Chapter 21
LiveWell – Promoting Healthy Living and Wellbeing for Parkinson Patients through Social Network and ICT Training:
Lessons Learnt and Best Practices

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ABSTRACT

About 1.2 million people in Europe have Parkinson's disease (PD). PD patients often suffer from social exclusion and depression due to progressive lack of control over the disease. Eventually, most require constant care, leading to huge socioeconomic burdens. To partially tackle this issue, 7 partners in 7 countries participated in LiveWell (EU-funded project, 2012-14) to develop an innovative Web-based

education, training and social community platform targeting PD patients, carers and clinicians. This paper describes LiveWell from conception to completion, presents lessons learnt over the course of the project, and highlights some identified main areas of best practice. The Project Consortium might not have had the chance to implement everything learnt in the current outputs, but these lessons and guidelines can be later used to improve LiveWell, and can also be generalised to benefit similar e-health services. The combination of appropriate online education and social communities could help patients and carers cope positively with PD, promoting social inclusion and better outcomes.

1. BACKGROUND: MOTIVATION AND MAIN CHALLENGES THAT LIVEWELL IS ATTEMPTING TO ADDRESS

About 1.2 million people in Europe (127,000 people in the UK or 1 in 500 people) have Parkinson's disease (PD). Its main symptoms include tremors and stiffness, which affect daily activities. PD patients often suffer from social exclusion and depression due to the progressive lack of control over their condition. Eventually, most of them require constant care, leading to huge socioeconomic burdens (Gustavsson et al., 2011; Kowal et al., 2013).

Furthermore, almost half of all EU and UK patients show limited health literacy. This poses an additional challenge when developing online education material for those patients to help them better cope with, and self-manage, their condition (Kamel Boulos, 2013). One common question the Livewell Project Consortium often receives regarding the education and training component of Livewell is 'why are you 'reinventing the wheel' when there are already so many quality (best evidence) online resources out there for PD patients and their carrers?' Our answer is that while there are many existing excellent resources, they are mostly targeting users with high/sophisticated reading levels (high literacy and (digital) health literacy levels)—Figure 1.

Livewell attempts to address this issue, and also adds a component of social networking and peer support to its educational provision to help patients and their carers combat social isolation and depression. Research evidence also shows that Internet use and online social engagement can protect against health literacy decline during ageing (and hence result in better health outcomes), independent of cognitive decline (Kobayashi et al., 2015).

Figure 1. Google search results for 'Parkinson's disease' filtered by reading (comprehension) level as at 12 September 2014 (for more information about this particular Google search filter, please see http://googlesystem.blogspot.co.uk/2010/12/google-shows-reading-levels-for-search.html)

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