

## The role of online peer support groups in the self-management of hearing loss: A mixed methods approach

### Section 1 – Project Details:

#### Rationale:

Globally, hearing loss is the third leading global cause of years living with disease<sup>1</sup>. In the UK, hearing loss affects 1 in 6 of the population (11m), predicted to rise to 15.5 million by 2030. If untreated, hearing loss results in communication difficulties that can lead to social isolation and withdrawal, depression, reduced quality of life<sup>2</sup>, and an increased risk (2-5x) of developing dementia.

In other health domains, it is recognised that patients with long-term conditions who actively participate in their care are more likely to adopt health behaviours that lead to better patient outcomes (Mosen et al., 2006). This is particularly the case in patients with chronic conditions who are required to play a role in their day-to-day management, such as those with hearing loss.

With increased access to the Internet and advances in information and communication technology, there has been an exponential increase in the number of individuals living with long-term conditions, who access and participate in online peer-to-peer support groups. Through online support groups, individuals are able to interact with similar others through either synchronous (e.g. chat rooms) or asynchronous (e.g. discussion forums) written communication and these groups may be professionally or peer moderated.

Whilst there is an increasing body of literature that has examined the reasons for this growth in popularity and the impact of engagement on psycho-social outcomes<sup>3</sup> across a range of long-term conditions, there has been a conspicuous absence of research which has considered how online support groups may support the ongoing self-management of individuals living with hearing loss.

The supervisory team will build on their previous research on the psychosocial consequences of people with hearing loss (Heffernan) and their communication partners (Barker et al) and online developments of self-management and educational programmes in tinnitus (Greenwell) and hearing loss (Ferguson). This PhD research will translate into a format that can be used within clinical populations and clinical practice.

#### Aims and methodology:

The PhD will use a mixed methods approach and include:

- 1) A synthesis of the existing literature on the psychosocial challenges of living with hearing loss, online peer support as well as a review of relevant online/face-to-face data collection methods;
- 2) A thematic/content analysis<sup>4</sup> of the communication between members of hearing loss online peer support groups (i.e. forums) and social networking sites;
- 3) A qualitative study (either face to face or online<sup>5</sup>) designed to explore the perceived benefits and challenges of engaging with online support groups, their role in the self-management of hearing loss and the ways through which engagement may empower individuals to address the various challenges of hearing loss;

- 4) A longitudinal study designed to examine the changes which may take place over time through engagement with hearing loss online peer support groups.

**Benefits and suitability as a PhD project:**

This PhD proposal represents a much needed exploration of the role of online support groups in the context of hearing loss. The supervisory package draws together experts who are world leaders in their respective areas (Dr Neil Coulson – online peer support and Dr Mel Ferguson – audiology) and are uniquely placed to support this highly original PhD project. The mixed methods nature of this PhD proposal will allow the successful applicant to develop their research skills across a range of methodologies, as well as benefiting from both condition and topics specific knowledge and understanding. The results of this PhD proposal will be used to design and test digital interventions to support those affected by hearing loss and therefore the project as a whole is likely to carry meaningful impact and benefit to patients in years to come.

**Key References:**

1. World Health Organization. WHO global estimates on prevalence of hearing loss. Geneva, Switzerland: WHO press; 2012.
2. Ciorba A, Bianchini C, Pelucchi S, Pastore A. The impact of hearing loss on the quality of life of elderly adults. *Clin. Interv. Aging.* 2012;7:159-163.
3. Mo, P.K.H. & Coulson, N.S. (2012). Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS. *Psychology & Health*, 27(4), 445-459.
4. Coulson, N.S. (2013). Sharing, supporting and sobriety: A qualitative analysis of messages posted to alcohol-related online discussion forums in the UK. *Journal of Substance Use*, 19(1-2), 176-180.
5. Shoebottom, A. & Coulson, N.S. (2016). Therapeutic affordances of online support group use in women with endometriosis. *Journal of Medical Internet Research*, 18(5), e109.

**Section 2 – Training Provision:**

The successful student will be supported through a tailored training programme which will extend across years 1 to 3 of the PhD. The student will have access to the Faculty of Medicine and Health Sciences Training Programme and be able to choose relevant short courses following a detailed skills analysis at the start of each year of registration. In addition, the successful student will be located in the centre for Doctoral Training in Rehabilitation and Healthcare Research. Through membership of this centre, the student will undertake the 2 day core training module in complex interventions and mixed methods research, This course introduces students to the MRC Framework for evaluating complex interventions, helps them to appreciate the value of mixed method designs in rehabilitation research and the factors important in their delivery and provides a unique opportunity to learn from experts (members of academic and research staff in the Division of Rehabilitation and Ageing and School of Health Sciences) who will share their practical experience of measuring complex interventions.