**Title**: **Responding to the information needs of patients with IgA nephropathy; a digital solution using social media**

**Introduction**: In 2016, Ofcom reported that 86% of UK adults used the internet, and that weekly length of time spent on the internet has increased from 9.9 hours in 2005 to 22.9 hours in 2016. Improvements in mobile technologies now mean that email and social networks such as Facebook, Twitter, Instagram (collectively known as Social Media (SoMe)) are the predominant way people communicate and exchange information (Ofcom, 2017). The rise of social media has also allowed patients to exchange health-related information (Van De Belt et al., 2010) and has evolved as a novel way for patients to satisfy their information needs (Vasilica, 2015).

**Method**: This paper outlines how our group is using SoMe as a digital solution to identify unmet information and education needs in patients with IgA nephropathy (IgAN). The study tests an innovative model to identify and understand patient needs, which could be transferrable across a variety of conditions. The study is being conducted in three phases:

* Phase 1) Understanding and identifying the information needs of people with IgAN - uses a bespoke developed BigQual data analysis programme to cross-examine data from IgA social media closed groups, Twitter activity and Instagram. The data analysis combines content and thematic analysis using a framework that provides a systematic approach to organise findings based on keywords, themes and issues. It is an iterative process, based on a framework that is refined, to expose key information themes,: diet, symptoms, cause of disease, IgAN, preventative mechanisms, cure/treatment/medication/transplant, additional support, co-morbidities, communication and access to information.
* Phase 2) involves the development and dissemination of resources via a dedicated IgA hub and social media channels to address information gaps identified during phase one. The resources will be created by a multidisciplinary team that include patients, clinicians, nursing staff, academic staff, physiotherapists, occupational therapists and dietitians and developed in a variety of formats including podcasts, videos, infographics and written materials.
* Phase 3) focuses on the dissemination of resources and evaluation of SoMe activity to understand and measure the impact of the project. The two-way nature of SoMe means that the resources created can be distributed back to patients through the same social media channels and evaluated using real-time analytics, tweets capturing patient feedback and online conversations related directly to resources, for example feedback on videos or patient information blog. Offline information resources will also be developed to meet the needs of those who don’t currently access SoMe channels.

Complying with ethics can be a major challenge in projects using SoME. This paper discusses the ethical implications of collecting and analysing public and semi-public data. It will address issues such as patient – clinician interaction, privacy, consent and representativeness.

**Conclusion**: A current scoping review revealed that most public health organisations believe that SoMe will trigger positive benefits but are not formulating a strategy of adoption and evaluating impact (Franco, Tursunbayeva, Pagliari, 2016). According to research social media is a form of communication for patients which could trigger positive social and health outcomes (Vasilica, 2015). This paper provides a clear example of how data available on social media are being used to address patients need and digital evaluation mechanisms.

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