

PRESCRIBED GROUPS WHICH MUST BE CONSULTED WHEN PREPARING OR REVISING INTEGRATION SCHEMES; PREPARING DRAFT STRATEGIC PLANS; AND WHEN MAKING DECISIONS AFFECTING LOCALITIES RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. Do these draft Regulations include the right groups of people?

Yes

No

2. If no, what other groups should be included within the draft Regulations?

Parkinson's UK particularly welcomes the inclusion of people who use services, carers, non-commercial providers of social care services and third sector bodies carrying out activities related to health and social care within the prescribed groups.

However, we are very concerned about how national charities such as Parkinson's UK fit in.

There are about 10,000 people with Parkinson's in Scotland. Half of all people with Parkinson's are in the more advanced stages of the condition, when medication typically offers more limited symptom control, and individuals typically require increasing amounts of care and support from both NHS and social care services. People with Parkinson's are a key group who are likely to benefit from health and social care integration – ISD has identified that about one in every ten people with Parkinson's is at very high risk (more than 50%) of a hospital admission in the next year.¹ In addition to mobility problems, the symptoms of advanced Parkinson's can include problems with swallowing, weight loss, frailty, falls, immobility, communication issues, mental health issues and dementia.

Parkinson's UK has more than 40 local groups in communities across Scotland from Shetland to Annan, and offers free confidential one-to-one support to people affected by Parkinson's in every NHS Board through our locally based Information and Support Workers. Our staff are home-based and live throughout the country. We do not directly provide care services. However, while we are active in communities throughout Scotland, realistically we lack capacity to support locality planning across 64 or more areas. People with advanced Parkinson's will typically require a great deal of support to participate in meetings - if they are well enough to attend at all - and our

¹ ISD (2011) SPARRA database: Number of patients in Scotland at risk of emergency admission/readmission in the period 1 July 2011–30 June 2012 by risk probability group, and those with an admission history of Parkinson's disease. Unpublished data. Reference: /conf/sparralive/Ad Hocs/Parkinson's UK

staff's time is already committed.

We are very concerned that there is no clear opportunity for organisations such as ours to contribute, despite the very useful insights and contributions that we are able to make, informed by the experiences of people with Parkinson's, carers and families with whom we work. We are concerned that the same issues will also affect many other national charities that work with people with conditions that have very high levels of health and social care need.

We believe that Scottish Government must consider how it can resource third sector organisations of all kinds to participate in this process.

3. Are there any further comments you would like to offer on these draft Regulations?

In common with the ALLIANCE, Parkinson's UK is very concerned about the language that is used in these regulations which frames people who use services, carers and others as "consultees" rather than true partners who are co-producing services. This represents a missed opportunity for the regulations to re-define the way in which services are planned, managed and delivered.

ANNEX 2(D)

MEMBERSHIP, POWERS AND PROCEEDINGS OF INTEGRATION JOINT BOARDS ESTABLISHED UNDER THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. Are there any additional non-voting members who should be included in the Integration Joint Board?

Yes

No

2. If you answered 'yes', please list those you feel should be included:

Please see comments above about the role of national third sector organisations like Parkinson's UK. We note that the regulations specify one third sector organisation representative, and are concerned that this is likely to be seen as a role for an organisation that provides non-commercial care services.

Parkinson's UK recognises the important role of voluntary sector service providers, and believes that they ought to have a place on Joint Boards. However, we believe that the voices of other types of voluntary sector organisation also have an important – and distinct - contribution to make at this level. We would like to see an additional category of membership to support participation of organisations that provide information, campaigning and advocacy in Joint Boards.

3. Are there any other areas related to the operation of the Integration Joint Board that should also covered by this draft Order?

No comments

4. Are there any further comments you would like to offer on this draft Order?

Parkinson's UK remains concerned about the two- tier membership of Joint Boards between voting and non-voting members, as we and others have previously noted, that the non voting members are implicitly less important

than the voting ones.

In addition, we are concerned about a lack of transparency about the arrangements to select and support service user and carer roles on joint boards. As the Act does not support the continuation of PPF (Public Partnership Forum) structures on the new Health and Social Care Partnerships, it is not clear how these representatives will be selected, or how it will be possible for them to represent a wider view, or experiences other than their own. There does not appear to be an explicit requirement for these individuals to engage with – or be drawn from - the members of the Strategic Planning Group, which at least ought to include a wider range of individuals.

There is no apparent provision to ensure that the service user / carer representatives are supported or resourced to represent the interests of the diverse community of people who use services or care for someone who uses services. The legislation does not currently stipulate that Health and Social Care Partnerships have a duty to support and encourage ongoing public and service user involvement, and community capacity, as is the case with the most effective PPFs and other types of involvement forums.

Parkinson's UK has earlier raised concerns about the difficulties of involving people with significant and complex care needs at this level, and we are concerned that the essential insights from those who are significant users or a wide range of services may be lost from the Joint Boards.

A similar issue exists with regard to the third sector representatives, given the considerable diversity of organisations in the sector, which is likely to give rise to a wide range of perspectives. The regulations are silent about how the representative will be selected, and how it can be ensured that they are linked in to local and national their sector organisations with a range of interests, activities and work with a wide variety of service users and carers.

We share the ALLIANCE and Alzheimer Scotland's concerns about the power to call a meeting at three days' notice, and agree that this would place service users and carers at a significant disadvantage in terms of ability to participate in any such meeting.

ANNEX 3(D)

ESTABLISHMENT, MEMBERSHIP AND PROCEEDINGS OF INTEGRATION JOINT MONITORING COMMITTEES ESTABLISHED UNDER THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

Consultation Questions

1. Do you agree with the proposed minimum membership of the integration joint monitoring committee, as set out in the draft Order?

Yes

No

2. If you answered 'no', please list those you feel should be included:

See comments above on Joint Integration Boards.

3. Are there any other areas related to the operation of the integration joint monitoring committee that should also covered by the draft Order?

As above

4. Are there any further comments you would like to offer on this draft Order?

As above

ANNEX 4(D)

PRESCRIBED MEMBERSHIP OF STRATEGIC PLANNING GROUPS ESTABLISHED UNDER THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. The draft Regulations prescribe the groups of people that should be represented on the strategic planning group. Do you think the groups of people listed are the right set of people that need to be represented on the strategic planning group?

Yes

No

2. If no, what changes would you propose?

See comments above relating to the role of national third sector organisations, and issues relating to involving people with very complex needs.

Parkinson's UK has previously recommended that regulations should stipulate that joint boards / monitoring committees need to provide information about how they have engaged with people with complex needs within their engagement plans. This should also be extended to membership of the strategic planning groups. We acknowledge that it is very difficult to involve people with complex needs, but believe that it is extremely important and valuable to include the views and experiences of those who make most use of services.

3. Are there any further comments you would like to offer on these draft Regulations?

-

**PRESCRIBED FORM AND CONTENT OF PERFORMANCE REPORTS
RELATING TO THE PUBLIC BODIES (JOINT WORKING)
(SCOTLAND) ACT 2014**

CONSULTATION QUESTIONS

1. Do you agree with the prescribed matters to be included in the performance report?

Yes

No

2. If no, please explain why:

-

3. Are there any additional matters you think should be prescribed in the performance report?

Yes

No

4. If yes, please tell us which additional matters should be prescribed and why:

Parkinson's UK believes that it is essential that the performance report should include detailed on how the joint board / monitoring committee has involved people who use services and carers in its locality planning and other work, with a specific category to include those with complex needs.

5. Should Scottish Ministers prescribe the form that annual performance reports should take?

Yes

No

6. If you answered yes, what form should Scottish Ministers prescribe?

Parkinson's UK believes that Scottish Ministers should prescribe that plain English is used in the report, and that alternative formats are made available, to make sure that they are able to be understood by people who use services, carers and the public.

7. Are there any further comments you would like to offer on these draft Regulations?

While we support the broad goal of shifting the balance of care into communities, and believes that it is important to monitor progress in this direction, Parkinson's UK is concerned that the requirement to report on the transfer of resources from institutional to community services may have the unintended consequence of leading to inappropriate commissioning.

People with advanced Parkinson's typically require a range of support, delivered through a multi-disciplinary team led by specialist consultant and nurse input (which may be budgeted as "institutional spend") along with community and social care support for individuals and families. Parkinson's is such a complex and individual condition, with complicated medication regimes and side effect profiles. While GPs remain an important part of the team looking after someone with Parkinson's, a typical GP will only see one new case of Parkinson's every three years, so they lack the experience needed to diagnose and lead the management of Parkinson's.

As the SIGN Guideline on the diagnosis and pharmacological management of Parkinson's Disease and NHS HIS Clinical Standards for Neurological Conditions make clear, it is essential that care is led by specialists to ensure that people remain as well as possible for as long as possible, and do not end up being admitted to hospital or care homes for want of a medication change or therapy intervention.

We are concerned that commissioners may not recognise the critical importance of this specialist input for this group of people, and reduce the budget for these specialist services. This would be a false economy, leading to more costly hospital or care home stays.