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ORIGINAL ARTICLE

Study protocol: responding to the needs of patients with IgA nephropathy, a social media approach

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Abstract

Background: IgA nephropathy is the most common cause of glomerulonephritis in the Western world and predominantly affects young adults. Demographically these patients are the biggest users of social media. With increasing numbers of patients turning to social media to seek information and support in dealing with their disease, analysis of social media streams is an attractive modern strategy for understanding and responding to unmet patient need.

Methods: To identify unmet patient need in this population, a framework analysis will be undertaken of prospectively acquired social media posts from patients with IgA nephropathy, acquired from a range of different social media platforms. In collaboration with patients and members of the clinical multidisciplinary team, resources will be created to bridge gaps in patient knowledge and education identified through social media analysis and returned to patients via social media channels and bespoke websites. Analysis of the impact of these resources will be undertaken with further social media analysis, surveys and focus groups.

Conclusions: Patients with chronic diseases are increasingly using social networking channels to connect with others with similar diseases and to search for information to help them understand their condition. This project is a 21st century digital solution to understanding patient need and developing resources in partnership with patients, and has wide applicability as a future model for understanding patient needs in a variety of conditions.

Key words: IgA nephropathy, patient need, social media

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Introduction

We are living in a digital age. The growth of the Internet and the advent of social media has revolutionized healthcare by providing new communication channels, allowing patients access to support and health-related information [1, 2]. It has changed the way patients are able to search and exchange health-related information in new and diverse ways [3]. Online health communities existed before social media as message boards, discussion forums, websites and interactive blogs that were 'governed' by individuals, traditionally termed 'webmasters' [4]. Large-scale, public, social networking sites deviate from this model as interactions occur between users, rather than through/via a 'webmaster'. These sites attract more patients and produce vast amounts of peer-to-peer interactions, with unprecedented potential to extract novel information to study content at scale [5].

'Social media' is a term that refers to content that is driven by users and shared on social networking platforms. The 'media' may exist in different forms across a wide range of platforms. Different social network sites exist to support the sharing of different kinds of media, for example, blogging (e.g. Medium), microblogging (e.g. Twitter), video sharing (e.g. YouTube), photos or pictures (e.g. Instagram), or online communities, which host most kinds of media (e.g. Facebook or Google Communities). These sites facilitate interactions between individuals, with users able to choose whether their accounts and posts remain private or public. Studies suggest that 70% of Internet users use at least one form of social media [6], and each social media platform may play a unique and differing role in engaging patients [7–9]. The volume, diversity and interrelated nature of information that passes through social media channels make them rich data resources and medical professionals are already starting to explore the nature of patient interactions on these sites [10].

Social media, an outlet to exchange information

The numbers of patients with long-term health conditions is increasing. Over 15 million people have a long-term health condition in the UK and the Department of Health has identified the need to provide better access to information for patients and improve communication with patients using technology [11]. Traditionally, patients with chronic illness obtain information relating to their condition from healthcare providers, who often focus on the clinical impact of disease and may ignore the effects on daily life or emotional well-being [12]. The rise of social media has allowed patients to exchange health-related information [1, 2], which satisfies their information needs [9]. Patients may seek information for any number of reasons, including to: prepare for or decide upon treatment; manage symptoms; understand potential adverse effects; reduce uncertainty; and fill knowledge gaps [13–15]. In addition, patients draw from enactive mastery experience (positive feedback as a result of posting), vicarious experience (other patients stories) and social persuasion (positive feedback, conversations), which contributes to an increase in self-efficacy [9]. Web-based resources and responsive interventions have had little clinical impact on outcomes for patients. Indeed studies in chronic back pain and in cancer survivors show that web-based interventions have variable impact on 'medical' or 'clinical' outcomes [16, 17]. The impact of bespoke web-based resources created directly in response to identified, unmet

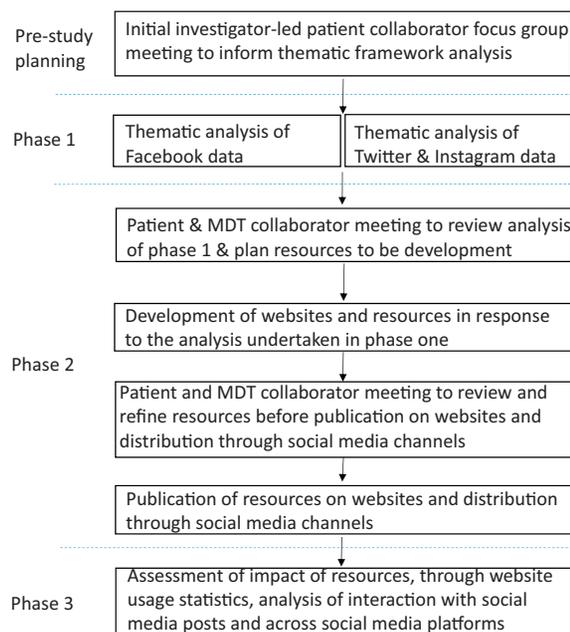


Fig. 1. Study protocol timeline. MDT, multidisciplinary team.

patient need on quality of life, satisfaction and experience has not been well studied.

IgA nephropathy (IgAN) is a rare disease, but is the most common cause of glomerulonephritis in the UK and the Western world. IgAN tends to affect younger patients, who are more likely to be active on social media than older patients. The nature of the questions patients pose, related to IgAN, are not known and the possibility of systematically analysing freely available social media posts to organically understand unmet patient needs is an attractive prospect. There are currently no specific treatments shown to be effective for all patients with IgAN and patients lack access to information to manage their condition. This project was developed from preliminary work which identified that large numbers of younger patients with IgAN use social networking sites to try to find information about their condition, to search for fellow patients and resources, and to look for clinical trials they may be able to join.

The objectives of this project are:

- (i) To identify the unmet needs of patients with IgAN through analysing data from social media platforms (Twitter, Instagram and Facebook).
- (ii) To develop resources to meet the information needs of patients and disseminate these to patients through social media channels and website hosting.
- (iii) To assess the effectiveness of resources developed in meeting the information gaps for people with IgAN.
- (iv) To explore and understand how social media can be used as a communication tool to improve patient experience, understanding of disease, networking and peer support.

Materials and methods

This research study is a qualitative data mining exercise to identify and respond to information gaps using publicly available social media. The project will be divided into three phases (Figure 1).

Phase 1: Understanding the information needs of people with IgAN

This phase will focus on understanding the information needs of patients with IgAN. Social media data will be or has been collected in the following ways:

- (i) Data scraping and analysis from Facebook groups. We have been granted permission to access and anonymously scrape data from two closed IgAN patient support groups on Facebook by the group gatekeepers. These groups have a combined membership of over 9000 patients and focus on offering peer-peer support for people with IgAN. Posts will be manually screened for content and anonymized before analysis.
- (ii) Interrogation of publicly available data from Twitter and Instagram. Over the last 20 months we have been working with the healthcare technology company DataTellsLife®. Using predefined search terms and DataTellsLife® searching algorithms, we have identified over 3500 discrete social media posts from patients with IgAN on Twitter and Instagram. Anonymized posts will be manually screened for content before analysis.

Social media data will be analysed using a framework thematic analysis approach. This will expose, describe and map conceptual findings from social media posts [18]. The framework analysis will be informed by a patient involvement exercise that will take place prior to study commencement (Appendix 1). Framework analysis provides a systematic approach to organize findings based on key themes and issues [19] and is acknowledged to be a suitable analysis technique for cross-sectional, descriptive data. It will enable us to highlight different aspects of the phenomena examined [20] and to draw meaningful themes from collected data whilst maintaining accuracy on behalf of patient views [21].

The extensive qualitative data source will be managed using specific software (Tableau, standard package 2017, London, UK) and bespoke digital tools developed at the University of Salford. The DataTellsLife® real-time social media data organizing and analysis platform will support Twitter and Instagram data management and analysis.

Phase 2: Development of website, resources and social media channels

The second phase of the project will focus on the development of resources to address information gaps identified during Phase 1. An investigator and collaborator meeting involving patients, clinicians, nurses, academic staff, dieticians, physiotherapists and occupational therapists will be convened to discuss the findings of the Phase 1 analysis. In conjunction with these individuals, a plan will be agreed for how best to produce resources to respond to the unmet needs of patients with IgAN. A range of multimedia information will be created, including podcasts, videos, infographics and written materials. This information will be co-hosted on two purpose-built websites:

- (i) A dedicated interactive 'MediSoci®' platform constructed in partnership with 'DataTellsLife®'. The MediSoci® platform is a novel, hybrid, social media platform that integrates the functionality of a hosting website with the ever-changing conversations that occur through social media.
- (ii) A traditional, multifunction Wordpress website designed in collaboration with patients, which will host materials, but

additionally will have patient blogging and message board capabilities.

The two-way nature of social media means that the resources we create can be distributed back to patients through the same social media channels. The speed with which information can be disseminated, the potential reach and the low-cost of utilizing social media channels make them attractive platforms to properly engage and work with patients.

Whilst we anticipate creating many of the materials ourselves, we anticipate that during our Phase 1 analysis we will discover certain web-based patient resources that are already being shared and used by patients. These will be reviewed by the multidisciplinary team during the initial planning meeting in Phase 2 and if appropriate, high-quality, reputable patient-focused resources already exist that answer an information gap that we identify, we will sign-post patients to these, and co-host the information on the websites if possible, rather than duplicating the information. By taking this approach, we hope to reduce 'silo-working' and draw together like-minded groups working for patients with IgAN in a collaborative way, developing a more inclusive IgAN social network. This will include promoting national research initiatives, such as RenalRadar, and patient support organizations such as the Kidney Care UK and the National Kidney Federation.

It is crucial to the success of this project that resources are created in partnership with all stakeholders. These will include patients, clinicians, nursing staff, academic staff, physiotherapists, occupational therapists and dieticians. We will hold two further focus group meetings with these multidisciplinary team members to review, critique and edit the resources we create before they are published.

It is also important that we coordinate a social media response to support the dissemination of these resources. To adequately respond to patients through social media channels, we will need to develop an active presence on social networking sites. These will include Twitter, Facebook, Instagram, YouTube and Google Communities. For each of these we will use the hashtag #IgAPatient to tag each message we send and encourage all who engage with the groups to do the same to gain an idea of the impact of our messages and reach and to develop a social marketing campaign. Setting up social media profiles is straightforward; however, engaging in the community will take time. This will be a key part of the process, however, as information shared contributes to sustained engagement [9].

Phase 3: Assessing impact

We will undertake an evaluation to assess the impact of the resources developed on patient experience and learning. This will be achieved through website usage analytics and through analysis of the online interaction with the resources we create, either through feedback from the websites or from interaction with social media posts.

General online activity, use and evaluation. Web analytics will be used to analyse performance and visitors' interaction with the site. Google Analytics will be used to undertake analysis of the traditional Wordpress website as previously described [22]. The MediSoci® platform that will be developed in conjunction with DataTellsLife® has in-built, real-time usage analytics that we will use to assess interaction with the MediSoci® platform. We will also undertake a further social media analysis using the hashtacking service Symplur to assess the performance of the

hashtag #IgAPatient and for further qualitative analysis of social media posts that have used the #IgAPatient hashtag.

Observation of interaction with social media posts. Throughout the study period the research team will observe patient engagement with resources, reported knowledge gaps and patient experiences to offer a deeper understanding and explanation of the role of social media in satisfying patients information need and maximizing engagement with resources. Collection and qualitative analysis of this data will offer more granular detail about the patient experience and complement the data obtained about general online activity and website, and resource usage.

Ethical considerations

This project received ethical approval from the University of Salford. A number of publications that focused on the ethical issues associated with big data and data mining from social media were consulted to inform the safety and ethics of this study [23, 24].

Zero patient–clinician interaction. We anticipate being asked medical and healthcare-related questions. Whilst it is imperative that we interact and engage with patients through social media channels to build a network, we will not offer any specific or personal medical/other advice through these channels. Patients seeking specific advice will be advised to contact local healthcare teams for any health or information concerns. It will be clear on all social media profiles we create and the websites we build that specific medical information or second opinions will not be given.

Zero privacy. All social media posts from Twitter and Instagram in conjunction with DataTellsLife® are publicly posted, but will still be anonymized before analysis. Where it is freely available, information about the demographics and locations of users who have posted have been collected if these are linked to the post in the public domain, but they have not been sought when not made available by the individual users.

Data ‘scraped’ from Facebook will be anonymized before analysis. The gatekeepers of both Facebook groups have agreed that members of the research team can join the groups and interact with patients to evaluate the impact of the resources we create. These interactions and the data acquired will be anonymous.

Importantly, no identifiers such as e-mail, usernames, IP addresses, pseudonyms, localization of networks or direct quotations that may be attributable via search engines will be included in any material made available to public.

Zero consent. Individual consent is not required for the analysis of social media posts as we are only undertaking analysis of material available in the public domain, or to which we have been granted specific access. Access to Facebook data is as agreed with the gatekeepers of these groups, and an agreed protocol that indicates how this data will be used will be signed with and by the gatekeepers of the closed Facebook groups.

Zero representativeness of findings. The representativeness of findings is a widespread issue around big data due to the fact that each platform is used by only a segment of the population. In order to capture the experiences of a diverse user segment, the

mainstream platforms have been chosen (Twitter, Instagram and Facebook).

Discussion

Patients with chronic diseases are increasingly using social networking channels to connect with others and to search for information to help them understand their condition. This project is a 21st century digital solution to understanding patient need and developing resources in partnership with patients and representatives of the multidisciplinary team. Whilst this study will be looking at patients with IgAN, we envisage that the findings will influence the design of similar studies for other conditions.

This project is truly patient-centred as we are reaching out through freely accessible social networking channels to patients and looking at the questions they are asking and the discussions they are having. This method differs from the traditional model as social media channels exist outside and independent of traditional clinical environments. Moreover, not only will we be reaching out to patients to discover the questions they would like answers to, but we will be responding through the same channels directly to them. If the model is shown to be successful it can be used as the paradigm for modern/electronic, two-way communication between patients, clinicians and researchers. The success of this project would lead to direct benefits for patients and contribute to our understanding of the personal needs of individuals.

Authors' contributions

T.O. is an NIHR Clinical Lecturer. M.P.M.G.-B. is a doctoral research fellow at the national centre for sport and exercise medicine, Loughborough University. J.B. has a research agreement with L.Y.J.C. (CEO of DataTellsLife®) to analyse social media data with their technology, with additional support to launch an educational program for patients with IgAN on their MediSoci® platform.

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Conflict of interest statement

None declared.

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