






## ORIGINAL ARTICLE

# Identifying strategies to support gynaecological cancer patients and carers during COVID-19: Learning from patient–charity interactions

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## Abstract

**Objectives:** Supporting cancer patients during COVID-19 has posed unique challenges for health care providers. We investigated patient and carer–charity interactions to explore the role of charities and identify concerns expressed by patients. The study aims to address these concerns and learn how health care providers can support patients.

**Methods:** Digital interactions on forum posts and social media were collected from four gynaecological cancer charities from March–May 2019 (before COVID-19) and 2020 (during COVID-19). Thematic analysis of forum posts and semistructured charity staff interviews investigated patient and charity-focused perspectives.

**Results:** Thematic analysis of forum posts and charity staff interviews ( $n = 8$ ) revealed three consistent themes: (1) Health care changes and the effect on cancer management concerns; (2) psychological impact of lockdown isolation and anxiety of changed treatment; (3) the complexity of shielding guidance on self-risk assessment. Patients valued cancer charities' responses through digital and conventional methods (webinars, social media, forums, and websites).

**Conclusion:** Gynaecological cancer patients had concerns about the risk and impact of changed treatment plans, contacting charities as the first port of call when anxious not to burden health systems. Real-time analysis of charities' communications can be used to identify concerns and to proactively provide patient support, together with health care providers.

## KEYWORDS

COVID-19, gynaecology, cancer, psychosocial, support, charity

## 1 | INTRODUCTION

The COVID-19 pandemic has been a time of extreme uncertainty, rapid change to health care systems and disruption of 'usual'

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processes. Patients have witnessed severe disruption to cancer care. Modelling estimates that approximately 2.3 million cancer surgeries will have been delayed or cancelled during the pandemic's first peak (March–May 2020) (COVIDSurg Collaborative, 2020; Nagar & Formenti, 2020). The impact on cancer diagnostics is estimated to be substantial, with >350,000 fewer people than usual being referred for a rapid referral for suspected cancer in the UK between March and September 2020, largely owing to fewer people seeking primary care advice (Greenwood & Swanton, 2021). The COVIDSurg Gynaecological cancer study reports that at least 15% of women with gynaecological cancer have suffered disruption/change to usual first-line surgery (Sundar et al., 2020).

Health care systems have instituted clinical prioritisation across cancer treatments to balance individual patients' needs against systems being overwhelmed by emergency admissions (British Gynaecological Cancer Society & Royal College of Obstetricians and Gynaecologists, 2021). The need to limit exposure of clinically vulnerable patients to COVID-19 has prompted several changes from 'usual care', such as delayed appointments or telephone follow-up. 54% of women with ovarian cancer report that their treatment has been impacted due to the COVID-19 pandemic, and 27% of women could not access care as they did before the pandemic (Target Ovarian Cancer, 2020). A Cancer Research UK patient experience survey investigating the overall impact of care reported gynaecological cancers were among the most affected, with 78% of patients with gynaecological cancers reporting impact (Cancer Research UK, 2020). Investigations of patient perceptions using surveys have demonstrated that fear about COVID-19 and anxiety about cancer progression due to changes in cancer care are serious and frequent concerns for cancer patients (Catania et al., 2020; Gultekin et al., 2021).

Cancer charities have interacted extensively with patient and carers during the pandemic. Understanding patient and carer–charity interactions with gynaecological charities before and during COVID-19 enables us to understand patient/carer concerns, cancer charity perspectives and also crucially how these concerns have been addressed in real time. Our study had two aims—first to understand the key concerns of patients and carers both from the perspectives of both patients and as inferred by gynaecological cancer charities, secondly to identify real-time communication methods that had been utilised to address these concerns. We aimed to identify best practice communication strategies through this study.

## 2 | METHODS

Gynaecological cancer charities were identified through a national collaborative invitation issued by a national gynaecological cancer organisation in England. Four of the six gynaecological cancer charities responded to the invitation and agreed to participate. These national charities offer a range of services for women with gynaecological cancer (Table 1). Three of the charities allowed access to quantitative and qualitative data, while one only provided access to qualitative data. Ethical approval was obtained through the University of Birmingham

research ethics committee (ERN\_20-0915), and appropriate permissions were in place for the collection and usage of anonymised patient data.

Qualitative analysis of semistructured interviews with charity staff and online forum posts was performed, along with quantitative analysis of the number and methods used for charity–user interactions. As COVID-19 is an unprecedented circumstance about which little is known, we chose a semistructured interview method with open ended questions that allowed participants freedom of expression. These were conducted with charity staff members. Purposive sampling of clinical and non-clinical staff members was used to identify members that interacted directly with patients and carers affected by gynaecological cancer. Given the limited relevant literature about interview structuring in the context of COVID-19, we framed interview questions based on clinical and research experience, and principles outlined by Cresswell (Creswell, 2008). Semistructured interviews followed prepiloted interview framework (Table S1) and were appropriate for clinical and non-clinical community-facing staff interviewees. University research ethics approval was obtained for the project, including interview data collection. Interviews were audio recorded, transcribed, and double-checked against original recordings prior to analysis.

The study team comprised of experts in clinical gynaecological cancer care and qualitative and quantitative research, and medical students who conducted the research work under supervision.

### 2.1 | Analysis

#### 2.1.1 | Quantitative

Data of interactions from three gynaecological cancer charities were collated. This nonidentifiable dataset represented a range of interactions: Patient–charity worker and patient–patient for the same period 23rd March to 23rd June in 2019 (before the COVID-19 pandemic) and 2020 (during the COVID-19 pandemic). This period in 2020 corresponded to the UK COVID-19 outbreak and consequent major changes to health care provision. Interactions included website access, online forum messages, webinar attendance, social media (Twitter, Instagram, and Facebook), and other communication methods (support calls, text messages, and emails). Website access data were provided via web analytics services monitored by the charities. Interactions related to COVID-19, where there is direct reference to or discussion of the pandemic, were labelled.

#### 2.1.2 | Qualitative

The qualitative analysis involved posts on online charity-moderated forums representing patient-focused perspective and semistructured interviews with charity staff representing charities' perspectives. Both datasets were treated independently and did not influence interpretation. Due to constraints of COVID-19 pandemic, all interviews were

**TABLE 1** Summary of the objectives and activities of the gynaecological cancer charities

	Charity 1	Charity 2	Charity 3	Charity 4
Purpose of charity	Education/training; the advancement of health or saving of lives	Education/training; the advancement of health or saving of lives	The advancement of health or saving of lives	Support provision, education, and research
Aim	To fund research related to and raise awareness about gynaecological cancers: uterine, ovarian, cervical, vulval and vaginal cancers	To provide support to those affected by ovarian cancer To make support services accessible to marginalised and less represented populations through the Reach Over project.	To provide support to women with gynaecological cancers, raise awareness of these diseases and campaign for earlier diagnostics and treatment advancements.	To provide support to those with ovarian cancer. To aid in the early diagnosis of ovarian cancer. To facilitate funded research about ovarian cancer.
Regular services offered to gynaecological cancer patients and carers	<ul style="list-style-type: none"> <li>• A confidential telephone and email service was used to provide information and support.</li> <li>• Health support articles, information leaflets</li> <li>• Support via social media platforms</li> </ul>	<ul style="list-style-type: none"> <li>• Information support telephone lines, text messaging service,</li> <li>• Support group sessions and workshops across the country.</li> <li>• Online forums, instant chat, and social media</li> </ul>	<ul style="list-style-type: none"> <li>• Information and support through an online chat forum</li> <li>• Email service</li> </ul>	<ul style="list-style-type: none"> <li>• Information support lines</li> <li>• Support events</li> <li>• Information material and guides</li> <li>• Local support groups and cancer centres</li> </ul>
Additional services offered in response to COVID-19	<i>Cancer and Coronavirus Information hub:</i> addresses frequently asked questions related to managing gynaecological cancer in relation to COVID-19	<i>Staying Connected Programme:</i> webinars and online workshops enabling support and information	COVID-19 webpage, FAQs on social media pages	<i>Wellbeing during the pandemic</i> webpage; website with COVID-19 resources and support services available during the pandemic <i>Virtual support events:</i> face-to-face events on digital platforms to extend support and information

undertaken online before analysis of forum postinteractions, and lasted approximately 1 h. All clinical and non-clinical staff were community-facing and therefore were interviewed using the same framework.

Three gynaecological charities utilised public domain forums; two of the charities use the HealthUnlocked platform, and another uses a private Facebook forum. All anonymised posts on these forums from March 23rd to June 23rd for 2019 (before the COVID-19 pandemic) and 2020 (during the COVID-19 pandemic) were considered. To enhance the overall validity of the analysis, interview transcripts and all 2020 forum data were double-coded by at least two reviewers. Any discrepancies were discussed with a third senior reviewer. Thematic saturation was achieved when further analysis revealed no new themes; therefore, subsequently 70% of the 2019 forum data were double coded.

Interview transcripts and online forum texts were analysed using thematic analysis. Braun and Clarke's stepwise approach was followed to develop themes by identifying commonalities and differences before considering relations between the data (Braun & Clarke, 2006). The process of coding and building themes using a deductive approach was used to relate different aspects of the data, such as identifying themes reflective of the usual patient-charity interactions,

which were unique to the COVID-19 context. Following data familiarisation, initial codes were generated and underwent further refinement and additional coding in a systematic manner until themes were developed from similar codes. The themes identified from online forums and interview transcripts were reviewed and finalised with discussion by the research team. The flow of study is detailed in Table S3.

## 3 | RESULTS

### 3.1 | Quantitative

Charities used both conventional and digital methods. Each charity used different methods of communication with no common single modality. Table 2 summarises the medium and numbers of interactions; there was a slight increase in the number of interactions via forum posts across the three charities between 2019 ( $n = 429$ ) and 2020 ( $n = 444$ ). Due to the heterogeneity in data availability between the charities, we could not carry out statistical tests to study the differences in the number or modes of interactions between 2019 and 2020.

**TABLE 2** Quantitative summary of charity–patient and carer interactions

Interaction	Description	Charity 1		Charity 2		Charity 3	
		2019	2020	2019	2020	2019	2020
Website visits (Google Analytics)	Total	NA	NA	25,786	32,917	2460	1098
	COVID-related	NA	NA	NA	1199	NA	56
Forum (number of posts)	Total	13	13	416 (9 by the charity)	371 (33 by the charity)	0	60
	COVID-related	NA	5	NA	NA	NA	45
Support emails	Total	86	291	110	104	17	2
	COVID-related	NA	113	NA	13	NA	2
Telephone interactions: text messages	Total			0	5		
	COVID-related			NA	0		
Telephone interactions: calls	Total	39	51	102	87		
	COVID-related	NA	13	NA	13		
Instant chat interactions	Total			53	83		
	COVID-related			NA	11		
Online events	Total number of events	NA	NA	0	67	0	13
	Attendance	NA	NA	NA	588	NA	Open to 756
Non-virtual events	Total number of events	NA	NA	16	0	4	0
	Attendance	NA	NA	199	NA	>100	0
Social media impressions (Twitter)	Total	NA	NA			54,900	132,000
	COVID-related	NA	NA			NA	11
Social media impressions (Facebook)	Total			354,965	270,974		
	COVID-related			NA	98,804		

Note: NA, not applicable; charities did not provide information (grey).

## 3.2 | Qualitative

Forum data ( $n = 873$ ; 2019, 429 posts; 2020, 444 posts) were coded from three online charity-run forums, and eight semistructured interviews were conducted during the pandemic with charity staff members (clinical,  $n = 3$ ; non-clinical,  $n = 5$ ) from four gynaecological cancer charities.

Thematic analysis revealed three main themes common to the patient and charity data. Key issues raised by charity staff members before and during the pandemic centred around individuals seeking charity support and the changing role of charities. These themes are summarised in Table 3 and Table S2.

### 3.2.1 | Theme 1: Individual access to care, changes in public policy and health care systems

#### *Patient and carers perspective*

The online forum posts revealed concerns reflecting the pandemic's impact on cancer outcomes related to their disease trajectory. The worries identified mainly stemmed from delayed or cancelled

chemotherapy due to impact of COVID-19 on management plans. These concerns were propagated by the inability to seek direct reassurance from clinicians due to appointment changes. Furthermore, concerns increased regarding changes in treatment regimens. The concern was primarily surrounding the restrictions and unavailability of medicine, coupled with worries of compromised treatment and prognosis. Women were seeking reassurance and tailored advice from patients with similar experiences, potentially also relying on response from charity professionals moderating the forum. Women sought further clarification about their appointments through the forum as a consequence of a perceived lack of lucid public information.

#### *Charity staff perspective*

Responses from staff members highlighted the impact of reduced or altered management plans and its long-term impacts on prognosis due to COVID-19 regulations. Women frequently reported concerns of risks associated with visiting clinical settings for fear of contracting COVID-19. Interviews described patient concerns in adapting to new forms of communication, such as through telephone clinics, as a side effect of the pandemic. Overall, staff members noted the frustration and anger of carers who could not support their loved ones at clinical appointments.

**TABLE 3** Quotations from patient-focused data sources (forum posts) and charity-focused data sources (staff interviews), categorised by key themes (short quotes)

<b>Theme 1: Individual access to care, changes in public policy and health care systems</b>	
<i>Patient/carers perspective</i>	<i>Charity staff perspective</i>
<p>“Any advice on how to treat/what to do? I didn't want to waste nhs time with the pandemic, so I've ordered self test sti [sexually transmitted infection]kits”</p> <p>“I haven't posted for a whole because basically nothing was going on with my treatment. Like many of you I was on 3 weekly phone appointments with my oncologist.”</p> <p>“I started weekly paclitaxel on Friday and I am relieved that I am back on treatment although I am disappointed by the rate of growth.”</p> <p>“Like a number of ladies who've posted in the last few days, my ongoing chemo treatment has now come up hard against the pandemic. [...] I had my fourth cycle (1st recurrence: caroplatin/caelyx) yesterday, and found out, as I suspected, that the chemo centre is being re-set up as a COVID-19 facility [...] they're encouraging me to go straight onto maintenance (Olaparib), due to the increased risk of contracting the virus. [...] It is clear that this pandemic has caused the powers that be to prioritise treatments while the spectre of a totally overwhelmed NHS looms over us. We are clearly far lower a priority than many others—however, is this also an opportunity for them to be a bit more honest about all of the alternatives?”</p> <p>“I was told on Thursday by my oncologist my last chemo session is cancelled and my next one may be, also the immunotherapy I was supposed to having is postponed all due to the Coronavirus. [...] Don't they understand Cancer also kills and stopping chemo and operations is a disaster. We also have the worst survival rates in the Western World. I'm petrified! How are you guys doing.”</p>	<p>“Right at the beginning of lockdown, there was obviously a lot of concern from the women who were contacting us about potential delays to their treatment. So we did get a lot of calls or participation in our online programme where people were talking about it. We had a few emails from people who were really concerned about other people's treatment stopping and things like that.”</p> <p>“a very basic example but “Hello, I've got my cervical screening next week,” and we're like “Okay,” and then there's the layer of “What do I do about Covid? What do I wear?” That sort of thing. So yes, there's the normal question unless it's purely Covid related, and then most of the time a Covid concern on top of their initial question.”</p> <p>“there's an abnormal result, they've got a colposcopy booked in, the colposcopy's cancelled, so lots of people are worried that the delay in whatever point there appointment was coming, whether it's basic screening or further investigation and colposcopy, they're worried that the delay will mean that whatever is wrong, if anything is wrong, will progress”</p> <p>“women being frightened to go to the GP with cancer signs and symptoms, for example, a post-menopausal bleed which is a signal symptom for endometrial cancer, and they are frightened to go to the GP or report to the GP because they don't want to go to the surgery because they fear that because it's a health environment, that there may be more people with COVID there than out in the general public.”</p> <p>“A lot of women are very, very worried about the cervical screening being postponed, lots and lots of calls about that”</p>
<b>Theme 2: Psychological impact of changed treatment plans</b>	
<i>Patient/carers perspective</i>	<i>Charity staff perspective</i>
<p>“I understand the importance of keeping me safe from Coronavirus but I'm so upset that I can't have treatment. I feel like I'm not worth saving.”</p> <p>“I've been looking online but can't find a real match. I can't get to a gyno due to the pandemic.”</p> <p>“Also, the oncologist said that given the Covid 19, it would be too dangerous to start chemo. That leaves me in a very awful situation as the tumour in the liver could just grow and grow. So frightened.”</p> <p>“I am due to start chemo again in the next month or so, and as I live alone, the thought of being confined to home for six months, while coping with chemo induced symptoms on my own is really depressing me”</p>	<p>“Fear of how that will impact upon their care and treatment, anxiety and some anger at are they being compromised as a result of everything being direction to COVID-19. And whilst they may feel they understand that at one level, as they are often facing a life-threatening illness, particularly in ovarian cancers, that led to increased anxiety.”</p> <p>“I think just recently, probably over the last couple of weeks, I would say that we've started to see some of the impact, the psychological impact, of lockdown and some confusion around shielding, because when the guidance changed, there were a few questions about that. But I would say that currently the biggest cause for contacting us is people feeling very low, low mood. I think that we're starting to see the longer term effects coming now.”</p> <p>“I think that women and their families have needed support more than ever.”</p>
<b>Theme 3: Patients making sense of individual risk</b>	
<i>Patient/carers perspective</i>	<i>Charity staff perspective</i>
<p>“Does anyone know if this means we should be on the Covid19 ‘shielding’ list?”</p> <p>“What are folks views of this letter. In particular it says you should sit on your own in a different room from anyone else, sleep in a different room, use different towels and bathroom if possible and use the kitchen when others aren't. Is this practical for folks”</p> <p>“If the Niraparib hasn't worked and I have to have chemo, so you think I will have to wait until the COVID 19 is at stable level.”</p>	<p>“I think the main purposes of women wanting to contact [...] is for guidance in a very uncertain time in terms of influence of a pandemic which is new to all and where that positions them in relation to their overall care and treatment.”</p> <p>“There are those women that were already smear avoiders, for example, that will have had their smear postponed, the cervical screening postponed and those women I worry, for example, will actually now dip out completely and think well it was postponed so it's not that important.”</p>

(Continues)

TABLE 3 (Continued)

Theme 3: Patients making sense of individual risk	
Patient/carers perspective	Charity staff perspective
<p>“Any ladies who are post 3 months chemo who are not shielding now just need to know there is light at the end of this dark tunnel as I'm living away from my family and would like to move back after the 12 weeks are done whilst obviously being careful - I'll be 4 months then”</p>	<p>“when the shielding advice was coming out or the shielding was starting, people were concerned about their risk and what they could do and what they couldn't do and sometimes around going to medical appointments, and they were worried if it was safe to go to a hospital appointment”</p>

### 3.2.2 | Theme 2: Psychological impact of changed treatment plans

#### Patient and carers perspective

Women expressed that lockdown restrictions negatively impacted their mental health and concerns related to their condition and environment. These feelings were prominent in shielding women who were unable to interact socially. Most of the prominent concerns reflected (a) new possible symptoms or disease progression; (b) the risk of visiting health care environments; (c) delays in receiving diagnosis; (d) adequacy of treatment and management plan for confirmed diagnosis; and (e) cancer treatment delays due to the lockdown and the subsequent disease progression.

### 3.2.3 | Charity staff perspective

Interviews highlighted the role of charities in providing emotional support to women. Charity staff noted a significant difference in women's feelings of fear, isolation, and anxiety, proposing the pandemic compounded these emotions that often accompany a cancer diagnosis. Interviewees highlighted the need to provide further psychological support to reduce distress and improved signposting to psychological support services.

### 3.2.4 | Theme 3: Patients making sense of individual risk

#### Patient and carers perspective

The complex effect of COVID-19 shielding guidance impacted women's personal assessment of risk; the risk of acquiring COVID-19 coexisting with the inherent risk of cancer management. Women undergoing chemotherapy appeared to be particularly worried about the treatment journey in physical isolation. The interactions revealed that the concept of shielding was an unclear domain. There was a perceived lack of guidance regarding lifestyle modifications. For example, confusion regarding advice of outdoor exercise.

The pandemic seemed to impact health seeking behaviours where some women were reluctant to seek support to not further burden the health care system. Additionally, women felt uncertain of the higher risk of infection at health care settings. Women personally assessed the risk of infection against the risks of cancer progression

and seeking clinical reassurance. Travel restrictions caused additional barrier to women accessing usual clinical care.

#### Charity staff perspective

Women sought charity support on accessing and applying individualised guidance, particularly with issues surrounding shielding. There was a perception of nonspecific and unclear guidance produced by the government and other organisations, which caused confusion. This lack of focused guidance, in combination with issues of misinformation, was suggested to contribute to fear and anxiety.

#### Differences in forum posts between 2019 and 2020

Prior to 2020, online forums' focus reflected patients' experiences of cancer. Women sought advice and similar experiences about symptoms, diagnoses, management plans, and complementary medicines, including personal challenges surrounding cancer. Similar content was reflected in 2020, but concerns were amplified in relation to COVID-19.

#### Patient-care responses to charity communications

Interviews from charity staff members demonstrated a notable increase in engagement with users through digital communication via social media, charity websites, and online workshops. Users' comments of appreciation towards charities' online interventions were targeted towards a range of services, including information provision about COVID-19 and online workshops. Further details are presented in Table 4.

## 4 | DISCUSSION

This paper identifies key concerns expressed by patients and inferred by charity staff, response taken by cancer charities to address these, and how these communications were received by patients. This can provide insight into how health care systems can communicate with patients in challenging times.

We identify individual access to care and changes in public policy/health care systems; psychological impact of changed treatment plans; and patients making sense of risk as key themes. Comparison of themes across patient expressed views on online forums and charity staff interviews showed consistency in patient concerns. ‘Uncertainty’ was the overarching concern seen in staff perceptions and forum interactions as both parties aimed to tackle heightened risk and

**TABLE 4** Quotations from patient-focused forum posts expressing gratitude towards charities for support and interventions

Thread headings from charities' forum posts	Quotations
Staying up to date with information on Coronavirus Covid-19	<p>"Please can you help me get my [...] posts back. I appear to have joined a [...] forum on wellbeing which I'm sure is very helpful for people but I don't want it to replace my [...] posts."</p> <p>"Thank you so much for replying to me. I'm going to try and follow your advice with my technically challenged brain. I know I somehow joined the wellbeing forum but now I'm a bit overwhelmed by all the posts on it. I wanted to stay in my cocoon of [...] posts. I may just get used to it but right now I'm more anxious about how cancer services are doing in the Corona virus crises. I have scans and follow up appointment very soon so I'm more anxious than usual. Thank you so much for responding to me"</p> <p>"Now I have just found the posts thanks to you. I'm very happy and back in m comfort zone of [...]"</p> <p>"Think this is a brilliant site, and it really does give me some hope."</p>
Updated One Cancer Voice information on coronavirus for people with cancer	"Thank you [...]. Answers many questions. Keep up your good work much appreciated"
Coronavirus few questions and advice	"Thank you [...] your wonderful,advice I know I can depend on you all to cpmebupmwith considered advice."
COVID-19—High-Risk Group self referral link	<p>"Thanks [...] still not heard from my GP - to be honest I doubt they are even aware I am on [...] given I have to remind them I am a cancer patient so having this to register on is VERY helpful - thanks again."</p> <p>"I think anyone on private treatment is being forgotten about too. This link is very useful for anyone living alone as it allows you to notify them should you need extra support."</p> <p>"good to know it was useful."</p>
New online workshops	"As soon as I received your email I went to book in for the workshops [...]. Will they be made available on YouTube or similar service so that we can access them at a later date, even if we can't participate? Thanks for all [...] support."
NICE guidelines	"Thanks [...] Team for this information. Much appreciated"
Ovacome online workshops on exercise and diet—Thursday 2 April	<p>"I've registered for the exercise workshop and although I've had an acknowledgement I cannot see any instructions how to go on-line"</p> <p>"Thank you, I will try and sign up for the diet one. Thank you [...] team!"</p> <p>"The diet one was quite interesting, good to know (by the sound of it!) that I am doing what I can! Thank you [...] x"</p>
Cancer Research UK survey—cancer treatment affected by COVID-19 pandemic—25th May.	<p>"Thank you for drawing our attention to this survey [...] this U.K. specific, so would benefit from as much input as possible."</p> <p>"I have completed this survey [...] and I can't help thinking that many countries have managed their response to the treatment of cancer patients during the COVID-19 pandemic differently and fear my responses will get lost in the noise. It seems to focus more on patients' perspective and anxiety levels. Having said that completing any survey on our experiences during this crisis has to be to the good."</p>
Starting a local support group	"Thank you [...]. Ladies, it's me setting up the [...] Support group. I've had one lady email me so far so this is now already taking off. I'll post on here when I've arranged the first support meeting. I will need you to email me for the link to the Zoom meeting so I can make sure it's the right place for you."

fears. Charities shared the goal of addressing patients' concerns and information provision. Results show that the pandemic has shifted uncertainty from cancer progression to wider health care decision-making and highlights the inherent uncertainty in the choices and decisions patients make (Guan et al., 2021). Our findings are consistent with those identified from patient-focused questionnaires in published literature (Colomer-Lahiguera et al., 2021; Gultekin et al., 2021). This work extends this by identifying a key concern of individualised lay risk assessment. Patients struggle with the risk calculus in non-COVID-19 times, and the uncertainty of COVID-19 embellishes this struggle. Patients need the understanding of efficacy and reasoning behind care modifications and the reassurance that

changes do not equate to reduced effectiveness. Families and carers feel particularly distressed at not being able to fully support their loved ones with cancer, which may lead to a breakdown of trust in cancer managements further down the patient's trajectory.

This study's results confirm the extent to which patients seek information and conduct lay risk assessments through online patient groups, for example, following advice to shield from COVID-19 exposure (Colomer-Lahiguera et al., 2021). The assessments are often informed through interactions with other forum users; patients value individualised clear cancer-specific advice. Additionally, the impact of change to planned cancer care, as perceived by patients, is a source of huge distress. Patients and carers worry about the long-term impact

on their trajectory, which may reflect these patients perceive their care plan to be the only or optimal one.

In response, cancer charities have used conventional communication methods and digital methods to support patients. Our research identifies a notable increase in interactions between charities and patients during the pandemic. Charities diverged in the choice of communication tools; this may reflect the 'scramble' to respond at the start of the pandemic with no established best methods. Charities have demonstrated agility in using social media to understand the key concerns of patients and proactively pivoted to digital communications to match the need for social distancing. Crucially, charities routinely use analytical methods such as Google Analytics to identify trending terms to plan proactive responses such as webinars (GO Girls, 2020). Our study shows that this strategy is well received by patients.

Much attention has focused on the adverse impact of COVID-19 on research funding and future research activity (Griffiths et al., 2020; Harris, 2020). However, we highlight the other key role of charities before and during the pandemic: vital sources of reliable information, support, and solace to worried patients. Emotional support was a common coping strategy for women with ovarian cancer during the pandemic, and cancer charities have provided a digital method of facilitating such support (Frey et al., 2021). Charities have been the first port of call for patients anxious not to burden an overstretched health care service, expanding on their social media presence in the form of webinars. Some have worked with specialist societies to reinforce trust in the care system (British Gynaecological Cancer Society, 2020; Gultekin et al., 2021). For instance, the European Society of Gynaecological Oncology has instituted, together with ENGAGE, a series of COVID-19 webinars for patients (Gultekin et al., 2021). In the United Kingdom, the British Gynaecological Cancer Society has worked with national gynaecological cancer charities to address patient concerns through the pandemic proactively (British Gynaecological Cancer Society, 2020).

'Trust' is often identified as a key component of successful cancer treatment (Wright et al., 2004). It is hard to quantify the emotional impact of this support—our paper acts as a surrogate indicator by quantifying the load on cancer charities and the nature of interactions between patients and charity staff. Cancer charities face an unprecedented reduction in funding—this will detrimentally impact the provision of compassionate and high-quality cancer care, diagnostics and health messages that are trusted by communities.

This work highlights the key need for health care professionals to work in concert with charities. Signposting patients and carers to charities and working with cancer charities to provide reliable information are proactive measures health care providers can take to alleviate some concerns.

#### 4.1 | Strengths

The strength of this paper includes our novel analytical approach of data mining of online forum posts and comparison with charity staff

perceptions. We performed a rigorous comparison of interactions both quantitative and qualitatively prepandemic and during the pandemic. Consequently, we identified perspectives of patients, carers, and charity staff members that were unique to the COVID-19 pandemic in 2020. Previous work has relied on surveys and limited qualitative work with health care professionals. Importantly, our methods allow for an unfiltered way of assessing patients' concerns. Whilst the work has been conducted in gynaecological cancer, the robustness of our methods suggests that themes identified and communication strategies instituted by charities in response are highly likely to be generalisable across other cancers, including in male patients.

#### 4.2 | Limitations

Similar to previous literature, our findings could not identify the specific concerns of patients who are less familiar with digital communication channels, such as elderly patients. A study imperative was to preserve the anonymity of participants. Results cannot be linked to demographic information to contextualise these experiences, preventing verification of cancer diagnosis and extrapolation of results. We were unable to investigate trends in posting patterns of forum posts for the same reason. Another limitation is that the results are specific to UK gynaecological cancer charities, and a group of self-selected charities that chose to participate in the study. Our work was conducted on interactions in the initial surge, and additional concerns may have emerged in subsequent pandemic peaks. As each of the charities used different methods of communications, quantitative analysis was limited.

### 5 | CONCLUSION

We identify key concerns expressed by patients and identified by cancer charities during the pandemic. These focused on the evolving nature of public care policies, health care provision, psychosocial impact, and consequently, its effects on information and support provision by cancer charities. Cancer charities have supported patients through proactive and agile use of technology, including data analytics, to identify recurring terms in forum posts. This has enabled responsive communications that are well received by patients. Close collaborative working between the charity sector and health care providers using these strategies will benefit efforts to address concerns of patients/carers around risk and the impact of changed treatment plans. A 'RESET' of cancer trajectories for impacted patients is now crucial. This will need health care systems to work in concert with cancer charities to deliver.

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**CONFLICT OF INTEREST**

The authors declare no conflict of interest.

**DATA AVAILABILITY STATEMENT**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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