

## Annex G Consultation Questionnaire

### The case for change

**Question 1:** Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older people, and then to extend our focus to improving integration of all areas of adult health and social care, practical and helpful?

Yes  No

Comments Parkinson's UK understands the Scottish Government's rationale for proposing an initial focus on outcomes for older people, but we have some concerns about the implications of this approach.

Although the majority of people living with Parkinson's are older people, there is a significant minority of people who are aged under 65. One in every twenty people with Parkinson's is under 40 when they are diagnosed. People with Parkinson's, their carers, and the professionals that care for them often tell us that it is more difficult to arrange appropriate care packages for people aged under 65 than for older people. This is sometimes because people of working age have different needs from services (eg a placement in a care home for older adults is not appropriate for a person in their 50s), and sometimes because the services are configured so that only people aged over 65 are eligible for the support as it is supplied.

Parkinson's UK believes that there is a risk that focussing on older people's services could entrench these divides in service provision, which would be extremely unhelpful. Drafting the legislation on the premise that older people's services will be prioritised for implementation could make it less likely that the legislation will reflect the needs of all age groups.

In order to overcome this risk, it will be necessary to make sure that the legislation reflects the needs and aspirations of people in all age groups and similarly that implementation does not assume that models of service provision that work for older people are automatically applicable to younger people.

### Outline of proposed reforms

**Question 2:** Is our proposed framework for integration comprehensive? Is there anything missing that you would want to see added to it, or anything you would suggest should be removed?

Yes  No

Comments Parkinson's UK welcomes the broad thrust of the integration framework, and the goal of achieving more integrated, person-centred experience of care. Within this it is important to acknowledge that:

- people with complex long term conditions like Parkinson's (which commonly has a wide range of symptoms and medication side effects including mobility and other physical issues with mental health and cognitive issues) require ongoing access to specialist healthcare throughout the course of their condition. The NHS Healthcare Improvement Scotland Clinical Standards for Neurological Health Services<sup>1</sup> state that people with Parkinson's require specialist care, provided by specialist multi-disciplinary teams, including specialist nurses. Without this specialist input, people with Parkinson's are at greater risk of hospital or care home admission. When Parkinson's nurse specialists visit care home residents with Parkinson's, they can identify changes to medication that prevent transfer to hospital.
- as the condition progresses, people's specialist medical needs increase, alongside their need for additional support provided through social care services. It will be essential to ensure that the new framework allows for ongoing specialist input, and that reallocation from acute budgets does not have the consequence of reducing specialist input to those who need it most.
- some hospital and care home admissions are entirely appropriate, and steps need to be taken to make sure that new systems do not raise barriers to necessary admissions
- while many people will wish to remain living at home as long as possible, it is not always the case, particularly if the person lives alone or the home is not accessible and cannot be adapted to make it so
- independent living is about being in control of your own life decisions rather than where you live. In itself, living in your own home does not promote independent living
- in light of the critical importance of housing, we believe that aspects of housing

<sup>1</sup> NHS QIS (2010) Clinical Standards for Neurological Health Services. Edinburgh: NHS Quality Improvement Scotland.

budgets should also be included within HSCPs

- the consultation document is largely silent on the implications of merging an NHS system which is free at the point of need with social care where variable charges can apply and eligibility criteria are introduced. Parkinson's UK has real concerns about the potential for people with complex care needs to have support currently provided by the NHS re-defined as chargeable services
- while the consultation document is clear on the need to support unpaid carers, it will be challenging to translate this into the meaningful support on the ground that is essential to enable carers to support people to remain at home. This will be particularly important when people require high levels of care and supervision, or are manifesting challenging behaviour.
- the needs of growing numbers of people with care needs who live alone, and do not have unpaid carers will need to be met without recourse to unpaid carers.
- loneliness is a strong risk for adults living alone, especially for those with complex care needs that limit time spent outside the home. Recent studies suggest that loneliness is associated with worse outcomes and higher mortality amongst older people.<sup>2 3</sup> Avoiding the risk of loneliness should be considered as part of the framework.

### National outcomes for adult health and social care

**Question 3:** This proposal will establish in law a requirement for statutory partners – Health Boards and Local Authorities – to deliver, and to be held jointly and equally accountable for, nationally agreed outcomes for adult health and social care. This is a significant departure from the current, separate performance management mechanisms that apply to Health Boards and Local Authorities. Does this approach provide a sufficiently strong mechanism to achieve the extent of change that is required?

Yes  No

Comments Parkinson's UK strongly supports the principle that NHS Boards and Local Authorities should be accountable for nationally agreed outcomes for health and social care, but we are concerned that there is a gap in terms of accountability

<sup>2</sup> Perissinotto CM, Censer IS, Covinsky KE (2012) Loneliness in Older Persons A Predictor of Functional Decline and Death *Arch Intern Med.* 2012;172(14):1078-1084. doi:10.1001/archinternmed.2012.1993

<sup>3</sup> Udell JA, Steg PG, Scirica BM, et al. (2012) Living Alone and Cardiovascular Risk in Outpatients at Risk of or With Atherothrombosis *.Arch Intern Med.* 2012;172(14):1086-1095. doi:10.1001/archinternmed.2012.2782

for local authorities.

The draft national outcomes provide a strategic steer, but they are not measurable. It is hard to see how national standards can be enforced because of the different systems of accountability between the NHS and local authorities.

We welcome the fact that HEAT targets provide measurable targets for the NHS, and that Boards are accountable for the achievement of these, but note that there is no similar national target setting for local authorities.

The huge variety in Single Outcome Agreements makes it very difficult to monitor outcomes between different local authorities, and there is no mechanism to ensure that SOAs are met. It also has the potential to exacerbate inequalities in service provision between local authorities.

Parkinson's UK would like to see national standards – perhaps relevant HEAT targets – applied to both NHS and local authorities.

**Question 4:** Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?

Yes  No

Comments Parkinson's UK believes that SOAs should include nationally agreed outcomes as a minimum. As outlined above, we would like to see more measurable targets to be included in SOAs.

### **Governance and joint accountability**

**Question 5:** Will joint accountability to Ministers and Local Authority Leaders provide the right balance of local democratic accountability and accountability to central government, for health and social care services?

Yes  No

Comments Parkinson's UK does not wish to respond to this question.

**Question 6:** Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?

Yes  No

Comments Parkinson's UK believes that this should be possible. There are significant resource issues for NHS Boards that include a range of local authority areas, such as NHS Greater Glasgow and Clyde, which covers 6 local authorities, and provides services to significant number of residents in a further two council areas. Furthermore, it is possible that organising HSCPs in this way would enable people to access suitable services currently provided by another local authority, improving access to services.

However, there are governance concerns when more than one local authority is involved, and it would be interesting to see proposals to maintain joint accountability in this case.

In addition, our experience of working on service development within NHS boards has illustrated that there are often very large differences in services and referral protocols between different local authority areas. It will be extremely challenging for an HSCP to ensure that an equitable service is provided across multiple local authority boundaries, and we would welcome additional guidance on how HSCPs will be able to facilitate and encourage this.

**Question 7:** Are the proposed Committee arrangements appropriate to ensure governance of the Health and Social Care Partnership?

Yes  No

Comments Parkinson's UK is concerned about the potential for third sector, service user and professional views to become marginal, given the proposal for voting rights to be limited to NHS Board and Local authority elected members.

We recognise that there may be concerns around accountability, but believe that the principle should be that all members of the HSCP have equal voting rights to avoid tokenism. There should be safeguards around conflict of interest in the case of service providers influencing outcomes In favour of their services.

**Question 8:** Are the performance management arrangements described above sufficiently robust to provide public confidence that effective action will be taken if local services are failing to deliver appropriately?

Yes  No

Comments Parkinson's UK does not wish to answer this question.

**Question 9:** Should Health Boards and Local Authorities be free to choose whether to include the budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?

Yes  No

Comments Yes, Parkinson's UK would welcome this. We would also welcome some move to include an element of housing budget in the HSCP.

### Integrated budgets and resourcing

**Question 10:** Do you think the models described above can successfully deliver our objective to use money to best effect for the patient or service user, whether they need “health” or “social care” support?

Yes  No

Comments Parkinson's UK shares the view that delivering best outcomes for patients or service users is about more than the legislative structures that are in place. In Highland, improvements in outcomes for older people<sup>4</sup> have largely predated the move to lead commissioning, and the formal amalgamation of

<sup>4</sup> Baker A, Leak P, Ritchie LD et al (2012) Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation *British Journal of General Practice* e113

health and social care systems in April 2012. Their success has depended upon cooperation between primary, secondary and social care workforces. This level of commitment, respect and interaction is driven by the culture of the health and care professionals and managers involved, and may not be guaranteed under the new model.

We have significant concerns about how pooled budgets might work in a time of austerity and increasing demand for services. In particular, we believe that there is a risk that people with complex care needs, such as those with advanced Parkinson's, may not have these needs adequately met. It is important to emphasise the need for input from a range of professionals – medical, nursing, allied health professional and care workers - for people with advanced Parkinson's, and that they are likely to require both specialist and generic support as the condition progresses.

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.<sup>5</sup> The symptoms of advanced Parkinson's can include problems with swallowing, weight loss, frailty, falls, immobility, mental health issues and dementia. People with advanced Parkinson's are at high risk of infections and other life-threatening situations.

Evidence from across Scotland shows that specialist Parkinson's nurses undertake home visits that can help to prevent admissions to hospitals and care homes.<sup>6</sup> Some forms of treatment, such as apomorphine pumps, require ongoing nursing support. There is limited understanding amongst non-specialist staff about the wide range of Parkinson's symptoms and the critical importance of people with Parkinson's receiving their medication on time every time. Failure to achieve concordance with complex medication regimes can have a very serious impact on people's Parkinson's symptoms, which can become dangerously uncontrolled.

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<sup>5</sup> 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 Hoc/Parkinson's UK

<sup>6</sup> Parkinson's UK (2012) Parkinson's nurses in Scotland: providing effective, safe, person-centred care. London: Parkinson's UK. Online [http://www.parkinsons.org.uk/advice/publications/professionals/scotland\\_nurse\\_report.aspx](http://www.parkinsons.org.uk/advice/publications/professionals/scotland_nurse_report.aspx)

People with Parkinson's and their families consistently tell us that they need their care to be provided by professionals that understand the complexity of Parkinson's and its treatment. We are concerned to make sure that the pressure to save money does not result in a false economy of reducing specialist and general health input to people with complex conditions like Parkinson's. The difficulty that people have in qualifying for NHS continuing care, despite having needs driven by their health condition, demonstrates that there are risks of setting the bar prohibitively high to qualify for NHS support within the social care system. Given that generic social care support is significantly cheaper than nursing or AHP support, we are concerned that budget minded HSCPs will respond by reducing nursing and AHP support in favour of cheaper social care.

As in the successful NHS Highland projects, it will be important to use specialist and acute resources to identify people at high risk or hospital and care home admission and intervene proactively to plan care, address polypharmacy and prevent unnecessary admissions. This model is dependent on using all members of the team, including specialist staff.

We are also very concerned that the consultation makes no reference to the considerable difficulties in integrating a free at the point of use NHS service with a chargeable social care one. We are very concerned that people with Parkinson's should not find themselves liable to pay for services which have been provided for free. There is also potential for the current inequalities in service charges to be perpetuated under the new system.

The related issue of eligibility criteria raises the risk that budget constraints could act against preventive care. Many people with Parkinson's do not meet the current eligibility criteria for social care intervention, because their condition is long-term and fluctuating. The eligibility criteria typically do not take account of the long-term impact of a condition, and can limit service provision to crisis interventions. People with Parkinson's report that in some areas of Scotland preventative services and early interventions that would enable them to receive care at home are not being funded. In some parts of Scotland, this is combined with long waiting lists once the criteria have been met. We would be extremely concerned if this culture were to prevail in the new arrangements, and the risk that eligibility criteria could govern access to support across health and social care.

Finally, we are concerned that there may be a lack of clarity around entitlement to self-directed support, given that there is no culture or legislation to encourage people to use self-directed support mechanisms within the NHS.

**Question 11:** Do you have experience of the ease or difficulty of making flexible use of resources across the health and social care system that you would like to share?

Yes  No

Comments People with Parkinson's and their families have a range of experiences, both positive and negative.

One of the major advantages of the Parkinson's nurse specialists is their ability to work across the acute, community and social care landscape and coordinate appropriate care, particularly in advanced Parkinson's and at the end of life.

However, there are significant failures in many areas, including cases where

- OTs have recommended aids and adaptations and local authorities have delayed funding for significant periods of time. In some cases, delays have been so long that the person has died before alterations have been approved
- People with Parkinson's have been discharged from hospital with no ongoing care package, sometimes in the middle of the night
- Waiting times for social care assessment and support are prohibitively long and have kept people dependent on hospital services and unpaid carers when they need more home-based support

**Question 12:** If Ministers provide direction on the minimum categories of spend that must be included in the integrated budget, will that provide sufficient impetus and sufficient local discretion to achieve the objectives we have set out?

Yes  No

Comments It is not clear whether the objectives will be achieved without having an idea about the categories of spend that Ministers will include. We do however support the idea that Ministers should provide some direction to make sure that there is some consistency between HSCPs.

### Jointly Accountable Officer

**Question 13:** Do you think that the proposals described here for the financial authority of the Jointly Accountable Officer will be sufficient to enable the shift in investment that is required to achieve the shift in the balance of care?

Yes  No

Comments Parkinson's UK does not wish to answer this question.

**Question 14:** Have we described an appropriate level of seniority for the Jointly Accountable Officer?

Yes  No

Comments Parkinson's UK does not wish to answer this question.

### Professionally led locality planning and commissioning of services

**Question 15:** Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?

Yes  No

Comments On balance, Parkinson's UK believes that it will be helpful for the Scottish Government to provide some guidance on locality planning, to avoid wide variation in service provision and inequalities in care. Our experience of developing care pathways for Parkinson's at NHS Board level shows that there is considerable potential for services to be very different between CHPs within the same Board.

We recognise the benefits of a locality based approach which pulls together professionals from all disciplines and all sectors. This approach is exemplified in

NHS Highland's work.

However, we do have concerns about a lack of accountability of the locality planning groups which could be given significant budgets without the accountability and scrutiny attached to the HSCPs.

In addition, Parkinson's UK has some concerns that relatively low prevalence conditions like Parkinson's could be overlooked in smaller locality groups. Although there are relatively low numbers of people with Parkinson's, they are very significant users of health and care services.

Evidence presented to the Westminster Public Accounts Committee about the NHS in England suggested that populations of 0.5 million are needed for optimal commissioning for neurological services.<sup>7</sup> We recognise that this refers to all acute services for people with neurological conditions and that the situation in Scotland is different, with many NHS Boards serving smaller populations. However, the complexity and sector-crossing nature of care for people with neurological conditions remains. We believe that the extremely small populations of the proposed localities may make it more difficult to plan for some high need conditions.

**Question 16:** It is proposed that a duty should be placed upon Health and Social Care Partnerships to consult local professionals, including GPs, on how best to put in place local arrangements for planning service provision, and then implement, review and maintain such arrangements. Is this duty strong enough?

Yes  No

Comments The NHS Highland example, and the partnership model of working within the NHS provides a positive model for staff involvement.

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<sup>7</sup> Committee of Public Accounts (2012) Minutes of Evidence HC 1759P <http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/120118.htm>

However, we are disappointed that there is no proposed mechanism for co-production in these groups. This is a missed opportunity. We would also want to see meaningful involvement from service users and the third sector in locality planning.

**Question 17:** What practical steps/changes would help to enable clinicians and social care professionals to get involved with and drive planning at local level?

Comments Parkinson's UK does not wish to respond to this question.

**Question 18:** Should locality planning be organised around clusters of GP practices? If not, how do you think this could be better organised?

Yes  No

Comments Parkinson's UK does not wish to respond to this question.

**Question 19:** How much responsibility and decision making should be devolved from Health and Social Care Partnerships to locality planning groups?

Comments Parkinson's UK is concerned about the risk of considerable divergence in service provision if services and planning are significantly devolved. It will be very important to balance the needs for locally responsive planning and engagement against the need for consistency and accountability about services.

**Question 20:** Should localities be organised around a given size of local population – e.g., of between 15,000 – 25,000 people, or some other range? If so, what size would you suggest?

Yes  No

Comments As noted above, we have concerns about commissioning for lower prevalence conditions in small populations. In most mainland areas, there is potential for much larger localities. Ross and Cromarty's community care team covers a population of over 50,000 people. If this can be achieved in such a remote and rural area, there is no reason why populations of this size and larger cannot be used elsewhere.

We would also suggest that there should be some attention paid to geographical factors, in particular in remote and rural areas, when creating areas for locality

planning.

**Do you have any further comments regarding the consultation proposals?**

Comments No.

**Do you have any comments regarding the partial EQIA? (see Annex D)**

Comments No.

**Do you have any comments regarding the partial BRIA? (see Annex E)**

Comments No.