



## The importance of social media for patients and families affected by congenital anomalies: A Facebook cross-sectional analysis and user survey ☆☆☆



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### ABSTRACT

**Background:** We aimed to define characteristics and needs of Facebook users in relation to congenital anomalies. **Methods:** Cross-sectional analysis of Facebook related to four congenital anomalies: anorectal malformation (ARM), congenital diaphragmatic hernia (CDH), congenital heart disease (CHD) and hypospadias/epispadias (HS/ES). A keyword search was performed to identify relevant Groups/Pages. An anonymous survey was posted to obtain quantitative/qualitative data on users and their healthcare needs.

**Results:** 54 Groups and 24 Pages were identified (ARM: 10 Groups; CDH: 9 Groups, 7 Pages; CHD: 32 Groups, 17 Pages; HS/ES: 3 Groups), with 16,191 Group members and 48,766 Page likes. 868/1103 (79%) of respondents were parents. Male:female ratio was 1:10.9. 65% of the users were 26–40 years old. Common reasons for joining these Groups/Pages included: seeking support, education, making friends, and providing support to others. 932/1103 (84%) would like healthcare professionals (HCPs) to actively participate in their Group. 31% of the respondents felt that they did not receive enough support from their healthcare system. 97% of the respondents would like to join a Group linked to their primary hospital.

**Conclusions:** Facebook Groups/Pages related to congenital anomalies are highly populated and active. There is a need for HCPs and policy makers to better understand and participate in social media to support families and improve patient care.

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Social media has changed the world's communication infrastructure and has become a popular point of reference and social support [1]. The General Medical Council (GMC) for the United Kingdom advises that doctors' use of social media can benefit patient care by engaging users in public health and policy discussions, establishing national and

**Abbreviations:** ARM, anorectal malformation; CDH, congenital diaphragmatic hernia; CHD, congenital heart disease; HCP, healthcare professional; HS/ES, hypospadias/epispadias; MDT, multidisciplinary team.

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international professional networks, and facilitating patients' access to information about health and services [2].

It is known that parents of sick neonates often feel isolated and poorly supported [3]. The use of Facebook in relation to rare surgical congenital anomalies has not been extensively studied. As a result, published data related to the demographics and needs of Facebook users in this population are scarce. Better understanding of this group would facilitate healthcare professionals (HCPs) in providing appropriate information and support to both patients and parents.

This study aimed to investigate the demographics and needs of Facebook users seeking information related to four congenital anomalies with associated long term morbidity: anorectal malformation (ARM), congenital diaphragmatic hernia (CDH), congenital heart disease (CHD) and hypospadias/epispadias (HS/ES).

### 1. Methods

#### 1.1. Identification of Facebook Pages and Groups

A Facebook profile was created for the purpose of the study. A preliminary Facebook search revealed that the most active Groups and Pages related to congenital surgical anomalies were for ARM, CDH,

CHD and HS/ES. Utilizing Facebook's inbuilt search engine, a keyword search was performed to find all relevant Groups and Pages related to the chosen conditions on February 2014. Keywords used for this search included: imperforate anus, anorectal, congenital diaphragmatic, congenital heart, and hypospadias. Any open or closed Groups or Pages that were primarily focused on the selected congenital anomalies were included. Groups and Pages not in English, commercial pages linked to profit and closed Groups that denied access were excluded.

## 1.2. Survey

A survey including 17 questions was produced (Appendix 1 in the online version at <http://dx.doi.org/10.1016/j.jpedsurg.2016.07.008>). Questions were related to user demographics, use of Facebook, the role of HCPs in social media, and whether users felt that they received adequate support through their healthcare provider. The survey was managed using a secure 'Google docs' account. No identifiable data were requested, and it was emphasized that participation was entirely voluntary.

The survey's condensed URL hyperlink '[tinyurl.com/paediatricsurgery](http://tinyurl.com/paediatricsurgery)' was posted on the wall of the selected Groups and Pages twice a week from 24th March 2014 to 6th June 2014. The link was also sent directly to Group and Page administrators. If requested, or after 3 deletions of the post by a Group or Page, the posting was discontinued. All queries were answered via a secure NHS e-mail account in order to maintain confidentiality.

## 1.3. Quantitative and qualitative analysis

Data were collected via Google Docs (<https://docs.google.com/>) and analyzed using Microsoft Excel. Continuous data are presented as mean  $\pm$  SD and categorical data as median (interquartile range) or mode. For qualitative analysis, comments were coded and grouped based on content themes, which were agreed upon collaboratively by all the authors.

## 2. Results

### 2.1. Facebook Group and Page characteristics

A total of 54 Groups with 16,191 members, and 24 Pages with 48,766 likes were identified. The distribution of Groups by condition was as follows: CHD, 32; ARM, 10; CDH, 9; and HS/ES, 3. The largest Group and Page were for CHD with 3606 members and 12,409 likes respectively.

### 2.2. Quantitative results

There were 1133 responses to the survey. The distribution of responses from Groups/Pages associated with each congenital anomaly is shown in Fig. 1. 30 respondents were excluded from analysis as they were either affected by conditions not included in the study, or

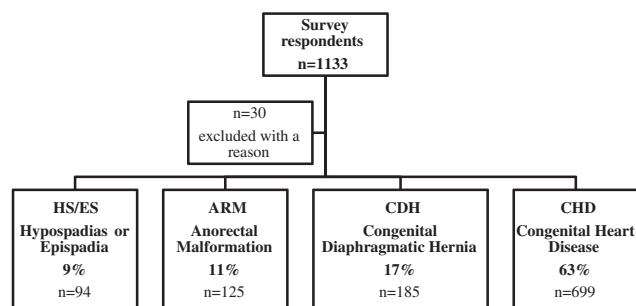


Fig. 1. Classification of the respondents to the survey based on the four congenital anomalies studied.

by more than one of our selected conditions. Respondents' country of origin included Australia, Croatia, New Zealand, Nigeria, United States, United Kingdom and the Channel Islands. 64% of the respondents were 26–45 years old, and 26% were aged 45–60 years. 868/1103 (79%) were parents of an affected individual. 189/1103 (17%) were the patient and 46/1103 (4%) listed their relationship with the affected individual as 'other'. 92% of the respondents were female with a male: female ratio of 1:10.9. The most represented demographic group responding to the survey included mothers aged 26–40 years. 33% of the responders stated that the age of the affected individual was 1–5 years old. This age bracket was the mode for ARM, CHD and HS/ES. The mode for CDH was younger, with 43% of the respondents stating that the affected individual was 0–3 months old. 84% (n = 924) of the respondents were using Facebook more than a few times per week and 46% (n = 510) were using Facebook more than once per day.

Respondents were asked to define the primary focus of their Group or Page. They were provided with the predefined options of 'Support', 'Educational', 'Fundraising' or 'Other'. 97% felt that the primary focus of their Group or Page was for support. Submissions in response to 'Other' were collated and categorized further as 'Advocacy', 'Friend and Family' and 'Location/Hospital based'.

Respondents were asked to identify why they chose to use that specific Group or Page from a selection of answers. Most commonly selected answers were 'emotional support', 'help with day-to-day management', 'to better understand their condition', 'to make friends' and 'to get recommendations on medications/treatments/hospitals'. 31/1103 (2.8%) of the respondents stated that the reason for using the selected Group or Page was 'to give help and advice to others'. This response was elicited as part of an open answer with free text option.

### 2.3. The role of healthcare professionals (HCPs)

31% of the respondents felt that they currently do not receive enough support from the healthcare system. However, there was variation among the conditions as illustrated in Fig. 2. Respondents from Groups/Pages related to ARM and HS/ES were more likely to report not currently receiving enough support.

85% of the respondents would like to have participation of HCPs with their Group or Page. Specialist nurses were the most requested HCP for respondents to have the opportunity to interact with online. The respondents had a free text option to suggest which members of an ideal multidisciplinary team (MDT) were important to be online. In total there were over 25 different professionals requested to be active online. The most commonly requested HCPs were: specialist nurse, pediatric surgeon, pediatrician, cardiologist, psychologist, urologist, social workers, respiratory physician and colorectal surgeon.

Respondents identified the following as issues they would wish to discuss with HCPs online: 'acute problems', 'chronic problems', 'social issues', 'medical management' and 'surgical management'.

When asked whether they would join a Facebook Group linked to the hospital that they are currently seen at, 83% of individuals responded positively with 919/1103 stating 'yes'. 154/1103 (14%) stated 'maybe', and 30/1103 (3%) stated that they would not join a Group affiliated with their current hospital.

### 2.4. Qualitative results

Respondents were asked to provide open comments regarding the participation of HCPs within their Group or Page. The majority of responses clustered around the following themes: 'positive gain from HCP's clinical experience', 'advice that they could trust', 'ease of access', 'instantaneous answers regarding medical and practical issues', 'education including basic physiology', and 'up-to-date information regarding new research and treatments'. Respondents suggested that online interaction between Facebook users and HCPs would be of reciprocal benefit. HCPs would achieve better insight of the daily problems associated with

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