiny of service change proposals help achieve the aim of better engaging and involving local communities?

PDS submitted a response to the Scottish Government's consultation on these proposals. The Society expressed some concerns that the independent scrutiny models proposed had the potential to further alienate local communities from the decision making process.

We argued that:

1. The independent scrutiny panel should have its remit expanded to include examination of the evidence about the impact of Boards' proposals on service users
2. The proposal that community and patient groups to submit "evidence-based perspectives" for analysis by the panel was problematic, as it risks disadvantaging those groups which do not have the training or resources to produce professional-standard reports. The Society suggested that guidance from the Scottish Health Council might be used to develop a model that did not disadvantage such groups.
3. There is a danger that if lay members are nominated, they are limiting the extent to which the panel would be representative
4. Involving the scrutiny panel at the pre-consultation stage could result in a perception that the public has been presented with a fait accompli.

Question 2: How could additional guidance to NHS Boards on making public consultation as effective as possible help achieve this aim?

The Society believes that additional guidance for Boards is essential. There seems to be considerable variation in the extent to which Boards are carrying out public consultation, and the experiences of PDS members are highly

variable, from those who feel that their involvement has been extremely valuable, to those who have felt the opposite.

One of the problems seems to be that the Boards have not amended their way of working in order to accommodate public consultation, outwith the PFPI officers or the groups set up by them. Rather, the public consultation has been “bolted into” existing structures and ways of getting things done. Most NHS Boards have yet to take on the principles adopted by Community Planning partnerships of avoiding jargon, complex language and bureaucratic structures when asking people to participate. The result is that people can find it difficult to navigate their way through power structures, and to identify the really important issues in a flood of information. There is a danger that meetings are dominated by those who shout loudest, at the expense of those who are less confident or assertive.

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The experiences of PDS Members suggest that some individual Health Service Managers are not using their Board’s own consultation procedures. Some concerted work is needed to ensure that this no longer happens.

Some members of the PDS who participate in PFPI fora have reported that they have not been given the opportunity to participate as partners in health service meetings. They report that no mechanisms were given for patient representatives to put matters on the agenda, and no opportunity to raise issues of concern at the meetings themselves. In one case, members of the society and other interest groups were asked to participate in an inquiry, and then denied access to the final report. All of this reduces people’s confidence in the process of consultation, and is – of course – in breach of the principles behind PFPI and Health Boards’ own stated policies.

The Society believes that additional guidance is particularly important when considering service changes which may not meet the criteria for “major service change”, but do affect certain groups of service users very profoundly. The Society is aware of at least one current case where a Health Board is planning big changes to the configuration of services for people with

Parkinson's. The Board has not consulted any of the current users of the service about its proposals. These changes are due to go ahead in a number of weeks, and we believe – based on the experience of other services which have adopted a similar model – that they will have a detrimental impact on the quality of care for people with Parkinson's throughout the Health Board area. Neither the PDS, nor people with Parkinson's, nor people with other conditions which will be affected by this change have been consulted. It is clear that the current system is not working, and more guidance is required.

Anecdotally, the most successful examples of public involvement seem to arise when Boards and individuals have a real commitment to capturing people's views and integrating them into the process of decision making, but this is not the case across the board.

Question 3: Would the appointment of more lay members to NHS Boards – perhaps to directly represent patients or other groups – help achieve the aim? How might this be achieved?

The appointment of additional lay members to NHS Boards might help to ensure that Boards integrate and value the voices of local communities and service users more effectively. However, this will only be the case if the lay people selected for the Boards have a personal commitment to wider community involvement and the influencing skills to ensure that this perspective is heard by other Board members.

There is a question to be asked about the role of lay people on Boards. If they are there to give a genuine fresh perspective to Boards' deliberations, then they should retain a community perspective. Training is needed to enable lay people to develop the skills and confidence to engage with health professionals and other Board members on their level - but training should also focus on developing lay members abilities to present the community's or service users' perspectives to professional members of the Board. However, it is also essential that Board Members receive training on how to engage with lay members at the person's level. This would help lay people to understand the process and feel able to speak up without having to turn into a 'psuedo

professional' losing the specific and different perspective the lay person brings.

PDS would support the expansion of boards to accommodate lay members with a specific remit to represent patient groups. Care would have to be taken to ensure that such lay members had a wide interest in general service users' issues, and not just those that directly affect their own constituency.

Question 4: In particular, would adding more local authority councillors (one councillor from each local authority whose area a Board serves is currently appointed to that Board) help achieve the aim? Could local authorities have a role in scrutinising public and community engagement?

PDS does not have a view.

Question 5: Should we develop further the role of the Scottish Health Council to bring about more effective engagement and involvement? If so, what additional responsibilities could the Council take on and what would the benefits be?

Yes. 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.

The Health Council's role could be usefully expanded to take on an "ombudsman" type role, allowing communities and groups that do not feel that they have been adequately consulted about service change to have recourse to an independent authority. This would empower community and service user groups, and encourage Boards and individual Managers (see comments in question 2 above) to take action to integrate public consultation into its processes from the outset.

Question 6: How could the Public Partnership Forums associated with Community Health Partnerships encourage greater public engagement?

The development of PPFs has been problematic. PDS echoes the concerns voiced by the Scottish Consumer Council¹ about the dependence of PPFs on the CHPs, which has the potential to allow the CHP to influence the activities of the PPF – a problem if patients and service users have a different view from the CHP management. PDS members who have been involved with PPFs report very different experiences, from positive to negative.

PDS Members report that, once they are known, it can also be difficult to limit their commitments to public involvement, as they may be approached to participate in more and more meetings. This is a challenge for those with busy lives and especially those who live with a complex long-term condition, or have extensive caring responsibilities. This may reflect the fact that Health Boards are finding it difficult to recruit people for public engagement, but may also be a disincentive to be involved in the first place.

As the development of CHPs is in its infancy and there are so many different configurations, it is hard to draw conclusions about efficacy. It will be interesting to see what lessons can be learnt once PPFs have had the opportunity to bed down.

Question 7: How could local Community Planning Partnerships best ensure improved public engagement with NHS planning?

PDS does not have a view.

Question 8: What other measures could be introduced to increase effective engagement and involvement of the public with the NHS in Scotland?

PDS does not have a view.

¹ Scottish Consumer Council (2004) Comments on advice note on public partnership forums. Glasgow: Scottish Consumer Council. Available online at <http://www.scotconsumer.org.uk/publications/responses/resp04/rs10pfp.pdf> Accessed 21.03.08