

Part A - General Information

Organisation/Individual Name

LivedHealth CIC

Organisation Type/Structure

Community Interest Company (CIC)

Theme/Nature of Project

Medical, Health and Social Care

Company/CIC Registration Number (if applicable)

12543266

Project Name (if same as Organisation Name, please leave this blank)

147,382

Name of Lead Contact

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Social Media Handles (Twitter, Facebook, LinkedIn, Instagram etc):

Twitter: @LivedHealth
Facebook: @livedhealth
LinkedIn: LivedHealth
Instagram: @livedhealth

Part B - Project Proposal

Project Mission: A snapshot of the project's intention (50 words max)

We share patient's experience of living with Parkinson's because we believe health information is more effective when powered by lived experience. Through our project, we aim to create learning opportunities for patients, break down barriers between patients and healthcare professionals and reach more patients in need of information and support

Situation (250 words)

1 in 37 people alive today in the UK will be diagnosed with Parkinson's in their lifetime; it is the fastest growing neurological disease in the world. Parkinson's is a progressive, neurodegenerative disorder that affects dopamine-producing neurons, causing widespread neuronal damage that impacts movement and cognition. Initial diagnosis of Parkinson's is a stressful, isolating and anxiety inducing experience. Depression can occur in up to 50% of Parkinson's patients and anxiety disorders are three times more common in people with Parkinson's than the general population.

In the UK, care for people with long term conditions, such as Parkinson's, consumes 70% of the NHS budget. To reduce this strain on the NHS, we need to improve self-driven condition management and monitoring amongst people diagnosed with Parkinson's. To achieve this, we need to increase patients' knowledge of Parkinson's, increase their confidence in managing their own condition and break down barriers between patients and healthcare professionals.

Furthermore, people with Parkinson's are still dealing with diagnosis and disease management with reduced social support and face-to-face time with clinical teams, due to the on-going impacts of Covid-19. There is therefore, a clear unmet need to provide clear, trusted and relevant information to people diagnosed with Parkinson's.

Complication (250 words)

Evidence shows that the inclusion of personal lived experience in health information has the potential to improve self-driven condition management and monitoring amongst patients with Parkinson's, by facilitating attention, comprehension and recall of health information.

However, peer-delivered content like this is not currently available to people with Parkinson's. The digital information and resources that are currently available are not appropriate for younger patient audiences at earlier stages of their disease journey and what is out there is not patient-led and is often top-down information provision - which we know can be less effective.

At LivedHealth, we create health information videos to provide peer support and expert advice to people with long-term health conditions, specifically Parkinson's. Published on YouTube to maximise access, our informative and entertaining videos feature people who have the conditions themselves, interviewing international experts on topics related to diagnosis, treatment and lifestyle advice.

An evaluation of our model showed that video viewers had increased health literacy: 85% of people understood more about their condition and 75% felt better informed about disease management and treatment. The evaluation also revealed an increase in patient activation: 79% felt more confident about managing their condition, 71% felt more empowered to be more proactive with healthcare professionals and 61% intended to make or had made changes to the way they managed their condition.

Our accessible patient centred approach at LivedHealth aims to tackle anxiety and isolation surrounding diagnosis, increase confidence and empower positive action and behaviour change amongst people with Parkinson's.

Solution (250 words)

At LivedHealth, we are passionate about sharing patients' experiences of living with long-term health conditions because we believe that health communities and health information are more effective when powered by lived experience. Following the successful rollout of our MS-specific video programme, we are now expanding our work to support patients with Parkinson's. We are developing a free, online video resource for patients recently diagnosed with Parkinson's.

By sharing high quality, credible information from our patient hosts and leading professionals, we aim to create learning opportunities for people with Parkinson's across the UK. Our videos explore disease modifying therapies and lifestyle interventions to create actionable health management approaches for people with Parkinson's. By sharing lived experience through storytelling style videos, we aim to increase experiential understanding of long-term health conditions.

Through authentic conversations between patients and professionals, we aim to break down barriers between people with Parkinson's and their healthcare teams. We share our videos on our YouTube channel and across our social media channels in order to reach more people with Parkinson's in need of information and support.

Your support will allow us to make a real difference to the Parkinson's community that we work with and are led by. Our future work will create new opportunities for the Parkinson's community to participate in and learn from our engaging and wide-ranging programme. We will offer authentic insight into the experience of diagnosis, managing their condition, living well and the broader global Parkinson's landscape across our distinct modules.

Part C - Wider Support

How would the Stephen Lloyd Award network of partners' support be beneficial to your project? (250 words max)

As we are a newly-registered Community Interest Company (CIC), founded in September 2020, we would benefit greatly from the Stephen Lloyd Award network of partners to support our organisation in various ways.

Firstly, our nature as a CIC restricts us from a larger number of funding opportunities as many Trusts and Foundations do not wish to fund CICs, instead choosing to focus their funding on more established registered charities. Support from Stephen Lloyd Award partners such as Social Investment Business, the Tudor Trust, the Paul Hamlyn Foundation could open up opportunities for further funding as well as offer financial advice, to help us continue to develop our project.

Secondly, monitoring and evaluation is deeply embedded within our approach at LivedHealth and feeds into the development and optimisation of all our work. Support from partners such as the Coalition for Efficiency, would enable us to fully understand our data and our impact, which would ensure we make the best content for our beneficiaries.

Finally, as we are a fledgling organisation, we would appreciate support from professionals such as Bob Thurst, Claire Pattie, David McLean and Michael Norton whose combined knowledge of governance, social innovation and films, graphic design and fundraising would be beneficial to us as we continue to develop our project and our organisation as a whole.

Part D - Financial Justification

In general terms, please explain how the winning funds would be used to carry out your project. (50 words max)

The winning funds would be used towards our costs of working with Parkinson's 'hosts' - including fees for people with Parkinson's who host our videos - ensuring the relevance of the content and engagement of the Parkinson's community. The funds will also contribute towards video resource production, outreach of the video resources to the Parkinson's community, and a contribution towards the impact and evaluation of the content.

Part E - Supporting Information

Governing Documents: Where relevant, please upload any recent charity accounts and governing documents as attachments.

- [LivedHealth-CIC-Annual-Accounts-1.pdf](#)

Team: We would like to learn a little more about the individual or team invested into the project. What are your individual credentials? Is there a story behind how you or your team all came together to support the project? (75 words max)

Our CEO George Pepper is passionate about the role that people living with the condition can play in their healthcare, having been diagnosed with MS aged 22. George co-founded LivedHealth in 2020 with Freddie Yauner, multidisciplinary artist and designer. Emma Lawton recently joined as our third Director. Emma was diagnosed with Parkinson's aged 29 and is a health-technology entrepreneur.

YouTube Video

<https://www.youtube.com/watch?v=uTYgjSOWjRs>

Additional References: You are welcome to provide a list of up to 5 links with any relevant supporting material or visuals, as further reference

Please follow the link below to view our YouTube channel. This is where we share our health education videos for people with Parkinson's: <https://www.youtube.com/c/LivedHealth?app=desktop>