



Media Release

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£100,000 funding for pioneering tool to help give people with dementia a voice

Two organisations specialising in communication services and support have been awarded £100,000 by the Life Changes Trust to develop a new online service which will help more people with dementia communicate their thoughts and opinions.

The service will be specifically designed to allow people living with dementia, and who have communication difficulties, to share their experiences of health and social care and communicate their thoughts and opinions about the quality of care they are receiving.

The two organisations receiving funding are Patient Opinion and Talking Mats. Patient Opinion has already pioneered an online feedback platform to allow the general public to share their opinions and experiences, both positive and negative, of health and social care. This feedback is then sent to providers of care who respond publicly.

Talking Mats specialises in supporting people with communication difficulties so they can express themselves using interactive visual storytelling and picture symbols. The new service will combine both approaches.

Communicating and articulating feedback can be a challenge for a wide range of people with cognitive or communication difficulties, and can be a feature of dementia as it progresses. Difficulties can include reduced vocabulary, repetition of thought, distractibility, lack of coherence and deterioration of reading and writing skills.

This innovative approach will enable more people with dementia to share their experiences of health and social services, so that they can say what works well for them and what does not. It will give them a voice that they otherwise may not have and will raise awareness about specific needs that may have gone unarticulated. This will give service providers an opportunity to respond to these needs.

The Life Changes Trust is an independent charity set up with a Big Lottery Fund endowment of £50 million to improve the lives of two key groups in Scotland: people affected by dementia and care experienced young people.

Anna Buchanan, Director of the Life Changes Trust dementia programme said: "We are delighted to award this funding to support Patient Opinion and Talking Mats. Many people living with dementia can find it hard to express themselves effectively and, as dementia progresses, there is a real danger that people lose their ability to have a voice and express their views. This project is one example of a human rights based approach in action. It is our hope that it will give more people with dementia an active role in shaping the development of services that are crucial to their mental and physical well-being."

Gina Alexander, Director of Patient Opinion Scotland and Lois Cameron, Director of Talking Mats said: "Patient Opinion and Talking Mats share the philosophy that "we all have a voice and our experiences count". We're delighted to be working together: combining our highly innovative services with the aim of enabling people with dementia to share their experiences of health and social care on an open and transparent online platform. This funding and support from Life Changes Trust is absolutely vital in enabling us to develop this potentially transformational service. A successful outcome would not only deliver considerable benefits for people affected by dementia but could also result in empowering others with communication difficulties to share their experiences, be heard and make a difference."

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EDITORS NOTES:

The Life Changes Trust was established by the Big Lottery Fund in April 2013 with a ten year endowment of £50 million to support transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.

Patient Opinion is a not for profit, social enterprise which exists for the benefit of people who use health and care services and staff. It runs two websites, the award winning Patient Opinion and Care Opinion, where people can share their experiences of health and care services across the UK. Services can respond online, show they are listening and demonstrate the impact of feedback on the services they provide.

Talking Mats Limited is also a not for profit social enterprise whose vision is to improve the lives of people with communication difficulties, and those close to them, by increasing their capacity to communicate effectively about things that matter to them. The award-winning Talking Mats communication framework is based on extensive research and designed by Speech and Language Therapists. It uses unique, specially designed symbols that are attractive to all ages and communication abilities and is used by clinical practitioners, carers and support workers in a wide range of health, social work, residential and education settings.