

Progress Report

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Title of Project: Improving Brain Tumour Care Online

Summary:

Online interventions for brain tumour patients have the potential to transgress geographic, physical and psychological barriers to healthcare, and to facilitate treatment, support and education for these patients within convenient timeframes and their own environment. Our literature review investigating online interventions for cancer patients found that, although there is significant promise and a plethora of interventions reported without analysis, current interventions demonstrated mixed efficacy when rigorously evaluated. These interventions appear to have been created based on researcher considerations, without prior needs analysis of the target population.

Using funds from a Brain Foundation Australia grant (2013) we are currently undertaking a needs assessment of online resources for brain tumour patients. The survey considers social media use, patient demographics and quality of life (FACT-B questionnaire) components. Using this important information we aim to develop the first evidence based online therapeutic community for brain tumour patients. The community will aim to augment outpatient care by providing on-line communication with the treating team, remote measurement of clinical status and connecting patients online for support and education.

The survey has been created using SurveyMonkey software, and is administered on iPads in the Outpatient Clinic waiting room. Participants include those >18 years of age with a diagnosis of primary brain tumour, attending the RMH Neuro-oncology multidisciplinary clinic.

We are currently approximately half way through this second phase of the research, with 100 or the 200 brain tumour patients surveyed. Preliminary results suggest social media plays a powerful role in self-management for patients with brain tumours, with many patients using at least one form of social media for brain tumour related use. This information emphasizes the importance of social media for brain tumour patients, and will help guide the creation of a specialized platform as an extension of the multi-disciplinary team.

The building of an online community for brain tumour patients will aim to enhance care for these patients by providing a means of ongoing communication with the treating team and ongoing measurement of appropriate parameters (e.g. pain,

quality of life), connecting patients online for support and providing patient education. The efficacy of the online community will be tested in a randomized controlled trial, with outcome measures including improved quality of life and survivorship.

We hope this online therapeutic network will help people with brain tumours enjoy a better quality of life, by bringing them closer to their treating team, providing them with peer support and quality educational resources.