ANNEX 1(D)

PROPOSALS FOR PRESCRIBED INFORMATION TO BE INCLUDED IN THE INTEGRATION SCHEME 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 Integration Scheme?

   Yes ☒

   No ☐

2. If no, please explain why:

3. Are there any additional matters that should be included within the regulations?

   Yes ☒

   No ☐

4. If yes, please suggest:

In common with the ALLIANCE for Health and Social Care - whose submission we contributed to and fully support - Parkinson's UK is concerned that the draft regulations marginalise the role of non-statutory partners in the process of integration, while providing extremely detailed guidance about the information provided about the roles of NHS Boards and Local Authorities.

In particular, integration joint boards / monitoring committees are not asked to provide information about how people who use services, including people with conditions and carers, as well as third sector organisations that work with people who use services, are actively involved in their work at every level, as equal partners. They are asked only to provide details of service users and carers appointed to joint boards / monitoring committees, and to detail processes for "consultation" and "engagement" with "the public, representative groups and other organisations". This language is very limited,

[continues]

and old-fashioned. The regulations do not promote a move towards active involvement and co-production, but rather suggest that people who use service and organisations that work with them need only be passively “consulted” or “engaged” on plans. We fear that this could very easily become a “rubberstamping” exercise, rather than a genuine process of engagement and partnership working. This is of particular concern in light of the fact that we are aware that some shadow boards currently have no service user, carer or third sector involvement. We believe that there is a real risk that wider involvement and partnership working could be an afterthought.

Parkinson’s UK believes that the regulations need to include more specific requirements, using language that reflects active involvement from people who use services and organisations that work with them. We fully support the ALLIANCE’s call for information to be sought on the outcome and impact of engagement with people through the regulations.

Involving people with complex needs like Parkinson’s

Parkinson’s UK has serious concerns about how people with Parkinson’s who use services and their carers will be able to be involved in the work of joint boards / monitoring committees. Parkinson’s is a very complex condition, and people’s care needs increase significantly as the condition progresses.

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 offers limited symptom control. 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.

These health issues make it very difficult for many people with Parkinson’s and their carers to make an ongoing commitment to involvement in local forums, yet their significant use of a wide range of services and support means that they often have extremely valuable insights to offer about the ways in which care is offered to individuals and families. We would like to see the regulations stipulate that joint boards / monitoring committees need to provide information about how they have engaged with people with complex needs within their engagement plans.

Involving National Charities

In addition, as a national charity, Parkinson’s UK, in common with other third sector organisations, has very limited capacity to participate in local strategic planning. We believe that Scottish Government needs to consider how the role and experience of important national organisations can be included within the integration landscape.

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[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

Communicating the work of joint boards / monitoring committees
We share the ALLIANCE's concerns that the statutory and technical nature of the regulations risks distancing people who use services and the public from the work that is being done. Parkinson's UK believes that the regulations should stipulate a duty to communicate with the public, including people who use services and carers, in accessible language about the work of joint boards or monitoring committees. This is particularly important to foster a spirit of true co-production and in times of change.

Complaints procedures
Parkinson's UK has repeatedly raised concerns about a lack of clarity on peoples' rights to engage with joint boards and monitoring committees once they are established. We see complaints as a major mechanism to facilitate and enable improvement in services, as well as providing essential avenues for people who use services to address individual issues. We therefore welcome the decision to stipulate that there is a statutory responsibility to outline complaints procedures.

However, there remain a number of areas where the status of people that will use integrated services is unclear. Looking at section 2 of the regulations, it looks as though the intention is to apply existing social care structures and policies to services currently defined as "social care" and NHS systems to those who are using services currently defined as health care. However, Parkinson's UK is concerned that this risks entrenching existing barriers to a seamless, person centred service, and causes confusion for people using services about which procedures apply to them.

In addition, there is an ongoing issue around the definition of "health" and "social care" services, and this is not a clear cut distinction.

In light of this confusion, Parkinson's UK believes that the regulations should specify a route into a single complaints process where people's rights are very clear.

Parkinson's UK also supports a mechanism to enable groups of people to take collective complaints, this would be particularly useful in situations where services are withdrawn or are changed – for example in the event of care home closures, or in cases where there are systemic issues where individuals may feel too vulnerable to raise a complaint as an individual.

Workforce Development
Parkinson's UK is concerned that matters relating to workforce development are addressed solely in terms of issues relating to the workforce employed by statutory partners. There are significant strategic issues that relate to workforce planning across other providers of social care services, and we believe that joint boards and monitoring bodies have a responsibility to consider these as part of their strategic planning processes if they are to provide adequate care and support packages. In some parts of Scotland, there appears to be no strategic plan to address local care worker shortages in the voluntary and private sectors, which provides much of the home care and residential care services. This is having a profound impact on people's access to the care packages that they need – and is also causing real issues with distress for individuals and families,

lack of appropriate respite provision, and delayed discharges.

We believe that the regulations must address the need for joint boards / monitoring committees to address strategic workforce planning issues across the whole range of providers, as well as addressing the issues that the legislation raises for them as employers of staff from the NHS Board or local authority.

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

No.

ANNEX 2(D)

PROPOSALS FOR PRESCRIBED FUNCTIONS THAT MUST BE DELEGATED BY LOCAL AUTHORITIES RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. Do you agree with the list of Local Authority functions included here which must be delegated?

Yes ☒

No ☐

2. If no, please explain why:

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

Please see comments in Section 1 above, which relate to the difficulty of maintaining a division between “health” and “social care” services in the light of integration, and the potential confusion for individuals who receive a mixture of services.

People with advanced Parkinson’s and their families should receive care from a wide range of services, including multi-disciplinary care from health care professionals based in specialist secondary care services, primary and community healthcare teams, and social care teams. We are concerned that it will be very difficult for individuals and families to understand which systems and rights apply to them in relation to their care.

We believe that the Scottish Government needs to address this confusion as it moves forward with integration.

ANNEX 3(D)

PROPOSALS FOR REGULATIONS PRESCRIBING FUNCTIONS THAT MAY OR THAT MUST BE DELEGATED BY A HEALTH BOARD UNDER THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. Do you agree with the list of functions (Schedule 1) that may be delegated?

Yes ☒

No ☐

If no, please explain why:

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2. Do you agree with the list of services (Schedule 2) that must be delegated as set out in regulations?

Yes ☒

No ☐

If no (i.e. you do not think they include or exclude the right services for Integration Authorities), please explain why:

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3. Are you clear what is meant by the services listed in Schedule 2 (as described in Annex A)?

Yes ☒

No ☐

If not, we would welcome your feedback below to ensure we can provide the best description possible of these services, where they may not be applied consistently in practice.

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4. Are there any further comments you would like to offer on these draft regulations?

Parkinson’s UK has major concerns about the unintended consequences of integrating medical services provided by care of the older people departments, but not those provided by other departments. We believe that this may have the effect of exacerbating variation in the services accessed by people with Parkinson’s depending on their age.

Most people who live with Parkinson’s are aged over 65, but a significant minority are aged under 65. One in 20 is aged under 40 when they are diagnosed. Some people have their care led by multi-disciplinary teams based in care for older people (which will be subject to integration), and others in neurology departments (which will not). In many cases there is close working between teams, which enables people to access appropriate services when required. We would hope that integration would not have the unintended consequence of making it more difficult for NHS services to work together in this way.

The distinctions are not always defined by age, but by referral patterns from primary care, geography and personal choice. Parkinson’s UK believes that people’s access to appropriate services should be based on their need and personal choice, and not age. We would hope that people would not be forced into changing their MDT at the age of 65, or be told that they have to see a certain team based solely on their age at diagnosis.

ANNEX 4(D)

PROPOSALS FOR NATIONAL HEALTH AND WELLBEING OUTCOMES RELATING TO THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) ACT 2014

CONSULTATION QUESTIONS

1. Do you agree with the prescribed National Health and Wellbeing Outcomes?

Yes ☐

No ☒

If no, please explain why:

Parkinson's UK strongly supports the points made in the ALLIANCE response about the National Outcomes, which capture our views on the limitations of the National Health and Wellbeing Outcomes and makes positive suggestions about how these essential outcomes might be reframed more positively and helpfully around people who use services.

2. Do you agree that they cover the right areas?

Yes ☐

No ☐

3. If not, which additional areas do you think should be covered by the Outcomes?

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4. Do you think that the National Health and Wellbeing Outcomes will be understood by users of services, as well as those planning and delivering them?

Yes ☐

No ☐

5. If not , why not?

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

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