

CONSULTATION QUESTIONS

Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but we want to consult on:

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes;
- Whether there are any gaps in the key challenges identified;
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

Parkinson's UK is glad to have the opportunity to respond to this consultation. We would particularly like to highlight the following:

- Significant gaps in mental health service provision for people with long term neurological conditions such as Parkinson's, despite very high levels of mental health need in people with these conditions – in Parkinson's these often include anxiety, depression, dementia, impulse control disorders and hallucinations, which can be caused by the condition itself or medication side effects;
- Stigma associated with mental health symptoms associated with Parkinson's and the issues this can raise for people with the condition, carers, families and professionals;
- Training needs for professionals working with people with Parkinson's and their families;
- Positive examples of work to meet the mental health needs of people with Parkinson's, including patient pathways, joint clinics, supported self management approaches, and research
- The willingness of Parkinson's UK to work collaboratively with the Scottish Government, NHS, local government and other organisations to help to ensure that the mental health needs of people with Parkinson's and their carers are met.

About Parkinson's

About 10,000 people in Scotland have Parkinson's.

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples' day-to-day lives. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'. There is no cure.

Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50-60 years of

age, and the incidence increases with age. Most people living with Parkinson's are over 65. However, one in seven people with Parkinson's will be diagnosed before the age of 50 and one in twenty are diagnosed before the age of 40.

About Parkinson's UK

For more information, please contact our Parliamentary and Campaigns Officer, Tanith Muller, email: tmuller@parkinsons.org.uk, telephone 0844 225 3726.

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone. We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's. As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services. Our work is totally dependent on donations.

We have a dedicated staff team in Scotland, and local groups across the country supporting people affected by Parkinson's.

Find out more about us at parkinsons.org.uk

Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes. An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

Question 1: In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes.

We believe that locally-specific patient pathways can help to enable people to access appropriate mental health services. Parkinson's UK is very keen to support this type of work. For example, in NHS Ayrshire and Arran, people affected by Parkinson's have played a central role in developing a patient pathway for people with Parkinson's, which indicates how and when people with Parkinson's should be referred to different levels of mental health support. We are also involved in similar work in NHS Dumfries and Galloway and NHS Tayside. If properly implemented, patient pathways can ensure that people's mental health issues are identified and appropriately

managed.

Parkinson's UK would support national initiatives to encourage NHS Boards to work with people with neurological conditions and the voluntary sector to develop specific patient pathways for neurological conditions. These pathways should cover all aspects of people's care, including access to mental health services.

Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes. Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

Question 2: In these situations, we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

-

Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

Question 3: Are there other actions we should be taking nationally to reduce self harm and suicide rates?

-

Question 4: What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

Stigma is a major issue for people with Parkinson's who have mental health symptoms. Many people find it difficult to disclose mental health symptoms put of embarrassment, shame and fear. Some healthcare professionals may benefit from additional training to enable them to ask people about issues such as hallucinations, cognitive problems and impulse control disorders such as hypersexuality and compulsive gambling, and to build relationships where people feel safe to talk about them. This will enable mental health issues to be addressed quickly, before a crisis develops.

Stigma can also prevent people getting the support they need in social care settings, when they are receiving care at home or in a care home. Social care staff would benefit from further training in supporting clients with mental health needs.

Parkinson's UK would welcome national training for health and care

professionals who do not work in mental health but work with people who have mental health needs alongside physical illness or disability.

As part of our ongoing work in professional education, Parkinson's UK has developed a developed and piloted a programme of training on mental health and Parkinson's for health and care professionals, and would be delighted to work with the Scottish Government, NHS and social care providers to roll out this programme widely.

Question 5: How do we build on the progress that see me has made in addressing stigma to address the challenges in engaging services to address discrimination?

-

Question 6: What other actions should we be taking to support promotion of mental wellbeing for irividuals and within communities?

Parkinson's UK is committed to providing information and support to people with Parkinson's, their carers, families and friends. We believe that this approach is crucial to enabling people to protect their wellbeing when living with Parkinson's. We provide a range of free information resources, which meet the NHS Information Standard. We also provide access to free, confidential, one-to-one information and support through locally based support workers, who cover every health board in Scotland, a free national helpline and peer support through 45 local groups and our online forum. All of these services are available to anyone affected by Parkinson's. We are building relationships with statutory and other providers to ensure that this information and support work is offered to people with Parkinson's and their families. We welcome the Scottish Government's support for joint working with health and care providers to disseminate this support.

Parkinson's UK believes that the Scottish Government should continue to promote and fund self-mariagement approaches to long term conditions, such as Parkinson's. We note the investment in the Living Better programme, and welcome this, but we would like to see wider coverage, including access for people living with neurological conditions. Living Better is currently only active in one fifth of CHPs and covers only two long-term conditions. It is hard to see how this will benefit those who are not eligible to participate because they have the wrong condition or postcode.

Parkinson's UK has developed a range of self-management approaches that aim to support mental wellbeing for people with Parkinson's and their carers. Our successful Sleep project was funded by the LTCAS Self Management Fund, and has trained Parkinson's nurse specialists to support people with Parkinson's and their carers to self-manage the sleep problems which are common in Parkinson's, and which have a major impact on mental wellbeing. The project has also enables us to produce a range of self help materials for people who have poor sleep. We have also developed and piloted self-care and peer support programmes for people affected by Parkinson's, which have been evaluated very positively. We

would welcome the opportunity to work with the Scottish Government and others to use these tools more widely.

We would also like to see national support to roll out successful self-management initiatives undertaken locally. For example:

- In NHS Grampian, Parkinson's nurses are leading courses for people with a new diagnosis of Parkinson's. These promote awareness of common mental health issues as part of the symptoms of Parkinson's.
- NHS Ayrshire and Arran has run a number of very successful "Challenge your condition" courses, which have received excellent feedback from participants.
- In NHS Lothian, Parkinson's nurses and psychologists are working together to help people manage anxiety in nurse-led clinics.

In NHS Highland, research is being undertaken to identify the mental health needs of people with neurological conditions, in order to identify gaps and develop systems that better meet people's needs. Similar research should be promoted in other NHS Boards.

Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.

Question 7: What additional actions must we take to meet these challenges and improve access to CAMHS?

-

Question 8: What additional national support do NHS Boards need to support implementation of the HEAT target on access to specialist CAMHS?

-

Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.

Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?

Please see comments above (Q4 and Q6)

Question 10: What approaches do we need to encourage people to seek help when they need to?

-

Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.

Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

People with suspected Parkinson's must be referred untreated to specialist Parkinson's multi disciplinary teams, including a Parkinson's specialist nurse and mental health services input, so that symptoms can be identified, monitored and treated, This recommendation is supported by SIGN guideline 113 on the diagnosis and pharmacological management of Parkinson's disease and the NHS HIS Clinical Standards for neurological health services.

We strongly welcome the growth of joint clinics involving psychiatry and Parkinson's specialists in areas including North Glasgow, Borders and Lothian, which enable rapid referral and well-integrated care covering all aspects of people's Parkinson's.

Outcome 5: Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

Question 12: What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

-

Question 13: What support do NHS Boards and key partners need to put Integrated Care Pathways into practice?

-

Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

Question 14: How do we continue to develop service user involvement in service design and delivery and in the care provided?

-

Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?

-

Question 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?

-

Question 17: How do we encourage implementation of the new Scottish Recovery Indicator (SRI)?

-

Question 18: How can the Scottish Recovery Network develop its effectiveness to support embedding recovery approaches across different professional groups?

-

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Question 19: How do we support families and carers to participate meaningfully in care and treatment?

It is very important for families and carers to be aware of the potential mental health issues that can affect people with Parkinson's and to be able to raise any concerns about these with professionals.

Parkinson's UK believes that professionals need to be encouraged to signpost people with the condition, their families and carers to good quality information, such as that provided by Parkinson's UK. We provide a range of free information resources, which meet the NHS Information Standard. We also provide access to free, confidential, one-to-one information and support through locally based support workers, who cover every health board in Scotland, and a free national helpline. All of these services are available to anyone affected by Parkinson's.

It is also important that professionals offer ongoing support so that families and carers have an awareness of possible mental health symptoms and have a relationship that enables them to raise any concerns.

In NHS Lothian, Parkinson's nurses have played an active role in carers' courses run by the Edinburgh Branch of Parkinson's UK, which includes discussion of common mental health issues and the impact that they can have on relationships. This good practice should be encouraged throughout Scotland, and this approach may be helpful for other long-term neurological conditions.

Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?

Please see comments above (Q4 and Q19)

Outcome 8: The balance of community and inpatient services is appropriate to meet the needs of the population safely, efficiently and with good outcomes.

Question 21: How can we capitalise on the knowledge and experience developed in those areas that have redesigned services to build up a national picture of what works to deliver better outcomes?

Outcome 9: The reach of mental health services is improved to give better access to minority and high risk groups and those who might not otherwise access services.

Question 22: How do we ensure that information is used to monitor who is using services and to improve the accessibility of services?

Question 23: How do we disseminate learning about what is important to make services accessible?

Question 24: In addition to services for older people, developmental disorders and trauma, are there other significant gaps in service provision?

There are significant gaps in provision for people who have neurological conditions such as Parkinson's. In many parts of Scotland, it is very difficult to access neuropsychology and psychiatry services, despite the fact that many people with neurological conditions experience mental health issues alongside their physical symptoms.

Mental health problems are common for people with Parkinson's. At any given time up to 40% of people with Parkinson's will have depression. Up to 40% of people with Parkinson's will experience anxiety and up to 50% will experience mild psychotic symptoms.

Dementia is common. One in three people with Parkinson's have some form

of dementia and up to 80% of people with Parkinson's may develop dementia. Parkinson's dementia is a specific type of dementia and one that often does not get the recognition or understanding it needs.

Despite the high rates of mental health need, many people go without treatment. As few as 20% of depressed people with Parkinson's receive treatment. This lack of treatment could be linked to under-diagnosis or the fact that some medications cannot be used because they have side-effects that make Parkinson's symptoms worse. However, in a recent national survey only one in ten (11%) of people with Parkinson's had seen a mental health professional.

Where referrals can be made, it is important to make sure that mental health symptoms are treated in balance with other symptoms, because some medications can make other symptoms worse and some mental health treatments have such a serious impact that they are contraindicated in people with Parkinson's. It is important that a Parkinson's specialist is involved in prescribing decisions and is able to provide ongoing monitoring.

In Scotland, there are some examples of excellent practice, where clinicians have worked together to meet people's needs. However, too often links between Parkinson's services and mental health are poor, and referral pathways do not exist.

The NHS Healthcare Improvement Scotland Clinical Standards for neurological health services state that people with Parkinson's should have access to a multi disciplinary team with input from mental health services. Despite this, both people aged under 65 and older people can have particular difficulty in accessing neuropsychologists, while some psychiatrists will not accept referrals from people with Parkinson's, and some consultants may be reluctant to refer. We are also aware that it can be very difficult to refer people with Parkinson's to their local community psychiatric nursing service.

Parkinson's UK welcomes the NHS HIS Improvement Programme's work with NHS Boards to ensure that people with functional neurological symptoms are able to access mental health services. We hope that better links between neurology and mental health services will benefit everyone who needs mental health support and treatment. However, there is a danger that the concentration on functional symptoms may mean that the mental health needs of people with a diagnosed neurological condition such as Parkinson's remain overlooked.

In addition, the communication difficulties that are commonly experienced in more advanced degenerative conditions such as Parkinson's may mean that people require communication support to enable them to make their symptoms known. Parkinson's UK believes that NHS services and other care providers need to provide appropriate communication support to enable people with neurological conditions to have their mental health needs identified and managed.

Outcome 10: Mental health services work well with other services such as learning disability and substance misuse and are integrated in other settings such as prisons, care homes and general medical settings.

Question 25: In addition to the work already in place to support the National Dementia Demonstrator sites and Learning Disability CAMHS, what else do you think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

In addition to the work on dementia in care homes, the Scottish Government should also begin to address the other common mental health needs of care home residents, such as depression, apathy, and anxiety.

Within the NHS it is essential that mental health services have strong and regular input into multi disciplinary Parkinson's teams as outlined in the NHS Clinical Standards for neurological health services. Strong joint working is particularly required because of the need to treat the full range of Parkinson's symptoms and medication side effects which can make motor and non-motor Parkinson's symptoms worse.

Question 26: In addition to the proposed work in acute hospitals around people with dementia and the work identified above with female prisoners, are there any other actions that you think should be national priorities over the next 4 years to meet the challenge of providing an integrated approach to mental health service delivery?

-

Outcome 11: The health and social care workforce has the skills and knowledge to undertake its duties effectively and displays appropriate attitudes and behaviours in their work with service users and carers.

Question 27: How do we support implementation of *Promoting Excellence* across all health and social care settings?

-

Question 28: In addition to developing a survey to support NHS Boards' workforce planning around the psychological therapies HEAT target – are there any other surveys that would be helpful at a national level?

Parkinson's UK would particularly welcome an audit of referral patterns from different specialties into mental health services by NHS Board. This would help to identify where there are issues and gaps in services and support, and enable a systematic approach to meeting people's needs.

Question 29: What are the other priorities for workforce development and planning over the next 4 years? What is needed to support this?

There is a particular shortage of neuropsychology posts in Scotland, for people of working age and older people and this must be addressed in order to meet the 18 week RTT HEAT target for psychology referrals and to address the significant rates of unmet need amongst people with neurological conditions such as Parkinson's.

For many people with Parkinson's, their primary source of support for mental health symptoms and mental wellbeing is their specialist nurse. It is essential that people with Parkinson's have access to Parkinson's nurses who can identify and monitor people's mental health symptoms so that appropriate action can be taken at an early stage.

Question 30: How do we ensure that we have sustainable training capacity to deliver better access to psychological therapies?

Outcome 12: We know how well the mental health system is functioning on the basis of national and local data on capacity, activity, outputs and outcomes.

Question 31: In addition to the current work to further develop national benchmarking resources, is there anything else we should be doing to enable us to meet this challenge?

-

Question 32: What would support services locally in their work to embed clinical outcomes reporting as a routine aspect of care delivery?

-

Outcome 13: The process of improvement is supported across all health and social care settings in the knowledge that change is complex and challenging and requires leadership, expertise and investment.

Question 33: Is there any other action that should be prioritised for attention in the next 4 years that would support services to meet this challenge?

-

Question 34: What specifically needs to happen nationally and locally to ensure we effectively integrate the range of improvement work in mental health?

-

Outcome 14: The legal framework promotes and supports a rights based model in respect of the treatment, care and protection of individuals with mental illness, learning disability and personality disorders.

Question 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?

--