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Impact of social media on adult CF centres across the UK

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People with chronic health conditions use social media to share experiences and seek advice from peers. Similarly healthcare organisations are using these tools to engage and communicate with patients. The aim of this study was to investigate the opinions of health care professionals on the use, motives and impact of social media used by patients and staff in UK CF centres.

Members of the Leeds adult CF MDT developed an online survey with 18 core questions relating to social media. The survey was sent to the clinical lead of each CF centre in the UK. The lead was asked to complete the survey and to pass it on to key members of their team to complete. Mixed methods were used with categorical, Likert and free text options.

66 respondents from 9 professional groups and 19 centres across the UK completed the questionnaire. 16/44 professionals had never used social media and 35/60 reported that their centre had no social media presence. There was belief that social media was having a negative impact on certain aspects of care including spreading inappropriate gossip and in some cases bullying. Only 30.2% of respondents felt social media had a positive impact at their centre in contrast to 73.3% of responders who felt social media had been used in a negative way. Verbal communication, directing individuals to use departmental social media channels and communication of acceptable behaviour to all patients via a website or newsletter were methods shared to deter negative content. Despite their negative experiences many felt social media had the potential to be a positive experience in areas such as communication with patients, education, adherence, peer support, amongst others.

Negative experiences involving social media use by patients predominate. Different methods to tackle these problems have been adopted. Sharing our experiences and being alert to such problems should help minimise distress in the future. Many potential areas of positive use exist and should be exploited.