**Final Report**

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Title of Project: Improving brain tumour care on-line

The role social media in management of disease is evolving. This study aimed to define current use and value of social media by participants with brain tumours, by exploring its uses and impact on health-related quality of life. This study was undertaken at The Royal Melbourne Hospital, administered on electronic tablets to 201 patients with brain tumours in the Outpatients Department.

Of the 201 participants, 55.7% were female and 61.2% were aged 30-59 years. Patients were isolated, both by distance, with 34% of patients living >50km from RMH, and functionally, with 46% unable to drive. Fifty-eight-point-two percent of participants were not working. The Internet was used by 85.9% of participants, and 71.6% of those used social media. The majority of patients used social networking sites (32.8%), wikis (28.1%) and blogs (13.2%) to access information and for communication or interaction related to their brain tumour. Participants indicated a strong preference for privacy and flexibility and greatly valued when a health professional contributed to the social media site.

For brain tumour patients, the perceived benefit of social media on social functioning and activities of daily living was substantial, with subjective benefits from SNS and blog use including improvement in relationships, the ability to participate in social activities, improved enjoyment of life and ability to take in new information.

Health-related quality of life was assessed using FACT-Br questionnaire. Considering all social media platforms, this study demonstrated similar health-related quality of life scores in participants who used social media compared with non-users. It may be that this study was underpowered to show a significant change, or that no such change in health-related quality of life is possible from social media engagement. It is also possible that unregulated platforms are not specific enough to the needs of brain tumour patients to see a change in health-related quality of life. Alternatively, they may contain information or processes that are harmful or lead to user distress, particularly due to poor outcomes for those they are interacting with.

Using a cut-off 75% of users expressing a preference (agree or strongly agree) for any item on the questionnaire, we make the following recommendations to guide construction of future online platforms or interventions. They should include:

1. The ability for patients to control the amount and type of information that others may know about them.
2. The ability for patients to use the platform at a time and location of their choosing.
3. The capability for patients to use the platform as a guide to useful information.
4. A health professional contributing to the platform.
5. The ability for patients to share experience, in particular, a method to read about the experiences of others who have chosen to share their experience.
6. The capability to record stories of people with brain tumours using a blog format.

This study characterizes patient with brain tumours as geographically and socially isolated, and therefore an ideal population to engage in on-line platforms and interventions. It is the first of its kind to look at the preferences and affordances of social media in brain tumour patients, and its impact on health-related quality of life. Using this data we have established 6 recommendations to inform clinicians for the creation of future online platforms for this and other patient populations.