Response to NHS Chief Executive’s Open Call for Evidence and Ideas

Respondent ID: 125

Organisation name: The Cure Parkinson’s Trust

Type of response: Email
Health Innovation

From: T Isaacs <tom@cureparkinsons.org.uk>
Sent: 30 August 2011 16:11
To: health.innovation@dh.gsi.gov.uk
Subject: Innovation Review

Dear Sirs,

I read with interest the invitation to comment on innovation in the NHS as part of the “Plan for Growth”.

It was encouraging to read that there is recognition for the need to create a ‘Pull” for new ideas from patients rather than relying on the traditional top down “push”. This, coupled with the need for collaboration, cooperation and integration across all organisations will help foster innovation.

The Cure Parkinson’s Trust (CPT) was founded by people with Parkinson’s and their opinions and views form the backbone of this small innovative organisation. Since its inception, CPT has funded studies that show the potential to have an impact on the lives of those of us living with this terrible disease. Identifying the priorities of people with Parkinson’s is at the heart of our work. The voices of people with Parkinson’s provide the inspiration, which in turn leads to innovative research being fostered. Delivering these treatments to clinic is one of our absolute priorities.

For CPT, one of the areas that stifles innovation is the length of time it takes for a new treatment to reach the market. Currently the gold standard medication available for Parkinson’s is Levadopa. It is worrying that it has retained this status for the past 40 years. I would argue that Parkinson’s is a very good example of a condition where innovation has been stifled, a position we are passionate and determined to address. It is rare that people with Parkinson’s are medicated with Levadopa for more than 10-12 years, after which, there is little treatment alternative, to maintain an adequate quality of life. In other words, it takes the same amount of time to develop a new treatment as it does for someone diagnosed with Parkinson’s to be confined to being a prisoner within their own bodies.

There are few better examples than Parkinson’s which demonstrate the need for increased incentive to the healthcare industry to develop pioneering new therapies. As someone who has lived with the condition for 16 years but who has also devoted much of this time in pursuit of a cure for Parkinson’s, I have been frustrated by the lack of urgency and joined up thinking. Yet at the same time, there is no doubt that by engaging with the Parkinson’s community, people with the condition can act as a catalyst and bring focus and momentum to delivering new science into the clinic. By identifying commonality of experience and prioritising this information, we have been able to look outside the traditional treatment paths for potential new targets. For example, we are currently funding a pilot study using a type II Diabetes treatment, which shows huge potential as an effective treatment for Parkinson’s.

The DH recently shelved the MHRA’s Early Access Scheme, which we see as a real threat for new treatments currently in the pipeline to treat Parkinson’s. I do understand that the Early Access Scheme would evaluate certain treatments at Phase III and this could impact clinical time within the NHS, however, the USA and France have similar schemes in place, which are proving effective as fostering innovative treatments in a range of conditions. Surely, speeding the time it takes for a treatment to reach the clinic reinvigorates the process, and supports innovation. It would be fantastic to see this scheme piloted, even as a series of Innovation Prizes or Awards, for specific treatments, as this would highlight both the need and the practicality of use of such an important scheme.

Patients are at the heart of this. Patients have a different perspective of risk and prioritisation, just as they have different interpretations of the word “cure”. Much of this depends on how far they have travelled on the journey
that is their own illness. Involving a cross-section of patients in these sorts of decisions is absolutely key, whilst maintaining a balance of safe treatments, delivered with scientific rigour.

In recent months, we have taken a further step in harnessing the opinions of people with Parkinson’s by creating Parkinson’s Movement www.parkinsonsmovement.com. As part of this new hub of information, there is a health tracker, enabling people to monitor and prioritise their own symptoms, which in turn leads to a better understanding of an individual’s condition, and will prompt improved dialogue between patient and health care professional, enabling targeted individualised treatment. Only by ensuring that people with Parkinson’s communicate as effectively as they can with their healthcare professionals, can they be assured of receiving the best possible and most targeted treatments.

In summary, my response for your call for evidence for innovation in the NHS is to harness the energy and experience of those living with illness and to support a culture which encourages a more patient centric approach to healthcare and bridges the gap between science and society. As patients, we have a role to play and some of that means taking some of the responsibility for our own health.

Yours faithfully

Tom Isaacs

Tom Isaacs
President and co-Founder, The Cure Parkinson’s Trust
1 St Clement’s Court
London EC4N 7HB
0207 929 7656
www.cureparkinsons.org.uk
Registered charity number 1111816

Support our GDNF appeal by Joining the 100 Club – 100 members, great prize money – just email me for more details

Make www.everyclick.com your home page and raise funds for The Cure Parkinson’s Trust.

This email was received from the INTERNET and scanned by the Government Secure Intranet anti-virus service supplied by Cable&Wireless in partnership with MessageLabs. (CCTM Certificate Number 2006/04/0007.)

DH users see Computer virus guidance on Delphi under Security in DH, for further details. In case of problems, please call the IT support helpdesk.