



# Patient knowledge, personal experience, and impact of the first wave of the COVID-19 pandemic in an Irish oncology cohort

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## Abstract

**Background** Oncology patients have had to make many changes to minimise their exposure to COVID-19, causing stress. Despite education, some patients still do not recognise potential COVID symptoms.

**Aims** We assessed patient knowledge of COVID, and its impact on their behaviours, concerns, and healthcare experience.

**Methods** A 16-page questionnaire was distributed to 120 oncology patients attending the day unit of a tertiary Irish cancer centre for systemic anti-cancer therapy (May/June 2020). The Irish 7-day COVID incidence during this period ranged from 2 to 11 cases/100,000 people.

**Results** One hundred and one responses were received, 1% had tested positive for COVID, and 31% had undergone testing. Participant insight into their knowledge about COVID and their own behaviour was limited in some cases. Seventy-five percent reported total compliance with restrictions, but many were not fully compliant. Self-reported confidence in knowledge was high, but did not predict demonstrated knowledge. Sixty percent did not recognise two or more symptoms; 40% did not self-identify as high-risk. Patients reported more health-related worry (72%), loneliness (51%), and lower mood (42%) since the pandemic began. Financial toxicity worsened, with increased financial worry (78%), reductions in household income (40%), and increased costs due to lockdown (62%). Use of facemasks introduced new communications barriers for 67% of those with hearing loss.

**Conclusions** Despite self-reported confidence in knowledge, some patient's recognition of COVID symptoms and the preventative strategies they should use are not optimal, highlighting the need for further education in this regard. COVID has been a significant stressor for patients and more practical, financial, and psychological supports are needed.

**Keywords** COVID-19 · Financial toxicity · Oncology · Patient education · Patient knowledge · Social support

## Background

The COVID pandemic has had a substantial impact on cancer care provision and on patients' lives. Those with cancer are much more vulnerable to COVID—in China, patients with cancer had a case fatality rate of 5.6% compared to 2.3% in the general population. Liang et al. [1] showed that cancer was associated with higher risk of severe events,

especially in those who had had recent chemotherapy or surgery. In Wuhan, patients with cancer were more than twice as likely to contract COVID [2].

The most prevalent signs of COVID-19 infection are fever, dyspnoea, fatigue, cough, myalgias, anosmia, and ageusia [3, 4]. Laboratory features include leukopenia/leukocytosis, lymphopenia, elevated liver enzymes, lactate dehydrogenase, C-reactive protein, ferritin, or d-dimer [3, 5]. All of these occur commonly in unwell oncology patients, making it difficult to distinguish between cancer-related, treatment-related, and COVID symptoms.

In Ireland, general community restrictions began on March 15th 2020, 2 weeks after the first Irish case was reported. By March 24th, non-essential businesses were closed and a 'stay at home' order was introduced, with

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exceptions for essential work, food shopping, and exercise within 2 km of the home only (see Fig. 1). High-risk patients were told to ‘cocoon’ and to avoid leaving home entirely [6]. Case numbers fell from a maximum 7-day incidence of 132 cases/100,000 people (April 15th) to 11 cases/100,000 at the beginning of study recruitment (May 24th), and 2 cases/100,000 by the end (June 12th, see Fig. 1) [7]. The most severe restrictions began to be relaxed in May, including an extension of the travel radius to 5 km and groups of 2–3 being allowed to meet outdoors, but most businesses remained closed and advice did not change for our ‘cocooners’ (‘Phase 1’ of the ‘Roadmap to Reopening’ [8]).

In Wuhan, 41% of COVID cases in cancer patients were nosocomial [2], so additional measures were put in place in our oncology service (Fig. 1) to minimise nosocomial transmission. Where appropriate, patients who were stable on maintenance therapy were offered treatment breaks or were switched to oral therapy. Some routine clinic reviews were moved to telephone reviews. Previously, unwell patients had been assessed directly by a member of the oncology team. Instead, these patients were admitted under general medicine (‘COVID pathway’ in Fig. 1). Inpatients were not allowed to have visitors, with exceptions on compassionate grounds for those who were receiving end of life care.

The Irish government provided clear messaging on restrictions and on recognition of COVID symptoms. Despite this, we noticed that many patients did not recognise some symptoms as potentially representing COVID or reported ‘risk behaviour’, e.g. having guests in their homes.

Furthermore, it was increasingly recognised that a ‘COVID denier’ narrative has become popular on social media. In studies in other countries, the vast majority of cancer patients trusted government (98%) and doctors (94%) for reliable information, with a minority more trusting of information obtained via WhatsApp, Twitter, Instagram, and Facebook [9]. The attitudes of Irish patients with cancer surrounding information about COVID have never previously been explored to our knowledge.

We assessed patient knowledge of COVID, and the impact of the pandemic on their behaviours, beliefs, concerns, and healthcare experience, to identify any further education/quality improvement needs.

## Methods

A 16-page investigator-created, self-reported anonymous qualitative survey (supplementary data) was distributed to 120 oncology patients attending the day unit of a tertiary Irish cancer centre for systemic anti-cancer therapy (May/June 2020).

Patients were excluded if they had an ECOG performance status of  $> 2$ , if they did not speak fluent English and needed a translator during medical consultations, or were too unwell to complete the questionnaire. The Flesch-Kincaid grade level of the questionnaire was 4.9. Questions that had a high ( $> 25\%$ ) non-response rate were excluded from analysis.

Data were analysed with the Statistical Package for the Social Sciences (SPSS) version 27 (IBM Corporation, Armonk, NY). Descriptive statistics for sample characteristics and study measures were calculated and reported as means and standard deviations for quantitative variables or percentages and frequencies for categorical variables. Differences between groups were evaluated using independent sample *t*-tests, chi-square analyses, and ANOVAs. A *p* value of  $< 0.05$  was considered statistically significant. The study was conducted under the supervision of the Tallaght University Hospital/St. James’s Hospital Joint Research Ethics Committee.

## Results

### Patient demographics

One hundred and one responses were received from 120 surveys distributed. Demographics are described in Table 1. Participant ages ranged from 22 to 87 years.

Percentage values not displayed—as 101 responses were received, these are almost identical to numerical values.

### COVID knowledge, screening, and symptoms

Most were aware of government restrictions and reported good understanding of and compliance with these (Fig. 2), with 75% ( $n = 72$  of 96 respondents, 5 non-responses) reporting complete compliance with cocooning. Despite this, of these 72 ‘cocooning’ patients, 36% ( $n = 24$  of 66, 6 non-responses) continued to shop in-store, of whom 42% ( $n = 10$  of 24) went as/more often than before, while 28% ( $n = 16$  of 57, 15 non-responses) received visitors to their homes.

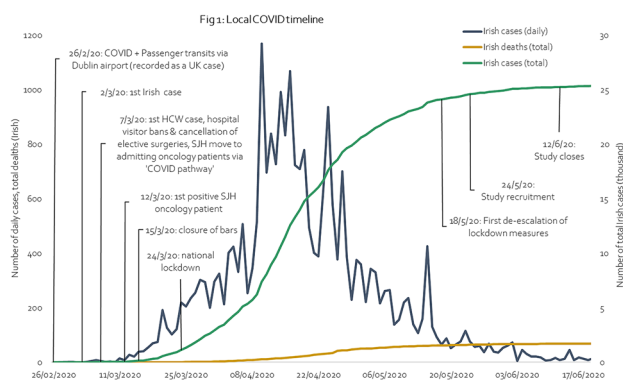


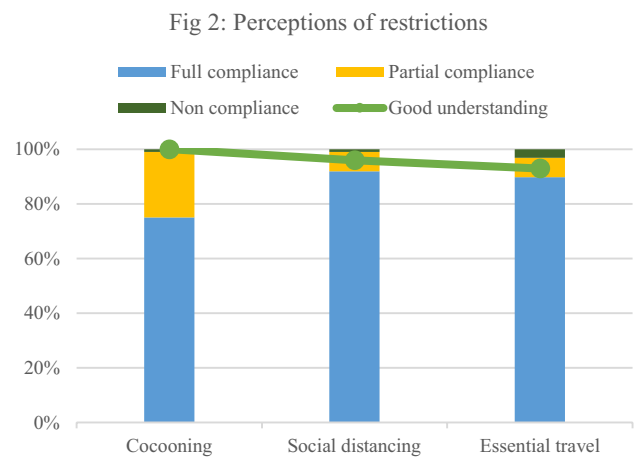
Fig. 1 Local COVID timeline

**Table 1** Participant demographics

		<i>n</i>
Gender	Male	40
	Female	60
	Non-response	1
Age	< 30	1
	30–40	11
	40–50	19
	50–60	28
	60–70	31
	70–80	5
	80+	1
	Non-response	5
	Treatment intent	Palliative
Curative		41
Non-response		7
Cancer type	Breast	19
	Upper GI	19
	Lung	14
	Head and neck	11
	Lower GI	10
	Skin	8
	Gynae	7
	Lymphoma	6
	Prostate	4
	Non-response	3
Employment status in January 2020	Active employment	47
	Sick leave	22
	Retired	20
	Homemaker	7
	Unemployed	2
	Non-response	3
Housing	House	88
	Apartment	11
	Residential care	1
	Non-response	1
Cohabitation*	Living alone	16
	With 1 other person	32
	With 3+ other people	29
	With an essential worker	7
	With people not taking COVID precautions	4
Home internet access	Adequate	80
	Limited	13
	None	6
	Non-response	2

\*Possible to select more than 1 category

Including all respondents (including those not cocooning), 43 regularly went shopping, of whom many were not using risk-reduction strategies (Fig. 3). Most shoppers (60%,

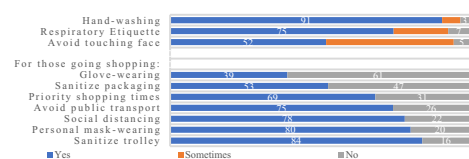


**Fig. 2** Perceptions of restrictions

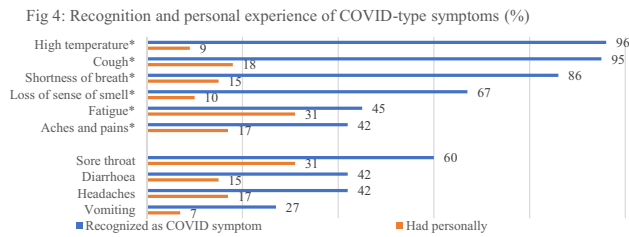
*n* = 25 of 42, 1 non-response) had alternatives to shopping in-store but chose to keep going out, most often (*n* = 19 of 34\*, 56% each) because they enjoyed it or wanted to maintain independence, and only 18% (*n* = 6 of 34\*) thought there was no risk in going out. A minority (24%, *n* = 23 of 95, 6 non-responses) now never went shopping. \**n* = 34 due to addition of 9 patients who earlier indicated that they no longer shopped for themselves but gave valid responses to this section.

Many patients (46%, *n* = 39 of 84, 17 non-responses) were somewhat/very fearful of COVID, but this did not strongly predict either protective (e.g. mask-wearing: OR 1.1, 95% CI 0.3–4.8, *p* = 0.9), or risky behaviours (e.g. shopping frequently: OR 0.5, 95% CI 0.1–1.4, *p* = 0.2).

We offered a list of 10 symptoms identified in HSE (Irish health service executive) patient information campaigns as potentially representing COVID infection (see Fig. 4). Patients were asked how many of these could potentially be COVID-related, and if they had experienced any of them as symptoms of their cancer/side effect of treatment (Fig. 4). Almost all respondents (95%, *n* = 93 of 98, 3 non-responses) reported feeling confident/very confident in recognising COVID symptoms, but 60% (*n* = 60) did not recognise two or more out of 6 major symptoms (indicated with asterisks in Fig. 4), most frequently fatigue (55%, *n* = 56), aches/pains (58%, *n* = 59), altered smell/taste (33%, *n* = 33), and dyspnoea (14%, *n* = 14). The mean number of symptoms recognised overall was 5.3 ± 1.9; the mean number personally



**Fig. 3** Protective strategies used (%)



**Fig. 4** Recognition and personal experience of COVID-type symptoms (%)

experienced (excluding vomiting/diarrhoea) was  $1.2 \pm 1.5$  symptoms (range 0–7 out of a possible 8). Most patients (59%,  $n = 60$ ) had experienced at least one symptom.

The number of symptoms recognised did not correlate with confidence ( $p = 0.9$ ) or desire for more information about COVID ( $p = 0.9$ ) but did correlate weakly to the number of COVID-type symptoms personally experienced ( $r = 0.25$ ,  $p < 0.01$ ). Patients who had been tested for COVID recognised more symptoms than those who had not ( $5.9 \pm 1.9$  vs  $5.2 \pm 1.7$ ,  $t(97) = 2$ ,  $p < 0.05$ ). Age, gender, level of fear around COVID, and being on curative or palliative-intent treatment did not predict number recognised or personally experienced.

Many respondents (40%,  $n = 40$ ) did not feel they were at higher risk of contracting COVID, while 15% ( $n = 15$ ) thought they were no more likely to be very sick than an average person if infected. Many did not know that chemotherapy, radiation, and immunotherapy can impact morbidity/mortality in COVID (31% ( $n = 31$ ), 44% ( $n = 44$ ), and 49% ( $n = 48$ ), respectively).

One patient had tested positive for COVID; two had been contacts. Overall, 31% ( $n = 31$ ) of patients had been tested, of whom most found testing stressful (53%,  $n = 15$  of 28, 3 non-responses), but were glad to have been tested (92%,  $n = 24$  of 26, 5 non-responses).

The majority (94%,  $n = 91$  of 97, 4 non-responses) knew COVID could be spread by an asymptomatic carrier, and many thought oncology staff should be screened for COVID routinely (82%,  $n = 75$  of 92, 9 non-responses), even if well, while some thought that patients should also be routinely screened (37%,  $n = 33$  of 89, 12 non-responses).

Most patients had obtained their knowledge about COVID from the television news (87%,  $n = 85$  of 98, 3 non-responses), or from government messaging (80%,  $n = 78$  of 98, 3 non-responses). A minority relied on information from family/friends or social media (33%,  $n = 32$  of 98, 3 non-responses each), though reliance on social media was numerically more common in those under 50 (45%,  $n = 14$  of 31) than older patients (25%,  $n = 16$  of 65,  $X^2(1, N = 93) = 3.7$ ,  $p = 0.053$ ).

While only 14% ( $n = 14$  of 98, 3 non-responses) wanted more general information about COVID, 66% ( $n = 65$  of 98, 3 non-responses) would have liked more cancer specific information. These 65 patients particularly wanted more information about prevention (46%,  $n = 30$  of 65) and symptoms (37%,  $n = 24$  of 65), with a preference for written (75%,  $n = 46$  of 61, 4 non-responses) over verbal, video, formal educational session, or helpline-based formats.

## Emotional and social impact

Interestingly, 76% ( $n = 66$  of 87, 14 non-responses) had thought more about their mortality as a result of COVID, and while some patients (19%,  $n = 16$  of 82) already had an advance directive in place, another 39% ( $n = 32$  of 82, 19 non-responses each) were considering one as a result of COVID, and of those who had not already made wills, 38% ( $n = 18$  of 47) had made/were making one because of COVID.

Many patients reported more health-related worry (72%,  $n = 63$  of 88) or lower mood (42%,  $n = 37$  of 88, 13 non-responses each) since the pandemic began.

Even though most reported the amount of social support they received was unchanged (58%,  $n = 47$  of 81), or had actually increased (22%,  $n = 18$  of 81, 20 non-responses each), many respondents felt lonely more often (51%,  $n = 40$  of 78, 23 non-responses). Of the 39 patients with a cough related to their cancer, 49% felt socially stigmatised ( $n = 19$  of 39), while 30% ( $n = 28$  of 94, 7 non-responses) of all patients felt stigmatised by the need to cocoon. A minority (18%,  $n = 17$  of 93, 8 non-responses) felt they needed more support during the pandemic, of whom most (94%,  $n = 16$  of 17) wanted more emotional support, and many (47%,  $n = 8$  of 17) wanted more financial support.

Thirty patients reported some baseline hearing loss, of whom 67% ( $n = 20$  of 30) found communication more difficult while others were wearing masks.

## Health-related behaviours

There was a significant decrease in reported exercise, with 64% ( $n = 59$  of 92, 9 non-responses) reporting doing less exercise, most commonly (69%,  $n = 41$  of 59) due to decreased motivation, but also because of travel restrictions (59%,  $n = 35$  of 59), closures of gyms/swimming pools (39%,  $n = 23$  of 59), and fear of meeting other people (22%,  $n = 13$  of 59). Forty-one percent ( $n = 24$  of 59) were worried this would impact their long-term health.

While some patients gained weight ( $n = 27$  of 81, 33%), others lost weight ( $n = 15$  of 81, 19%, 20 non-responses each). Overall 15% ( $n = 13$  of 88) felt they were eating less healthily, and 25% ( $n = 22$  of 88, 13 non-responses each)

worried their dietary changes would impact their long-term health.

Only 39% ( $n=35$  of 90, 11 non-responses) drank alcohol, many of whom had increased their intake: 17% ( $n=6$  of 35) by a little, 23% ( $n=8$  of 35) significantly. Of the 14 patients with increased alcohol intake, boredom was the most common reason where one was given (57%,  $n=4$  of 7, 7 non-responses). A minority of patients (8%,  $n=7$  of 93, 8 non-responses) felt they drank excessively.

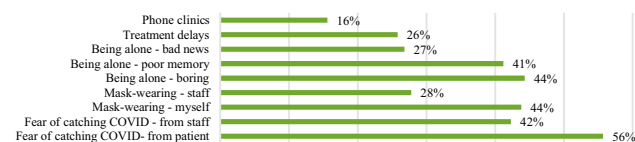
### Financial toxicity

Many respondents faced increased financial stress and reported increased worry about money (78%,  $n=67$  of 86, 15 non-responses), reductions in household income (40%,  $n=32$  of 80, 21 non-responses), and increased costs due to lockdown (62%,  $n=53$  of 85, 16 non-responses), most commonly grocery ( $n=32$ ) and heating ( $n=25$ ) costs. Ten patients had lost their jobs as a result of COVID, and 7 had been put on reduced working hours (19% of respondents), with 34% of households ( $n=28$  of 82, 19 non-responses) in receipt of the pandemic unemployment payment. Of the 15% struggling to pay bills ( $n=13$  of 87, 14 non-responses), 38% ( $n=5$  of 13) had not been struggling prior to COVID. Financial worry was not predicted by age, gender, or palliative/curative treatment intent.

### Health service adaptations

Patients found several aspects of changes to the oncology service difficult (see Fig. 5), particularly attending appointments on their own, not only because they found the waiting room more boring without company (44%,  $n=43$  of 97), but also because they had a poor memory of the visit outcome afterwards (41%,  $n=40$  of 97) or had been given ‘bad news’ on their own (27%,  $n=26$  of 97, 4 non-responses for all). At the same time, many worried that they would contract COVID from another patient/visitor (56%,  $n=54$  of 97, 4 non-responses).

COVID adaptations caused difficulty in accessing some form of healthcare in 34% ( $n=26$  of 77, 24 non-responses), most commonly ( $n=19$ ) dental services. At least one patient was not able to access fertility preservation before their chemotherapy began. Despite this, only 17% ( $n=14$  of 84)



**Fig. 5** Most disliked aspects of changes to the oncology services due to COVID

were less satisfied with the healthcare system overall compared with pre-pandemic, while 29% ( $n=24$  of 84, 17 non-responses each) reported greater satisfaction. A vast majority of patients (84%,  $n=70$  of 83, 18 non-responses) reported a lot more respect for healthcare workers since the pandemic began, and 7 patients (8%) a little more. Of the 6 patients who reported no change, 4 hand-wrote addendums explaining that this was because their respect was already very high. No patient reported less respect.

### Discussion

Even by mid-2020, most Irish adults had received many hours of government messaging about COVID, including education about common symptoms, and guidelines on infection control measures for vulnerable people, such as those with cancer. Despite this, our study conducted during the first wave of the COVID pandemic has shown that there remained some gaps in knowledge regarding COVID among Irish cancer patients, in particular with respect to symptom recognition and risky behaviours, with resultant clinical implications.

Of concern, 60% of patients failed to recognise 2 or more classic symptoms (cough, fever, fatigue, ‘shortness of breath’, ‘aches and pains’, or altered smell/taste) as possibly suggesting infection with COVID. This has important clinical implications given that patients may delay presentation with symptomatic COVID infection, while also increasing the risk of potentially exposing others to infection. Moreover, we observed that many respondents had low insight into their knowledge gaps, with poor correlation between demonstrated knowledge of COVID symptoms and self-reported confidence in knowledge or desire for more information.

The majority of our patients self-reported complete compliance with social distancing and cocooning measures, yet many of those were engaging in at least some risky behaviours which were clearly in contradiction to government guidelines. For example, 33% of all patients accepted visitors in the home, while 28% continued to shop even when they had alternative options. A significant proportion of cancer patients also underestimated the risks posed by COVID to their own health. Many felt they were no more likely to contract COVID than someone without cancer and/or underestimated their risk of developing severe illness if infected. It is unclear whether this reflects complacency due to high self-perceived compliance with safety measures or simply a lack of knowledge. Nonetheless, it highlights the ongoing need to regularly reinforce public health advice in the clinical setting, while also assessing patients understanding in this regard.

One potential consequence of these issues is that patients who feel they are already ‘doing everything right’ may be

at risk of complacency regarding their risks. Such patients may be harder to target and engage in further education, yet at the same time may continue to expose themselves, their families, staff, and other patients to increased risks of transmission, and may not seek appropriate care for themselves if they have potential COVID symptoms that they do not recognise. We have anecdotally noted episodes where patients have been attending the hospital for a routine visit, passed through multiple symptom-screening checkpoints, and yet only in the clinic room report a new cough or pyrexia, for which they had not isolated or sought care or testing. Such instances may provide an opportune moment for patient re-education, and particular care should be taken that patients who are self-isolating with symptoms/confirmed infection understand exactly what this means, as extrapolating from our study many of those who believe they are self-isolating correctly may not actually be taking all necessary measures.

It is possible that the deficits in knowledge regarding COVID and/or the lack of compliance with safety measures which we observed among some oncology patients reflect active absorption of misinformation, rather than patients simply being uninformed. Fortunately, the majority of our patients reported that they derived most their information from reliable sources such as government messaging, with only 33% receiving information about COVID from social media. This is similar to data from the Middle East [9], but different to US data, where almost 80% rely on the internet as a main source [10]. Though not inherently harmful, reliance on social media has previously been shown to increase the risk of being exposed to potentially damaging/dangerous misinformation, which predict lack of compliance with public health advice and vaccine hesitancy [11]. As the use of social media information was slightly more common in younger oncology patients, there is an opportunity to target this population with reliable information from a trusted source (e.g. through use of HSE or hospital social media applications).

As expected given the COVID/cancer symptom overlap, the proportion of our patients who had ever had a COVID test (31 tests/100 people) was far in excess of the rate in the general population (7.8 tests/100 people) [7]. At the time of our survey, no mass population or ‘pop-up’ testing had taken place in the Irish population. Patients were only tested if they had symptoms, were a known close contact of a case, or were admitted to hospital. COVID knowledge was better in those who had actually been tested or who had reported more symptoms. It is unclear if this reflects cognitive reframing as a result of having been tested, or if those with better knowledge reported their symptoms differently or were more likely to seek testing.

COVID has placed a very significant burden on our patients, particularly in terms of mood, anxiety, financial stress, and changes to their treatment. We know that a cancer

diagnosis has always put a large financial burden on patients, with a mean loss of income of almost €20,000 a year and additional costs of €756 per month in 2019 [12]. Given that 40% of our patients experienced a loss of household income due to COVID, and that even in a study conducted in the summer months 25% noted significant extra heating costs, it is not surprising that a majority of our patients reported increased financial concerns due to the pandemic. Moreover, practical supports (e.g. the volunteer driver service) were greatly reduced during this time period, often requiring patients to fund alternative arrangements privately, thereby significantly adding to costs. Our study once again highlights the considerable financial strains faced by cancer patients which have been further significantly impacted due to the pandemic. Additional financial supports such as expanding access to the winter fuel allowance should be considered to help cancer patients offset increased expenses.

Of concern, we detected significant levels of distress among our oncology patients, with more than 40% reporting lower mood due to COVID, a finding replicated across other studies [13]. Moreover, 72% reported worrying more about their health as a result of COVID, while 76% reflected more on their own mortality. Unfortunately, the increased levels of distress reported by our patients early in the first wave of the COVID pandemic also coincided with a time when many of the usual support services were unavoidably significantly curtailed. For example, many support groups had to cease in-person meetings, while virtual meetings were not yet well established. Furthermore, access to in-hospital support services such as psycho-oncology and medical social work departments were also somewhat curtailed due to the pandemic. The increased uptake of virtual services later in the pandemic helped to substitute some of these supports, but demands on the services are high, e.g. the Irish Cancer Society Cancer Support line has reported a 63% rise in calls [14]. The high levels of distress detected among cancer patients in our study highlight the need for ongoing resourcing of both in person and virtual support services to address the increased psychological and social needs of such patients due to the pandemic.

Many of our new approaches to providing healthcare in a pandemic, such as universal mask-wearing or the use of telephone clinics, have inadvertently introduced barriers to care for some patients. This is a particular issue for patients with hearing impairment. Of note, 30% of our patients reported some degree of hearing loss, of whom 67% reported that they found communication more difficult during the pandemic due to mask wearing. While Irish sign language interpreters and smart devices are available for those with profound hearing loss, many patients with milder hearing loss, who previously managed without additional supports, face new communication barriers due to the requirement for mask wearing. Clinicians should be mindful of this and

follow the guidelines for communication while wearing PPE, such as that issued by the National Healthcare Communication Programme [15].

The COVID pandemic was associated with some maladaptive behavioural changes among our study population. While the numbers of patients who regularly drank alcohol was somewhat lower than expected at just 39%, many (40%) of those that did drink reported that they had increased levels of consumption of alcohol as a result of the pandemic, with 23% reporting a significant increase. As alcohol consumption is often underreported by Irish drinkers [16], and abuse is associated with negative outcomes and cancer-related mortality [17], this has important clinical implications for our patient cohort. As such, clinicians should be mindful of the potential impact of COVID on alcohol consumption, and alcohol abuse should be screened for in clinic. Our study also noted a reduction in levels of activity due to COVID, with 64% exercising less than usual. This is of particular concern for cancer patients, given that physical activity is associated with better outcomes in survivorship research [18], and in some studies was associated with better tolerance of treatment [19] and overall survival [19, 20]. As such, there may be scope for more hospital-led interventions to overcome this issue, such as online-based exercise programmes [21]. Subsequent to our study, advice for ‘cocooners’ has changed, and current advice is that ‘The risk of catching COVID-19 is low if you go for a walk ... and you keep away from other people’. This contrasts with initial advice that people should not leave their own properties except to attend medical appointments or similar. Patients should be made aware of this change in public health advice and there is an onus on clinicians to reassure patients and encourage moderate exercise with appropriate safety precautions in place.

In the time since this survey was conducted, we have seen 7-day COVID-19 incidences ranging from 1 case/100,000 people in July 2020 to an estimated 3000/100,000 in January 2022, along with the introduction of vaccinations, mask mandates, and novel variants. With fluctuating incidences, public health guidance has changed, and restrictions have eased and been re-introduced multiple times. These factors may substantially alter how patients would respond to these questions today. Most (80%) of our patients frequently wore masks pre-mandate, it is likely that this would be now almost-universal, in keeping with the 98% of adults who reported wearing a mask while shopping in 2021 [22, 23]. In a subsequent study conducted in our hospital in February–April 2021 with a similar participant profile and similar methodology [24], 6% of patients had contracted COVID (compared to 1% in our study), and despite very low vaccine hesitancy, 5% still believed that ‘the pandemic is not serious’, and 20% disagreed/were unsure if they were more vulnerable to severe illness because of their cancer/treatment, suggesting that a

small subset of patients still have not been reached by public health messaging. The failure of patients to recognise ‘classic’ COVID-19 symptoms has become less important with the dominance of novel variants, and indeed patients who were very attentive to education regarding almost-pathognomonic symptoms of the original strain (e.g. anosmia/dyspnoea) might now be disadvantaged if they remain fixed on these.

There are some limitations to our study. As the sample population was gathered from those attending for treatment in the dayward, patients on treatment breaks or oral therapy were not represented. The questionnaire was at an appropriate level for 10–11 year olds; however, our hospital is in a deprived inner city area. While we did not formally assess educational level, some patients may have found some questions challenging. We noticed that more complex questions had higher non-response rates, such as an item querying what treatments patients had previously received, posed in a multi-stem question/answer format. This item was excluded from analysis due to a 26% ( $n = 26$ ) non-response rate. Any future work should avoid multi-stem questions and should include ‘I don’t know’ as an option for all responses. Some patients reported fatigue towards the end of the survey, and the non-response rate rose from a median of 3% for items on pages 1–2 (demographics, see supplementary data), to 12% by page 12 (changes in shopping practice) and 17–18% by pages 15–16 (social and emotional impact/access to services/respect for healthcare workers). Results from later sections of the survey may under-represent views from some groups, particularly those with lower performance scores, and future surveys should be shorter and more focused to reduce effects of participant fatigue.

## Conclusions

Despite self-reported confidence in knowledge about COVID, patient’s self-assessments of their own knowledge, their risk category, and the preventative strategies they should use are not optimal. Increased education about risk, symptom recognition, and public health guidelines is necessary, both for patient safety and to minimise staff and community exposure. COVID has been a significant stressor for patients and more practical, financial, and psychological supports are needed.

**Supplementary information** The online version contains supplementary material available at <https://doi.org/10.1007/s11845-022-02999-8>.

**Availability of data and material** On request.

**Code availability** NA.

## Declarations

**Ethics approval** Tallaght University Hospital/St. James's Hospital Joint Research Ethics Committee.

**Consent to participate** All patients gave written consent.

**Consent for publication** All patients gave written consent.

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