

## Annex B CONSULTATION QUESTIONNAIRE

Question 1 :

Do you agree that the arrangements that should be in place to support an organisational duty of candour should be outlined in legislation ?

Yes  No

Parkinson's UK strongly welcomes the proposal to outline the arrangements for an organisational duty of candour in legislation. We are aware of instances where people with Parkinson's have experienced significant harm in both health and social care settings. Parkinson's UK strongly supports measures already taken by Scottish Government, professional bodies, regulators and care providing organisations to promote a culture of openness around mistakes through ethics and policy, but the experience of families affected by Parkinson's in Scotland reflects the evidence outlined in the consultation paper that these measures have not been successful in achieving consistent change across health and social care.

We believe that legislation is also needed to ensure that change happens at every level, and that anyone who uses services - in whatever setting, and in whichever part of the country - can expect that mistakes will be treated in the same way.

We believe that achieving a consistent approach is particularly important in the light of health and social care integration, where people who use services are likely to receive both NHS and social care services, and ought to have the same rights in relation to all their care.

Question 2:

Do you agree that the organisational duty of candour encompass the requirement that adequate provision be in place to ensure that staff have the support, knowledge and skill required ?

Yes  No

Parkinson's UK believes that it is essential that people who use services, and their families and carers are given information about mistakes made during care in the most sensitive way possible. Given that disclosure is very likely to occur in situations that are already potentially difficult and emotional, where someone has experienced significant harm or even death, it will be very important to make sure that disclosure does not have the unintended consequence of increasing distress or causing other emotional or psychological harm to individuals and families by being poorly delivered.

We believe that it is essential that staff receive the training and support that they need to deliver this information appropriately, and to respond to the individual needs of individuals and families.

In addition to the needs of people who have experienced mistakes, there is also a strong issue of staff welfare and organisational culture. We believe it is essential to create an organisational culture where staff disclosing mistakes receive support and training to conduct these conversations effectively.

Question 3a: Do you agree with the requirement for organisations to publically report on disclosures that have taken place?

Yes  No

Parkinson's UK agrees that organisations should report on disclosures, as this is a key measure of accountability and transparency. We believe that a consistent and binding legal duty to disclose harm for all organisations will minimise the potential for bodies with good practice on disclosures to appear to be performing less well than those with poor practice (ie those which do not disclose harm). Reporting on the outcomes of the disclosure will also enable important learning to be shared within and outside the organisation. Taken together, they could be a valuable resource enabling patterns of similar types of harm to be identified and measures developed to avoid repeated preventable mistakes.

Question 3b: Do you agree with the proposed requirements to ensure that people harmed are informed ?

Yes  No

Yes, individuals who use services, and carers and families, should be informed where there has been harm. Parkinson's UK also believed that they must also have the opportunity to participate in the review process, as proposed. This is important both in situations where individuals, carers or families have raised concerns that an error may have been made, and in cases where no concerns have been raised.

Parkinson's UK believes that in most cases, individuals would want families and carers to be involved, but recognises that in some cases people will prefer their confidentiality to be respected. We would hope that this area will be dealt with sensitively, so that the key role that carers and family members often have in supporting individuals is not lost in the guidance when addressing necessary issues of confidentiality for individuals.

People with Parkinson's are at very high risk of lacking capacity – either through temporary issues such as medication issues, or infections that impact on people's cognitive function, or through the development of

Parkinson's dementia, or mental health symptoms like depression or psychosis. About 1 in 3 of all people with Parkinson's have dementia,<sup>1</sup> and more than 80% of people who have lived with Parkinson's for twenty years or more have dementia.<sup>2</sup>

However, Parkinson's is a fluctuating condition, and people's cognitive symptoms can vary considerably over time. People can also have communication issues, including slowness of speech which can be lead to misleading assessments of cognitive function.

Parkinson's UK believes that, even where an individual is assessed as lacking capacity to make decisions about their care and treatment, that they should have the opportunity to be included in the review process. This right to participate should be open to everyone.

Question 3c: Do you agree with the proposed requirements to ensure that people are appropriately supported ?

Yes  No

Parkinson's UK strongly supports the principle that individuals, carers and families should be supported. It is very unclear from the consultation document what would be deemed to be appropriate support, however. We would hope that these would be subject to further consultation once there are clear proposals about the support that organisations should offer.

Parkinson's UK believes that it will be very important for some individuals and families to receive support that is **independent** of the organisation that is disclosing harm. We believe that independent support should be offered in all cases, although the individual or family should have the choice about whether to take up the offer.

Each situation will all be different, and different people, carers and families may require different kinds of support. Parkinson's UK believes that services that should be offered must include the following:

- independent advocacy to enable people to participate fully in the review process and make their views known
- counselling and emotional support
- accurate, up to date, and accessible information
- referrals to PASS for those whose harm took place in the NHS, and to other appropriate organisations for those whose harm took place elsewhere.

Question 4:

What do you think is an appropriate frequency for such reporting ?

Quarterly  Bi-Annually  Annually  Other  (outline below)

Parkinson's UK believes that there should be a fixed timetable for reporting on disclosable incidents, and that this should be published regularly. We believe that this should include all live reports, with a note where investigations are not yet complete, as well as those where investigations have been concluded.

Question 5:

What staffing and resources that would be required to support effective arrangements for the disclose of instances of harm ?

Please see comments above about independent resources required for people who have experienced harm.

There may also be a case for offering independent support to professionals who have been involved in a disclosure or instance of harm.

Question 6a:

Do you agree with the disclosable events that are proposed ?

Yes  No

Parkinson's UK supports the definitions of disclosable events proposed, although we note that the precise definitions that the legislation might adopt are subject to consultation with professional stakeholders. While we recognise that there are different cultures within health and social care, it is important for people who use services to have consistent definitions of a disclosable event, applicable in every setting, or at least to achieve equivalence between them. This is particularly important in the context of health and social care integration. We would hope that the resulting definitions would be subject to wider consultation before being finalised.

There is currently some ambiguity about whether points 9.11 and 9.12 are intended to apply in all settings, or just to those using health services.

Parkinson's UK has some concerns about the exclusions around death or shortened life expectancy "[as a result of] the natural course of their illness or underlying condition" / "as a result of a long-term condition where this is an expected outcome". We are concerned about how these may apply in the case of incidents affecting people with conditions like advanced Parkinson's. While we recognise that it will be important to acknowledge that not all deaths or injuries can be prevented, and are an inevitable consequence of having a condition, we would be very concerned if these

provisions were to result in an effective exclusion for people who are frail or are reaching the end of life, or those with certain conditions. It will be very important to make sure that, where an error has taken place, that people who are frail have the same entitlement to disclosure as other people who use services, and we would suggest that this should be made clear in the legislation.

Parkinson's UK particularly welcome the range of disclosable events that are proposed – ranging from events resulting in a preventable death or injury or prolonged harm through to harms that result in prolonged treatment.

People with Parkinson's are at high risk from a range of harms as a result of errors in their care, and the impact of mistakes can include death, ongoing impairment, and extended treatment.

For example, people whose movement and / or swallowing are affected by Parkinson's can be at particular risk of malnutrition, dehydration and choking for example. People who have severe mobility issues are at particular risk from pressure sores and infections. Falls are a major risk for people with gait, movement, and balance issues, and people with incontinence need to receive regular continence care to protect their dignity and skin integrity. In addition, medications management is a particular issue for people with Parkinson's throughout the course of their condition. We believe that failure to support people to get their Parkinson's medication on time should constitute a disclosable incident.

Parkinson's UK has a well-established Get It On Time campaign, which aims to ensure that people with Parkinson's get their medication on time, every time in hospital and care homes. This is reflected in the NHS HIS Care Standards for Neurological Health Services.

The main treatment for Parkinson's is medication. Medication can help to manage symptoms but does not stop the underlying progression of the condition. If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their brains can become severely disrupted – leading to the symptoms of the condition becoming uncontrolled.

Uncontrolled symptoms can include:

- being unable to move, speak, eat or swallow
- uncontrolled movements
- distressing psychotic symptoms

It can take weeks to restore effective symptom control. In some cases, the person never recovers to the same level they were before their medication was missed or administered late.

A 2013 YouGov survey completed by 4,777 people with Parkinson's, family members or carers of a person with the condition in the UK, found that of

those having been in hospital or a care home, 30 per cent reported not having received their medication on time.<sup>3</sup>

Every person with Parkinson's who does not receive their medication on time will be affected differently. Some are never able to fully recover their health, while some face few long-term complications as a result. However, even in cases where the person makes a full recovery, extended hospital stays are common, along with severe distress at the symptoms that people have experienced as a result of missed doses. It is common for people with Parkinson's who have had medication issues in hospital to report that they are terrified of going back into hospital.

Question 6b: Will the disclosable events that are proposed be clearly applicable and identifiable in all care settings ?

Yes  No

On balance, Parkinson's UK believes that these disclosable events are broadly applicable in all care settings, subject to our comments above.

Question 6c:

What definition should be used for 'disclosable events' in the context of children's social care?

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Question 7

What are the main issues that need to be addressed to support effective mechanisms to determine if an instance of disclosable harm has occurred ?

Parkinson's UK believes that infrastructure around the duty of candour needs to take account of the often central role of individuals, carers and families in raising concerns about their care. Care providers need to have effective mechanisms to capture feedback which must be linked to the duty of candour processes.

Question 8:

How do you think the organisational duty of candour should be monitored ?

Parkinson's UK supports the direction of travel laid out in the consultation.

Question 9:

What should the consequences be if it is discovered that a disclosable event has not been disclosed to the relevant person ?

Parkinson's UK believes that organisational consequences could include fines, closure of the organisation, removal of care contracts where relevant, or removal of the organisation's leaders and banning them from holding leadership roles in the future. There should also be the option of issuing a public reprimand of the organisation.

Although the duty of candour is framed as an organisational responsibility, there should also be the option to report individuals who fail to disclose incidents to their professional body, and for them to be subject to internal disciplinary or performance measures.

### **End of Questionnaire**

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<sup>1</sup> Aarsland D, Kurz MW (2010) The epidemiology of dementia associated with Parkinson's disease. *J Neurol Sci.* 2010 Feb 15;289(1-2):18-22

<sup>2</sup> [Hely MA](#), [Reid WG](#), [Adena MA](#), [Halliday GM](#), [Morris JG](#). (2008) The Sydney multicenter study of Parkinson's disease: the inevitability of dementia at 20 years [Mov Disord.](#) 2008 Apr 30;23(6):837-44.

<sup>3</sup> Parkinson's UK and YouGov, *Survey of people with Parkinson's and their friends, family and carers*, 2013