

How do parents use social media and the internet in the context of their child's genetic neurodevelopmental disorder (GND)? A mixed methods analysis from the GenROC cohort study

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Abstract

Social Media groups (SMG) enable individuals with rare disease to connect with one another, and access instant support and advice. Accelerated diagnoses of GNDs over the last decade have driven rapid expansion of gene specific SMG membership. Limited literature regarding parental use of SMGs in the context of managing their child's GND exists. We undertook a mixed methods study within a cohort of children with GNDs (GenROC). 351 Parents provided quantifiable survey responses regarding their use of social media. We also interviewed 17 parents to understand how they use SMGs and regarding their views on the data held within these groups.

Our survey found 92% of parents use SMGs related to their child's genetic disorder and of these almost all are on Facebook. Most SMGs are closed, international, have more than 200 members, are specific to the GND and associated with a corresponding charity or foundation. Most parents could not recall what they had consented to when joining the group with respect to the use of their posted data. Most parents trust the data that is shared but acknowledged the anecdotal nature of it. Parents found the most valuable element of the SMG to be shared lived experience with other families.

Interview data from 17 parents were coded and analysed thematically. Four main themes were identified: 1) SMGs for support and shared lived experience; 2) Possible harms from participation in SMGs; 3) SMG composition, demographics and dynamics; 4) Usefulness and use of data shared within the groups.

This mixed method study shows the evolving landscape of SMG use in neurodevelopmental disorders, highlights its benefits and downsides and is widely applicable to all parent SMGs for specific niche medical conditions. Utilising the strength of these groups in a more collaborative approach in the future could prove useful to clinicians, families and researchers alike.

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Original Manuscript

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GTE: Methodology; formal analysis, writing – reviewing & editing

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JJ: Methodology; supervision; Writing- review & editing

JP: Methodology; supervision; writing – review & editing

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Ethics declaration

The GenROC study received Research Ethics Committee (REC) approval on 15 December 2022 and Health Research Authority approval on 9 February 2023.

Conflict of interest statement

None declared.

Patient consent statement

All participants provided informed consent for interview as per GenROC study protocol.

Abstract

Social Media groups (SMG) enable individuals with rare disease to connect with one another, and access instant support and advice. Accelerated diagnoses of GNDs over the last decade have driven rapid expansion of gene specific SMG membership.

Limited literature regarding parental use of SMGs in the context of managing their child's GND exists. We undertook a mixed methods study within a cohort of children with GNDs (GenROC). 351 Parents provided quantifiable survey responses regarding their use of social media. We also interviewed 17 parents to understand how they use SMGs and regarding their views on the data held within these groups.

Our survey found 92% of parents use SMGs related to their child's genetic disorder and of these almost all are on Facebook. Most SMGs are closed, international, have more than 200 members, are specific to the GND and associated with a corresponding charity or foundation. Most parents could not recall what they had consented to when joining the group with respect to the use of their posted data. Most parents trust the data that is shared but acknowledged the anecdotal nature of it. Parents found the most valuable element of the SMG to be shared lived experience with other families.

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approach in the future could prove useful to clinicians, families and researchers alike.

Author summary

Parents of children with rare diagnoses are often left with very little information about their child's condition. This drives them to the internet and in particular to social media groups to try and find out more information about their child's condition and to connect with other families going through a similar experience. Here we use two different approaches to better understand the way that parents are participating in these groups, what they use them for as well as the pros and cons. We found that almost all parents take part in these groups and that almost all groups are on Facebook. We found some evidence to show that this may be changing and that the dynamics within the groups are changing with increasing size. Through detailed interviews with parents, we describe the way that parents use groups; their benefits and downsides. This study highlights the extensive use of groups in rare disease and is widely applicable to many other niche medical conditions. Better understanding of the way these groups are used will enable improved collaboration and data sharing between families, clinicians and researchers in the future.

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Introduction

Social media groups (SMG) have dramatically changed the way individuals seek and share information online, particularly in the context of healthcare and are used by parents both as a support mechanism but also as a way of finding out information to help them look after their child(1, 2). Genetic neurodevelopmental disorders (GNDs) are rare with wide geographic spread, heightening the need for connection and increasing the information drought. Our recent literature review (Bogaert et al, submitted) showed that SMGs empower parents by providing key information and a support role. Most parents use social media to help them manage their child's GND and the majority use Facebook groups that are gene or GND specific and are 'closed' requiring authorised access by a

group 'admin' based on group specific set criteria(3).

Regardless of underlying disorder parents use social media to acquire health related information about specific medical concerns both before and after their child receives a medical diagnosis, and to seek out information based on other parents' lived experience. This also provides a sense of support and community. Parents increasingly use this acquired information to discuss and sometimes challenge healthcare providers regarding the treatment options that are being offered for their child(4).

Medical health care was named as one of the key information needs identified in a study of parents of individuals with rare genetic disorders in a Facebook community group(5, 6). Tozzi et al (2013) undertook a survey of 516 Italian families with rare genetic disorders to describe their internet use and found that 99% searched on disease characteristics with 93% looking for therapies and 63% for alternative therapies indicating high level of need around treatments and therapy(7).

The number of diagnosed individuals with GNDs has changed substantially over the last decade largely due to changes in technology and access to genomic testing (8). This means that the number of SMGs and number of individual members within each SMG have rapidly increased since 2010 and continues to climb(3,9).

However the data about how SMGs help parents are limited and with increasing numbers of diagnoses the landscape of social media use is shifting. Our study aimed to describe this landscape and lived experience shared in SMGs by parents of children with GNDs in order to inform improved digital collaboration for the benefit of patients and families, clinical care and scientific advancement.

Materials and Methods

Two methods were used: surveys of parents and interviews with parents.

Parent surveys

This study is nested within the GenROC study, a UK based cohort study of children age 6 months-16 years old with rare monogenic neurodevelopmental conditions (GenROC: REC22/EM/0274)(10).

Parents were asked to complete two separate questionnaires PQ1 and PQ2 which were developed with stakeholders (three Genetics researchers, two Genetics charity representatives, two Neurodisability Paediatricians, two Digital health academics, one qualitative researcher) and patient

participant involvement (PPI) input (six parents of GNCs, one adult with GNC) and tested with three parents of GNDs using a Thinkaloud approach(11).

PQ1 and PQ2 both included social media questions (see supplementary figure 1) and development of PQ2 was informed by the results of the qualitative study described below.

Parent interviews

17 parents (5 fathers, 12 mothers) of 13 children were purposively sampled (Low et al, submitted) and interviewed using a topic guide which was informed by the literature, clinical expertise, and PPI input. Most parents were interviewed 1:1 but 4 couples chose to be interviewed together. In one case a mother was interviewed with her child present throughout.

Interviews took place on Zoom and were recorded, transcribed and anonymised then imported into NVIVO qualitative data management software (Release 1.71) for coding and data management. All interviews were undertaken by the first author.

Data were analysed following the principles of inductive thematic analysis(12-14). An iterative approach was used to develop an initial codebook (deductive component)(15). After 8 parents were interviewed the process was paused to review the data and to develop and refine the coding matrix. This was then used for the remaining transcripts. We determined that we would continue with interviews until no new code categories were being generated and no new themes were created (13, 14). No repeat interviews were undertaken. The first 8 transcripts were coded by the first author and additional codes that were not covered by the initial codebook were then added (inductive component). Twenty percent of the transcripts were double coded by an experienced qualitative researcher who was not a clinician and had no prior experience of paediatric genetic disorders. All discrepancies were reconciled through consensus. Data are reported according to COREQ guidelines(16).

Results

Parent surveys (Figure1)

351 (89%) responded to the optional social media questions; 98.5% of the SMGs were on Facebook as shown in figure 1a. Figures 1b, c, d and e show the category of genetic group, geographical distribution, numbers of SMGs used, and size of groups respectively. The four participants (1.5%) who stated that the SMG was not on Facebook did not provide information regarding location of the group. Only one parent answered that their child was a member of a SMG. Those who participate in more than one SMG did not consider the information to be conflicting.

Almost half (126, 44.8%) remembered being asked when joining to keep information within the SMG confidential, but almost as many parents (113,40.2%) weren't sure. Most parents (191,61.2%) did not recall providing consent for their data from the SMG to be used elsewhere, with 30% (84) not being able to remember whether they had been asked. Of the 29 parents (10.3%) that recalled giving consent, three quarters remember giving consent to information being shared outside the SMG; seven (24.1%) for any purpose; 15(51.7%) to be shared with doctors and researchers working on the condition; and seven(24.1%) could remember giving consent but could not remember any further details. Sixty-five (18%) respondents did not take part in any SMG with respect to their child's GND.

The results of the statements about attitudes towards the information held in the SMG are summarised in Table 1 (1 representing the lowest agreement and 10 the highest) with the distribution depicted in Figure 2.

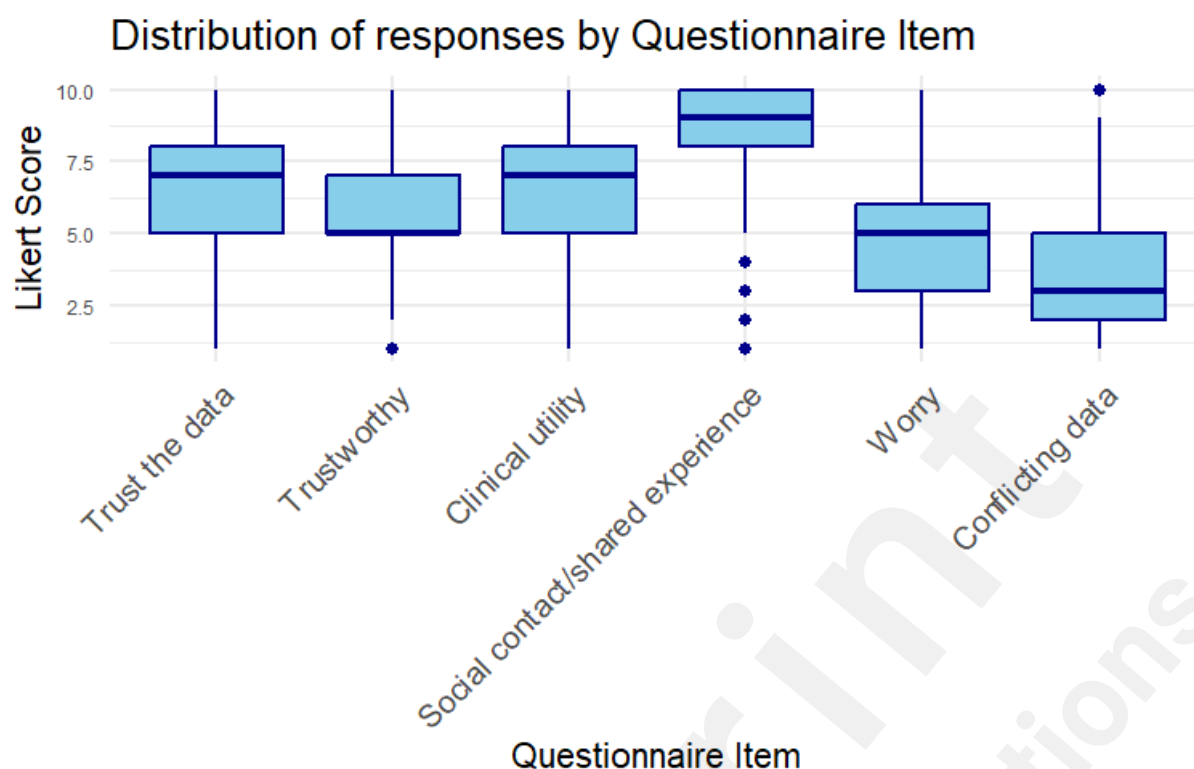
Table 1. Responses by Likert scale to attitudinal statements

Statement	Response rate count/360(%)	Mean	SD	Min	Q1	Median	Q3	Max
Statement 1. "I completely trust the information provided in the group."	271(74%)	7.03	1.98	1	5	7	8	10
Statement 2. "To what extent do you agree with the statement 'the information provided	263(72%)	5.77	2.02	1	5	5	7	10

the group is completely biased (for example a feature might look more common because people only respond to poll if their child has the feature)”								
Item 3. “To what extent do you believe that doctors or healthcare professions could be using the information from these groups when making clinical decisions?”	272(75%)	6.79	2.03	1	5	7	8	10
Item 4. “To what extent do you agree with the statement: The social media group helps by giving me contact with other people who have similar experiences”	277(77%)	8.52	1.85	1	8	9	10	10
Item 5. “To what extent do you agree with the statement: I find that the information from the group can make me worried or anxious”	269(75%)	4.69	2.11	1	3	5	6	10
Item 6. “I find that there is conflicting information in the different groups “	145/158(92%)*	3.51	2.2	1	2	3	5	10

Table 1 Legend: 1 represented the lowest agreement and 10 the highest. Response rates were calculated as a percentage of parents who responded to the question out of a total count of 361, the number of parents who replied ‘yes’ to being a member of a social media group in the question already discussed. *Denominator of 158 used as this question was only asked of people who had responded that they were part of more than one social media group with respect to their child’s genetic condition.

Figure 2. Distribution of responses by questionnaire item



Most activity occurs in Facebook; 18 (8.3%) reported using a gene specific WhatsApp group, with five (2.3%) using LinkedIn and 14 (6.4%) using Instagram. Ten (4.6%) follow an influencer on social media relevant to their child's diagnosis :eight followed a parent of a child with the same condition; four a parent of a child with another genetic condition; one a person with a genetic condition. Only seven (3.2%) reported listening to relevant podcasts.

Parent interviews

Four main themes (figure 3) were created from the parent interviews.

Figure 3 Summary of themes from parent interviews regarding parent use of SMGs with respect to their child's GND

PARENTS' USE OF SOCIAL MEDIA IN GENETIC NEURODEVELOPMENTAL DISORDERS : 4 THEMES



Social media groups as an essential source of support and shared lived experience: seeking advice; inspiration; polls

Possible harms from participation in social media group: upsetting content; initial anxiety soon after diagnosis; nefarious/unethical purposes



The inclusion criteria for the group dictates dynamics: Broad vs GND specific; Composition; use of other platforms

Usefulness and use of data shared within the group: understanding of privacy and consent rules; reliability and use of data ; scientific validity of data; parent research



Quotes and participants are numbered in the tables and identified as mother or father.

1.SMGs for support and shared lived experience(Table 2)

Some parents reported that clinicians signposted them to the gene specific Facebook group after diagnosis as a possible avenue of support, (Q1)

Parents all described the SMG providing them with a feeling of shared lived experience which is vital for them as a coping mechanism (Q2)

The lack of natural history data in GNDs makes it hard for parents to know what the future might look like for their family which they find very difficult. SMGs allow them to get more insight (Q3);

and how parents rely on the SMG as an easy way of accessing information about their child's GND and as a way of staying up to date and well informed (Q4).

Parents described some of the reasons for searching or posting. These included:

- i. To help find information before attending an appointment with a healthcare professional for their child (Q5)
- ii. To get ideas for specific aids, interventions, days out or toys that might be particularly appropriate or enjoyable for their child (Q6)
- iii. For medical advice about their child from other parents in the group (Q7)
- iv. For polls to find about prevalence of symptoms, features, interventions as well as to help researchers (Q8.)

Table 2. Quotes from parents- SMGs for support and shared lived experience

Theme	Quote number	Quote	Source
Signposting by professionals	1	"So then I was directed to the Facebook group, which is really the only support group, and to contact the Office for Rare Conditions which is the Scottish version of Unique, and then... and Unique, and I was told to give them a shout and see if I could [get] any help."	#16,mother
	2	"...but as parents it's scary for us because we don't actually know what's going on with our son...But when we listen to other parents on the group we know kids are different but they're all going through exactly the same thing, and the same journey."	#1,mother
See the future	3	"We can see what a day in the life for their family [...] going back to the progression and what the future could possibly hold for [son], [...] and you get the camaraderie of being part of a group that can work together."	#6,mother
Stay informed	4	"You just find so much more out from other parents, and then with the [X] group they post all the research and everything in there, [...] and they post the conferences. So it's an easy way to get to all of the information."	#3,mother
Reasons for posting (preparing for appointment)	5	"So I do go onto the Facebook group but I typically go on to look for something ahead of an appointment. [...]. So I looked up the information that was on there, [...] [...] because she's got a squint, and I wanted to know if I could get the consultant to look at her eyes to check for those optic nerves."	#16,mother
Reasons for posting (to	6	"But if they're like have you tried sensory play in a dark room? Or have you tried taking him to an aquarium or	#6,mother

get ideas)		something like that? We're like oh okay that really helps...Or suggestions of toys ...[...] like birthdays when family and friends want to buy things,	
Reasons for posting (medical advice)	7	"I said, "He's starting to get a lip drop..." [...] another parent said, "Oh actually my child had, when they had a virus it went into[...] and I said, "Okay, he has just had a virus, okay I don't need to worry," I don't need to now take him to hospital"	#5,mother
Reasons to post (polls)	8	"I do polls actually, we get really good information, but I always tell people what it's for, ... so for example I think [researcher] is hopefully going to do an MRI study, so he needed to know how many patients actually have more than one MRI[...]so I could say yes actually we do have enough, and how many would be happy to actually be part of a study."	#10,mother

2.Potential harms from participation in SMGs (Table 3)

Parents described three subthemes of potential harms through participation in SMGs.

i)Parents become upset by the content that they read/see in the groups

Reading the posts in the SMGs can cause anxiety and this can lead to reduced use (Q9); or have an impact on mental health (Q10).

Parents talked about how they are particularly distressed when they read posts about children in the group dying. One parent explained that it isn't simply the subject matter itself but also the reflex anxiety it generates about one's own child and a tendency to heightened anxiety and emotion within the group which can be difficult to deal with (Q11).

For some, the distressing content was about their own child. One parent explained that another member of the SMG was the first person to suggest the diagnosis for her child. (Q12).

ii) Joining a SMG soon after a child's diagnosis can result in a spike in anxiety

Participation in the SMGs can cause considerable anxiety in parents when joining soon after their child's diagnosis (Q13). This was highlighted by a foster carer with her viewpoint on this initial spike of anxiety in biological parents (Q14).

The process of participating in the SMG, experiencing anxiety and learning to manage that may be helpful in enabling parents to come to terms with their child's GND (Q15). Another parent described this phenomenon of initial anxiety and tried to highlight positive stories for newly joined families but recognises that even she can get anxious in the groups (Q16).

iii) SMGs can be used for harmful purposes but this is infrequent.

Parents described use of data in SMGs for unintended/unacceptable purposes including a description of members of the group whose children had variants of uncertain significance which “didn’t look likely” and how they were trying to use information acquired in the group to try and obtain a diagnosis or “proof” for their child. A more extreme example of this misuse of data is where one parent describes a safeguarding case arising from a feeding tube Facebook group (Q17).

Parents reported that occasionally groups can be targeted for commercial purposes such as unsolicited marketing of equipment. Whilst unwelcome, most of these instances are genuine, however occasionally they can be preying on vulnerable families as part of a scam (Q18).

Table 3. Quotes from parents -Possible harms from participation in SMGs.

Theme	Quote number	Quote	Sc
Content increases worry about what might happen	9	“So I don’t want to start researching [...] and then thinking the worst and then he doesn’t have that[...] I feel like I don’t want to waste the energy doing all of that, and worrying, and then stressing over him.”	#4
Impact on own mental health	10	“It’s not enjoyable to read articles or watch videos about children suffering, or having 50 plus seizures a day [...] even if you know that’s not necessarily you. It’s quite a negative thing to be constantly seeing [...] it can weigh quite heavy on your mind and your emotions ”	#6
Child death	11	“When we have a death there’s suddenly all this drama[...] you suddenly get all the other parents going oh my god is my child going to die? [...] But yeah, I think you get more aware of the fatalities, which probably isn’t very good for anybody’s mental health, and they get shared around a lot, so that’s pretty depressing.”	#3
Distress caused by interactions with others in the group	12	“They said she looks like she has [X]..I was insulted by yeah, because I’d read it and was like no, I’m sure she’s just got [x], even though they told me [my child] was small. [...]. It’s like telling somebody you might have cancer but you might not[...] the person would probably [...] prefer to be told nothing until they knew I would think.”	#3

Joining soon after diagnosis spikes anxiety	13	"I think it did to begin with, because I thought is she going to be like that? Or how it was already hard how she is now, let alone how she could be, and I think it was the uncertainty..."	#3
Looked after perspective	14	"... because I don't have those genetic connections to these children[...]I haven't passed this to them... So people [...]get upset because obviously they're going is it me?...They're coming to terms with what they thought might have been a short term issue, actually becomes a lifelong issue, because actually if it's a genetic problem it ain't going to go away."	#3
Dealing with anxiety may help come to terms with diagnosis	15	"You tend to hear from the people that are having the worst time. [...]you can see some things that make you anxious, but you're going to be anxious anyway...learning how to deal with that anxiety is the journey that you're on anyway, so it's like a necessary downside."	#3
Other parents support newly diagnosed families	16	"some families have commented on the Facebook forum that they have just been diagnosed and it's been really overwhelming and upsetting, "Is there anything positive to hear? I'm so terrified," [...]actually there is lots of positive stuff on there, [...] we will always post on there and reassure them that this is a safe place, and that's why you'll see the overwhelming stuff, because this is the place where we can share that, that absolutely there's lots of positive stuff as well..."	#3
Groups can be used for unsavoury purposes - Safeguarding	17	"There was a mother asking for help, and I described everything about when [child] got his feeding tube, and the fights with gastro to get the fund, going to get his button put in and everything, [...] and it turned out she was abusing her child. He didn't need a feeding tube, and she was using our group to get the information to tell the doctors. It went to court, and they used my words as part of the evidence in court to prove that she'd been going digging for information."	#3
Groups can be used for unsavoury purposes -Scams	18	"I know that on the special needs websites for equipment that people try and scam you, trying to purchase for example a specialist wheelchair and whatnot, and marketplace and whatnot, and people are trying to purchase equipment that is really expensive at the normal price."	#6

3.The inclusion criteria for the group dictates dynamics (Table 4)

i)Parent experience differs in groups that have broad inclusion versus specific criteria

Whilst most parents were members of GND SMGs, some were members of broader SMGs as well. A foster parent reported preferring a broader fostering SMG to the GND SMG as members were less likely to be offended by posts (Q19). In contrast another parent explained that the mixed SMGs can result in a competitive dynamic between members who wish to be seen as the one having the most difficult time (Q20).

ii) Group dynamics are impacted by geographical spread, size and composition

For some GNDs the number of children being diagnosed has increased significantly which has resulted in a much bigger SMG. This has resulted in some SMGs being split by composition (parents; grandparents; researchers) and has impacted the content within the SMG (Q21). Some GNDs will have an international SMG as well as country specific SMGs (such as UK families only). Parents explained the pros and cons of being part of one of the big international SMGs (Q22). Another problem with the international SMGs is that non-English speakers tend to receive fewer responses to their posts (Q23). As the SMGs get bigger, and more children are diagnosed more specific charities are set up which can result in competition between charities within the groups. The same mother, who has set up a GND charity, described some of the competing politics arising in a big SMG (Q24).

iii) Group composition and dynamic may prompt use of other platforms.

One parent explained that for the GND there is a UK only Facebook group and then a bigger International one, hosted by the US charity. She reported that the UK SMG is very “quiet” and suspects that people think they have a higher chance of getting relevant information in the bigger SMG. However, there is still a desire for local or UK specific support. For this reason the UK based charity are trialling a WhatsApp group just for UK families. in (Q25).

Another parent advocate who had set up a UK charity explained that she also uses LinkedIn for her charity work but in a professional capacity and in a different way from how she would use the Facebook group. (Q26).

Table 4. Quotes from parents – Group composition and dynamics

Theme	Quote number	Quote	Source
Broad vs Specific	19	“(I prefer the) Fostering groups, because nobody is hurting anybody else’s feelings, nobody is very fragile, and you can just say it how it is.”	#17,mother
Prefers GND specific	20	“you end up feeling a bit like the oppression Olympics where whose kids are the worst off, and I can’t complain that mine isn’t verbal, because other people’s children will not only be non-	#16,mother

		verbal but will never walk, [...]. you end up starting to feel quite othered in a group that's supposed to be inclusive"	
Subgroup	21	"There's a private group just for parents and carers[...]and then there's a public forum, so the grandparents have joined that one as well... But definitely the theme of the stuff [...] is much more people introducing themselves and saying they've just had this diagnosis[...] a lot more of that [...] in the last year than there was at the beginning."	#12,mother
International vs country specific	22	"For certain treatments it's useful. [...]. But also because it's a much bigger group it's quite chaotic, and you just... there's just loads of posts from people just having a terrible time kind of thing. Yeah, but because their health system is so different it doesn't seem so useful."	#15,father
First language	23	"It's getting a bit too big now, because obviously more people are getting diagnosed, and I think what I see happening is that some of the people whose English isn't a first language their questions get ignored. [...]. I always try to answer theirs, because I feel like they're the ones that need the most support, they don't have any community."	#10,mother
Group politics	24	"The newest [country] one is not supportive of our charity, which I don't understand, because obviously we're not competing...the Facebook group is more I don't know if political is the right angle, but they use it definitely for their own means as well as for support. [...]. So they friend them immediately[...], and they basically are accumulating families for the knowledge of their charity through this Facebook group."	#10,mother
Group composition/dynamic can prompt use of other platforms	25	"The UK group just doesn't get enough traffic...Because it was feeling like it was just disappearing, and obviously new parents want this community really. So we came up with the idea only to have a WhatsApp group, because your counts were so small. Obviously if you have a few hundred people in a group it's not going to be possible..."	#10,mother
Use of LinkedIn for professional purposes	26	"So that's how I've reached out to all of the doctors, and the scientists and the researchers. The more I post about a certain topic the more I see people that are involved in those topics. It's how I become aware of conferences and congresses, and it's a really quick informal way of reaching out to those to be, "Hey we're here, can we come and present at your conference?" And, "Is anyone interested in this condition?"	#11,mother

4. Usefulness and use of data shared within groups (Table 5)

i) Parent understanding about their data in the groups, privacy, consent

Parents varied in their recall of what they had been asked or what rules they agreed to when they

signed up for the SMG (Q27). However, one parent was certain the only question they had been asked was whether their child had the specific genetic diagnosis.

Some parents considered the need to decide about sharing information in terms of their child's best interests (Q28). Parents reported they have noticed that many parents in the SMGs appear to trust it implicitly and will share highly confidential data (Q29). However some parents stated that they had little confidence in anything they shared being kept private (Q30) and that there are no guarantees that the people who join are genuine (Q31).

Foster carers described a nuanced aspect regarding privacy of data and the need to protect a looked after child's identity particularly within a small SMG in which a birth parent may be a member if they have the same genetic condition as the child, (Q32). This need for heightened privacy limits their ability to access the same amount of support from the SMG as others.

ii) Parent views on the reliability and use for the data in the groups

Parents discussed how they assess digital content for scientific validity. All report using search engines, mostly Google, as a starting point. Many reported that they would trust information that was in a scientific journal or if it was affiliated with a university in some way, (Q33).

iii) Parent views on trustworthiness of the data in the groups

Parents perceived a bias in the frequency of posters but there were differing views. One parent commented that "you do tend to hear more from the people that are having the worst time" (#15, father) whereas another parent reported that the parents who post most have the "mildest" children (Q34).

Nonetheless parents feel they are objective about the information being presented and consider it useful but anecdotal (Q35). Another parent talked about the need to verify, and fact check information from within the SMGs (Q36).

iv) Parent independent research and participation in research

Although a lot of data are being collected in SMGs, most parents doubted that useful information could be extracted, or that it would be legal to do so, but felt that it was helpful to be able to search

old threads such as regarding treatment options, (Q37). Parents suggested that the data could be used to identify themes which could guide researchers towards avenues for future studies (Q38).

One parent reported that a large language model application is being used within their group which she found out about recently at the family conference (Q39).

Most parents described researching their child's specific genetic variant themselves. For some this would be through the SMG and some parents would develop expertise and answer other members' questions about the variants within the group. To gain understanding and expertise they use online data sources with a search engine as a starting point (Q40).

Many parents reported taking part in online registries and in rare disease portals where they are asked to complete questionnaires at intervals. Parents considered this as being very different from their posting in Facebook groups, thinking of the former as scientific research and the latter as anecdotal and social.

Table 5. Quotes from parents – Usefulness and use of data shared within SMGs

Theme	Quote number	Quote	Source
Data privacy, consent	27	"I can't remember what they are to be honest. I feel like one of them was probably about confidentiality, about it is a closed group, you have to ask to join, you do have to be a carer..."	#5,mother
Concerns about child's right to privacy	28	"I think with her consent is always going to be difficult because she won't understand. So I think it's always down to me and her dad to decide what's best for her at that time, so if at 16 we think actually this is enough now, there's no need to do this, we have information that we have that's relevant for her then we won't do it, but we will always do it in her interest, not for us but for her."	#14,mother
High levels of trust in the group	29	"But it's definitely people share everything on it, it's not secure. People are a bit silly, and will give genetic report to anybody, like to any other members,."	#10,mother
No trust	30	"My assumption is that by posting I've just given them open access basically to anything that I post. [...] I wouldn't post anything that I didn't want shared."	#3,mother
	31	"It can be genuine people, it can be people who are not genuine. So normally you have to say what your connection is and why you want to join, you can make that up... that's what people have to remember, that actually it's social media, and there are no givens, there's nothing that's concrete on there."	#17,mother
Privacy	32	"So as foster carers you can't share photos of your children on	#5,mother

and booked after children		social media, you can't really share any identifiable information, [...] So I just call myself foster mum, and I have a picture of a teddy bear, [...] I don't think his birth family will be scrolling through the internet trying to find him, but [...] you have to just cover yourself for these things, yeah, which can be frustrating."	
How parents evaluate data	33	"Just if it was a scientific paper. [...] if something turned up on PubMed with an abstract and it made sense then I'd take that as being pretty reliable, [...]... some of them are just looking at 12 kids or whatever, and they're all quite small studies. But yeah, definitely placing any published paper above random opinions, but not really going any deeper than that I suppose."	#15,father
Perception of bias	34	"So the parents who are most active seem to have milder children, like the ones that are walking, and that should be a minority based on the data, and I just wonder if [...] maybe the families with children who are really struggling aren't sat on social media."	#10,mother
Data is anecdotal	35	"I'm lucky in that my husband and I we both study sciences at university, so we both have a very good understanding of what is a good level of evidence. [...] people will give you their experience as if it were the gospel truth, because obviously it is to them. But it doesn't mean that's what's going to happen to my child"	#16,mother
Need for fact checking	36	"So you get people going on about it a lot, saying, "This girl's epilepsy was completely cured by cannabis," and it wasn't quite like that. It helped her a lot, it didn't cure her... [...], I guess I'm just confident to navigate these things, and yeah look at the actual research and stuff."	#15,father
Ability to search on threads	37	"But could you do anything with it? [...] some of it's very personal as well. [...]. So every six months somebody is asking about [treatment] or something, and then whoever's around will give their opinions, and they could go back and look at what people have said before. [...] Yeah, I guess there would be so many privacy problems trying to extract anything from it, that you probably can't."	#15,father
Data could guide themes or research	38	"But it's just poorly structured research basically. [...] if you're looking for high quality research you would do it in a better way. [...] You can perhaps get some insight, and some points of what to look into further from looking at the group..."	#7, father
Covert research in group	39	"We also have this clever [...] data collection something or other attached to it, which doesn't take any personal information at all, but it syphons out frequently mentioned or referred to topics, so that it can pick up more on the anecdotal family feedback as opposed to what the researchers decide to talk about."	#11,mother
Self-directed research	40	"I think if you type the actual variant code into Google [...] I found a university in China had an [gene name] database online which tracked all the different mutations, and all the different	#15, father

	papers that had mentioned each mutation and stuff. So I did a lot of research around there, but that didn't really make much difference to anything except I learnt a lot about genetics I suppose."	
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Discussion

Use of SMGs is highly prevalent in this cohort and provides support and information to fill an existing gap. However the information in these SMGs is largely anecdotal, requires a degree of critical assessment and can cause anxiety. Understanding SMG use and activity is important to ensure optimal support for parents, to address information needs adequately and to improve collaboration between parents, clinicians and researchers. .

Some parents told us in interviews that they were directed to the SMG by their child's healthcare professional who suggested it to them as an avenue of support and information. Unfortunately this was not specifically quantified within our parent survey but is consistent with a previous study in which a quarter of parents were directed to the group by their child's healthcare professional (4).

Parents value these SMGs very highly as shown by their high Likert response and qualitative analysis which is consistent with the literature(5-7, 9, 17, 18). Most parents view the SMGs as an opportunity to connect with other families who are in the same situation and develop real connections with them and friendships. Parents particularly valued the chance to understand the spectrum of the GND by looking at other members' posts about their children. Having members with older/adult children allowed them to get some understanding about the long-term outlook for their child which is consistent with previous literature(5, 18-20).

Some parents also use the SMG to obtain quasi medical advice from other members and would trust it implicitly. We cited one example whereby a parent chose not to present for an acute review of her child based on medical advice provided within the group. One important factor here may be responsiveness – Facebook groups provide rapid responses and ongoing support and feedback(21) which may empower a parent to make a decision to 'watch and wait'. However, some parents in our study reported concerns about using the group in this way and expressed concerns that the level of trust placed in the reliability of such advice might be unfounded or too high. This is echoed in a previous analysis in Hirschsprung's disease in which the Facebook group was shown to have reach

and responsiveness but lacking consistent evidence-based guidance in the posts(21). A particular use detected in our study was to prepare a parent before a child's health appointment to ensure they knew what to discuss and request from the provider. Whilst this behaviour is cited as common amongst parents of all children(1) it is more nuanced in GNDs where parents may feel that they need to undertake this preparatory research to negate their clinician's lack of expertise.

Most parents indicated high levels of trust in the SMG (by Likert scale responses), and are not worried about their data or put off posting for this reason although a small proportion did discuss their concerns around this. A study in 2022 of 231 parents indicated that parents do express concern about privacy issues and that the SMG's privacy setting can be a critical factor influencing active support group participation(4). However almost half of our respondents could not recall whether they had been asked to agree to any statements regarding consent or privacy when joining, but continued to participate in the SMGs. The analysis of parent interviews suggests that parents with the highest levels of concerns around privacy would be most cautious about what they post in the SMGs. It is also noteworthy that one SMG appears to be using some form of natural language processing model to mine the data for themes. This raises questions regarding consent within the groups and use of data.

Looked after children represent a particularly vulnerable group within social media, and foster or adoptive parents are required to hide their identities to protect them. This can be difficult with a rare GND where patient numbers may be very small. Genetic variants can be unique to a family or individual and could theoretically be identifiable and so this may limit the foster/adoptive parents' options for interactions and questions within a social media group limiting their support opportunities compared to other families.

SMG participation is not without its downsides. A spike in anxiety can occur initially after joining, particularly when this occurs soon after receiving a diagnosis (which is the most common time that parents join). Nonetheless most of the survey respondents did not agree that the SMG made them worry more. The potential negative impact is sparsely discussed in the literature to date(6).

There was recognition of posting bias within the SMGs but some of the parents who talked about this felt that they were able to assess the posts and come to conclusions about bias themselves. However, parents trust the data that are shared as evidenced by the high levels of trust reported by Likert scale,

and with parents reporting making healthcare decisions about a child presenting with new symptoms based on the SMG responses.

Our results show that there are many GNDs which have more than one SMG which families can join, consistent with a previous estimate that 33% of monogenic disorders had more than one SMG(9). It is likely that this percentage will have increased based on the rapid acceleration of diagnosis in these conditions. The same study found that SMGs with large numbers of members were more likely to be active and have the most posts(4). This is in keeping with our findings that parents are likely to go to larger SMGs where they feel they have the highest chance of getting data that they seek. However, these larger SMGs appear to have downsides, as does the presence of more than one group per GND. Our results suggest that there are increasing politics and tensions within groups particularly where there is suggestion of increasing competition for members within GND charities and foundations and that the SMGs may be being used to steer members towards particular organisations. These changing dynamics are scarcely explored in the literature to date which may be because this is a newly evolving phenomenon with time and rapidly increasing numbers of diagnosed conditions.

The changing dynamics within groups has resulted in some groups trying options that are not Facebook. This has included WhatsApp as an option for one UK based group who has fewer than 50 families. The decision was made to try and create a more UK specific option for families. However, functionality may become a barrier as the group increases in size as might its lack of interactive options and easy search tools. Our results otherwise suggest that parents are not using other platforms very much for this specific purpose. A smaller number of parents do use LinkedIn, but particularly for professional advocacy purposes.

Facebook groups are closed and it appears this is vital for ensuring families feel able to participate in a way that protects their privacy needs(8). Nonetheless our findings suggest that SMGs could increasingly be utilized by researchers to engage with patient groups better. In addition, we report several examples within groups to determine appetite for a topic of research or assess the availability of data before embarking on a research proposal. Using poll results could also identify important topics that matter to families. Researchers need to establish positive connections with group administrators to do this successfully. Very little exists in the literature to date on this theme, again reflecting this rapidly advancing field and area.

Strengths and Limitations:

This study utilises a large cohort of parents of children with a mix of genetic conditions from across the UK. The majority of survey respondents and interviewees were mothers but some fathers were included. Our methods were able to capture responses from parents who don't use SMGs or who have stopped doing so, as well as regular users. The lead investigator is a clinical geneticist but the second coder for the interviews is a non-clinical experienced behavioural and psychological qualitative researcher. Parents described negative experiences with healthcare professionals suggesting that they felt able to express their views despite the researcher's clinical background. The PQ2 survey had questions which had hoped to capture parental behaviour change regarding SMG with time but were limited in the short interval between survey administration for some families who were recruited later.

Conclusions and implications for practice:

Data poverty in rare disease drives parents to do their own research and propels them into SMGs for connection. Parent reported data in groups reflect lived experience data. SMGs are essential for parents as a space to connect and compare experience and may represent an opportunity as an avenue to drive forward research connections and priorities and allow for opportunities for advocates and peer mentoring to flourish. Parents utilise SMGs as a quasi-clinical advisor in some situations and for preparation before attending healthcare appointments – it is therefore essential that healthcare professionals evolve to integrate better in light of this. The rapidly changing landscape of GNDs may shift the dynamics within groups which could result in an evolution in the number of groups, and platforms used. Limited reports exist on the negative aspects, and these appear to be a minority, but some parents reported reducing or stopping their use of the group altogether which may be associated with these problems. Further research should ascertain if this is an increasing trend as this could result in a support gap for parents in the future. Changing behaviour over time and evolving information needs represent an avenue for future research.

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