



Impact of Covid-19 Pandemic on people living with cholangiocarcinoma

**Findings from
Cancer52's Patient Survey
Summer 2020**

Introduction

About Cholangiocarcinoma and AMMF

Cholangiocarcinoma, or bile duct cancer, is a primary liver cancer that arises within the biliary system. This form of cancer is rare, although the incidence and mortality rate of cholangiocarcinoma is rising.

AMMF is the world's first charity dedicated solely to cholangiocarcinoma, founded in 2002. Today, AMMF remains the UK's only cholangiocarcinoma charity. AMMF provides information and support to those who need it, campaigns to raise awareness of this devastating disease, and encourages and supports specialised research teams in their work towards better diagnostic techniques and treatments and, ultimately a cure. For further information about AMMF please visit www.ammf.org.uk.

About the patient survey

AMMF is a member of Cancer52, an organisation of nearly 100 patient groups and organisations that represent rare and less common cancers (for more information about Cancer52 please visit www.cancer52.org.uk). In summer 2020, Cancer52, supported by its members, conducted an online survey of people with rare and less common cancers to understand the impact of the Covid-19 pandemic so far, including any changes to treatment and care and their experiences of shielding.

AMMF took part in the survey and shared it through its own network. Cancer52 received over 1000 responses to the survey, including 27 from people with cholangiocarcinoma, which, considering the very difficult nature of this cancer, represented a good response rate.

Cancer52 has kindly shared with AMMF the responses from the patients with cholangiocarcinoma, which AMMF now presents in this report. Cancer52's survey was undertaken anonymously, so all results here are anonymous and care has been taken to remove any information that could be identifying. A full list of the survey questions can be found in Appendix One.

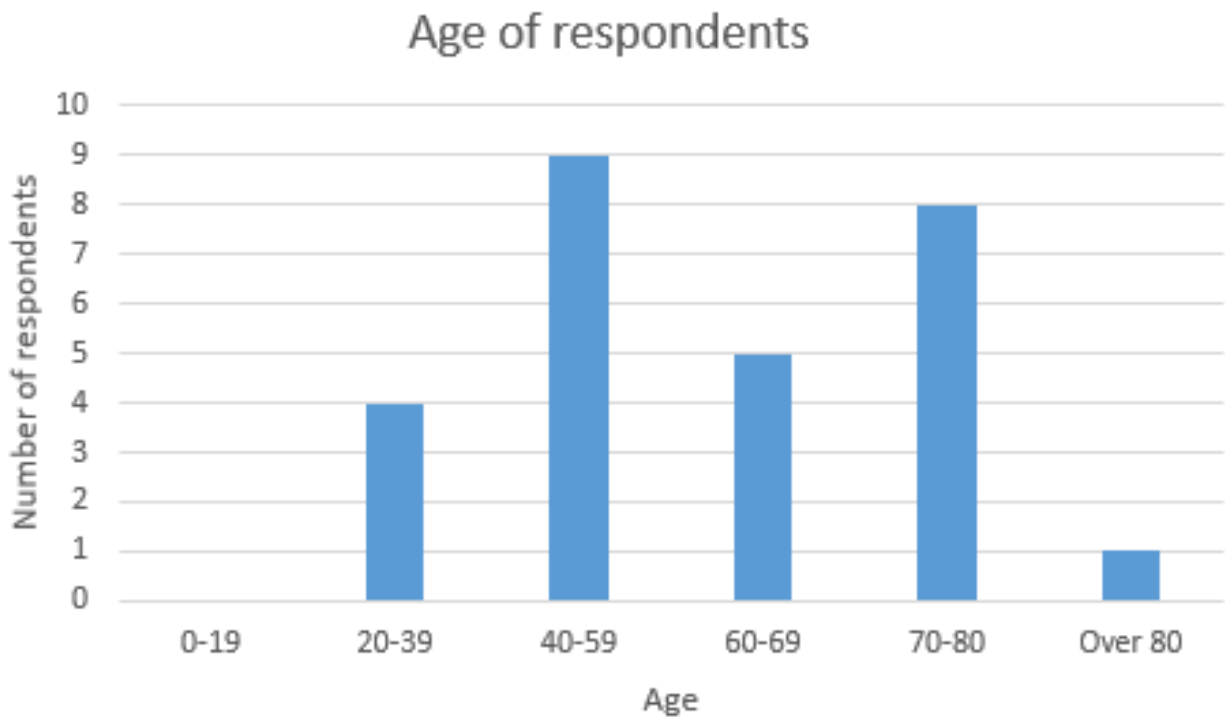
AMMF thanks Cancer52 for conducting the survey, and would also like to thank sincerely all those with cholangiocarcinoma who took part.

About the respondents

Twenty-seven people with cholangiocarcinoma responded to the survey. The majority of these people live in England. Their ages ranged from twenty to eighty plus, with 18 respondents being aged between 20 and 69.

None of the respondents were in a clinical trial, possibly reflecting the fact that there is little awareness of available trials for those with cholangiocarcinoma.

Only one respondent had had a positive diagnosis of Covid-19.



Concerns about Covid-19 compared to cholangiocarcinoma

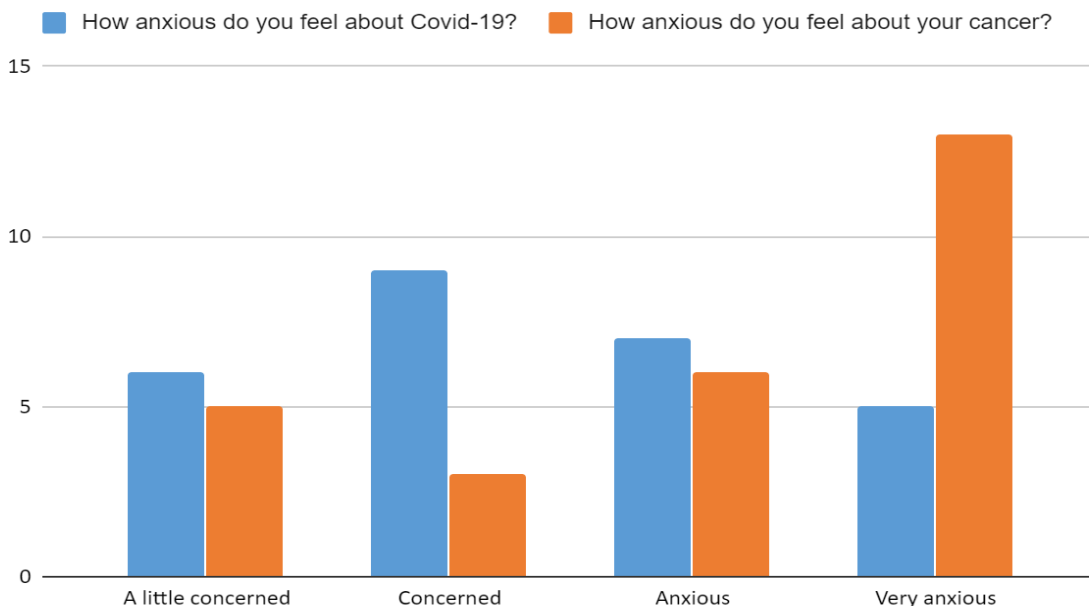
The survey asked people what they thought their risk of Covid-19 was:

- ❖ Eight felt their risk was low.
- ❖ Five felt it was medium.
- ❖ Eight felt it was high.
- ❖ Four didn't know.

Twenty two people responded to a question asking if they were still happy to attend medical appointments if it meant visiting a hospital or medical centre. Only one person was unhappy to do so.

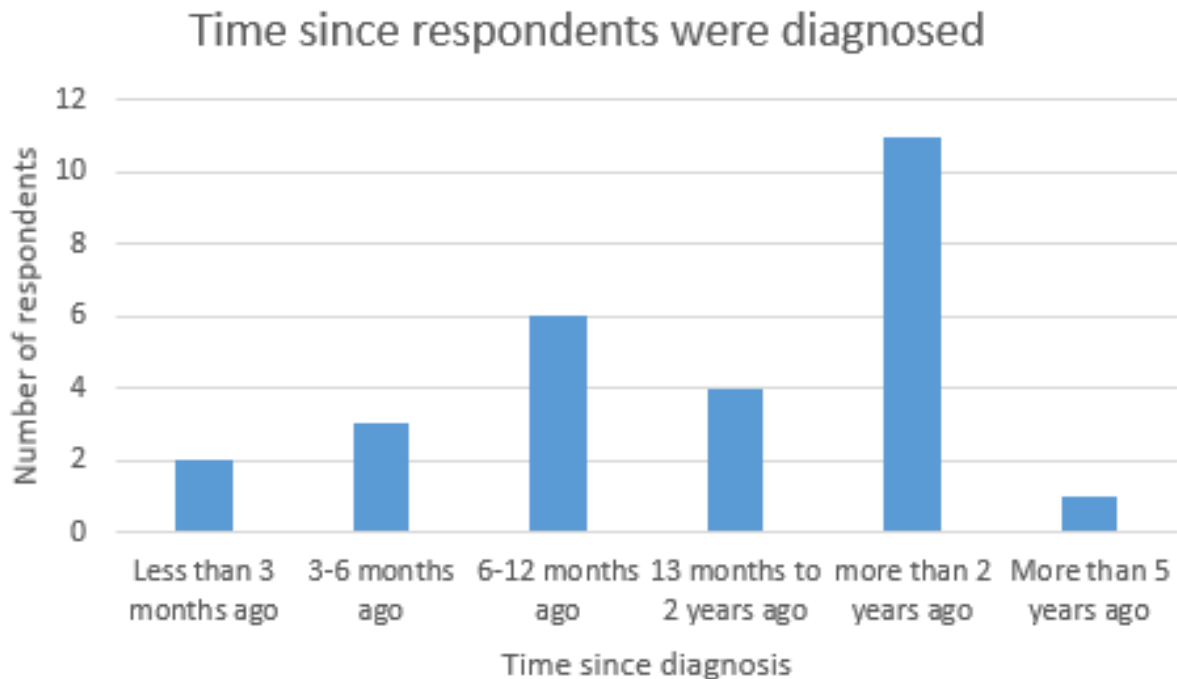
The survey asked respondents how concerned they were about Covid-19, and also how concerned they were about their cancer diagnosis. People with cholangiocarcinoma appear to be more anxious about their cancer diagnosis than Covid-19.

Although the number of cholangiocarcinoma responders was relatively small, which makes comparisons to the wider survey of rare and less compare cancers survey indicative only, it appears a greater proportion of people with cholangiocarcinoma answered that they were very anxious about their cancer compared to all respondents to the survey. 18% of respondents to the Cancer52 survey said they were very anxious about their cancer, compared to 48% of those with cholangiocarcinoma.



Impact on diagnosis and treatment

The chart below shows how recently respondents had been diagnosed. Two people had very recently been diagnosed (the survey was completed in June 2020). Both reported delays to treatment starting, one because treatment had been delayed and another because they had delayed going to the GP because of concerns about the coronavirus pandemic.



Treatment

- ❖ Eight people were currently having, or were due to begin, treatment.
- ❖ Three were in follow-up.
- ❖ Six were under surveillance.

Of those in treatment, two had had their treatment or surgery delayed, although they were told when it would restart. The other six people had not seen any changes and had undergone treatment.

Outpatient appointments

Twenty people responded to a question about how their outpatient appointments had been impacted.

Only two had experienced no changes to these appointments and had attended as normal. Twelve had seen their appointments conducted by telephone or video, three had had their appointments delayed or moved, and a further two had had their appointments cancelled with no alternative offered.

Test and scans

Twenty people also responded to a question about how scans and blood test appointments had been impacted by the pandemic:

- ❖ Eight people had seen no changes to these tests and had had them as usual.
- ❖ Four had seen the location of their test changed (eg from a hospital to community setting).
- ❖ One person's tests had been cancelled and they had not been offered an alternative.
- ❖ Three had had their tests delayed and hadn't been told when they would restart.
- ❖ A further person had had their tests delayed although they were informed when they would restart.

One person commented that they had delayed their scans planned for March and April due to fears about catching Covid-19.

Two more people gave other responses.

Changes to tests and scans	Number of respondents
No changes	8
Location changed	4
Tests delayed and not told when restart	3
Cancelled	1
Tests delayed and told when will restart	1
Chose to delay tests and scans	1
Other	2

Information and support services

Respondents were asked if their use of any support services had been affected by the pandemic. Seven respondents used regular support services to help manage the effects of their cancer (eg physiotherapy, counselling). Five of these people were not able to access support during the pandemic. Two were able to access support but it was in a different format or less frequent.

People were asked what sources of information they had used during the pandemic and could choose as many options as they wished. People had accessed a variety of different sources of information to find out about their cancer and coronavirus, and some had used more than one source:

Source of information	Number of respondents
GP	6
Hospital cancer team	8
Charity website/ helpline	7
NHS/ Government website	10
Online forums/ patients' groups	7

Sixteen people had tried to contact their cancer team for support during the pandemic. Twelve had been successful but four had not. Another person had wanted support from their cancer team but had not tried to make contact.

Shielding

The survey asked respondents if they had been told to shield. Eleven respondents had been told to shield, another eleven had not been told to shield and the other respondents did not answer the question. Most of those who had been told to shield were told to do so by the Government, with a few informed by their GP, hospital team or family.

All those who had been told to shield were doing so, and a few others who had not been told to shield were also shielding. People were informed to shield via a range of methods, including text, telephone calls and letters.

The survey did not ask about other health conditions, but the fact that some people who have cholangiocarcinoma were told to shield and others were not, suggests a lack of clarity regarding shielding at national and local level. Of the eight respondents who were currently undergoing treatment, six had been told to shield and two had not.

Respondents were also asked about the impact of shielding on them. They reported that following the shielding rules and remaining at home had affected their mental health. They had faced difficulties obtaining groceries and had needed to rely on the support of family members to cope.

‘Not seeing friends and family and having support and all complementary therapies stopped severely impacted my mental health to point I am now on anxiety meds’

‘Even when we make the effort to shield, other professionals coming into the house do not - not even wear a mask or wash their hands’

Positive and negative changes

The survey asked people if there were any positive changes from the pandemic that they would like to retain. A few respondents stated that there were positive changes, the majority of them relating to having treatment at home or having telephone appointments, though some said they would prefer to be back in clinic.

'Access to GP by phone has been good. I've had telephone contact with cancer consultants but video calls would be better as my wife could also participate.'

The survey also asked respondents what negative changes, if any, the coronavirus crisis caused to treatment, trial options and care that the NHS should address.

There were a range of answers to this question, though not all respondents provided an answer. Respondents stated that they did not feel safe in hospitals because of Covid-19, with staff not wearing masks. Some respondents also stated that there had been delays to treatment or they had found it difficult to get in touch with staff.

'... it does not feel safe to attend a medical setting. After cancelling 2 scans I braved attending a third appointment only to see 4 members of staff huddled talking with no face masks on. ... I couldn't get chemo in a 'clean' site with ring-fenced staff, so it felt like dicing with death to go in for treatment. Other trusts moved chemo to buildings to reduce the numbers of people you had to come into contact with, gave chemo at home, or on adapted buses. But not my trust. I was told several times just to accept that the virus was everywhere.'

'Lack of support and contact unless I make contact ... it's all about covid like rest of stuff forgotten .. got a temperature [check and had] covid swabs when it was actually bowel infection and blood clots!'

What needs to be done

Respondents were asked what could have been done to make this time easier for them. Not everyone had suggestions, but those who did suggested things such as more contact from hospital support teams and ensuring that chemotherapy and complementary therapies could continue in safe, Covid-19-free environments.

*'Make chemo safer by housing it in separate buildings, with ring fenced staff.
Perhaps utilising the private hospitals so patients can be in a room alone
so I don't have to breathe in air shared with someone
who isn't taking shielding seriously'*

'Update on when appointments will recommence'

Conclusion

The results of the survey show that people with cholangiocarcinoma are more concerned about their cancer diagnosis than Covid-19, perhaps reflecting the seriousness of a diagnosis of cholangiocarcinoma.

There is a mixed picture, with care continuing for some as close to normal as possible, while others have been subject to delays. Though only two people had been recently diagnosed, it is worrying that these two were both subject to delays in treatment. Generally the earlier cholangiocarcinoma is diagnosed the greater the possibility that it can be operated providing a potentially curative treatment. This is why it is vital to diagnose cholangiocarcinoma as early as possible and for treatment to go ahead quickly if possible.

Of concern is that some people were told to shield themselves, while others were not. The survey did not ask respondents about other health conditions, which could have been the reason people were told to shield.

This suggests that there is a lack of understanding about cholangiocarcinoma at potentially both national and local level, as decisions on who should be asked to shield were made both nationally and locally. In the event of further local lockdowns or another national lockdown, advice to people with cholangiocarcinoma needs to be consistent.

There also appears to be a feeling among respondents that people with cholangiocarcinoma have been left behind as the NHS focused on treating people with Covid-19; it is vital that now the NHS has moved into a recovery phase that services, treatments and surveillance for people with cholangiocarcinoma are stepped up to normal levels without delay, in Covid-19 safe environments.

AMMF will continue to press for wider awareness of cholangiocarcinoma, for better and more equal treatment for all those with cholangiocarcinoma independent of where they live or who they are, as well as for more research into understanding the causes of this disease and finding ways to achieve earlier diagnosis and effective treatments.

The charity will share the results of this survey with its network of patients and clinicians.

It will also seek clarity on shielding requirements for people with cholangiocarcinoma.



For further information or to get in contact:

AMMF – The Cholangiocarcinoma Charity

Enterprise House

Bassingbourn Road

Stansted

Essex CM24 1QW

UK

General enquiries: info@ammf.org.uk

Registered charity no 1091915

Appendix One

Full list of patient survey questions

1. What age group do you fit into?

- ❖ 0-19
- ❖ 20-39
- ❖ 40-59
- ❖ 60-69
- ❖ 70-80
- ❖ Over 80

2. What type of primary cancer do you have?

Appendix and/or pseudomyxoma peritonei; Bladder; Blood; Bone; Brain cancer; Cancer of unknown primary; Cervical; Cholangiocarcinoma; Endocrine; GIST/Gastrointestinal; Gynaecological except cervical or ovarian; Head and neck; Kidney; Liver (hepatocellular carcinoma); Mesothelioma; Neuroendocrine; Ocular Melanoma; Oesophageal; Ovarian; Pancreatic; Sarcoma; Skin; Testicular; Thoracic; Thyroid; Other

3. Where do you live?

- ❖ England
- ❖ Wales
- ❖ Northern Ireland
- ❖ Scotland
- ❖ Other

4. How long ago were you diagnosed?

- ❖ Less than 3 months ago
- ❖ 3-6 months ago
- ❖ 6-12 months ago
- ❖ 13 months to 2 years ago
- ❖ More than 2 years ago
- ❖ More than 5 years ago

5. If you were diagnosed in the last three months, has the coronavirus affected what has happened so far?

- ❖ Yes, I delayed seeking help because of concerns about going to the GP during the coronavirus pandemic
- ❖ No, I have faced no delays and have started treatment
- ❖ Yes, tests and investigations were delayed
- ❖ Yes, I have been advised to wait before I am treated.

6. Have you already had Covid-19, diagnosed by a doctor or positive test?

- ❖ Yes
- ❖ No

7. If not, what do you feel is your risk of Covid?

- ❖ High
- ❖ Medium
- ❖ Low
- ❖ Don't know
- ❖ Not applicable.

8. How anxious do you feel about Covid-19?

- ❖ Very anxious
- ❖ Anxious
- ❖ Concerned
- ❖ A little concerned
- ❖ Not at all.

9. How anxious do you feel about your cancer?

- ❖ Very anxious
- ❖ Anxious
- ❖ Concerned
- ❖ A little concerned
- ❖ Not at all.

10. Are you currently having treatment or due to have treatment?

- ❖ Yes
- ❖ No
- ❖ In follow up
- ❖ No - in surveillance - watch and wait
- ❖ Not applicable
- ❖ Other

11. If you are currently being treated, or are due to start treatment (including surgery, radiotherapy, immunotherapy or chemotherapy) in the next 3 months, have you been told of any changes?

- ❖ No, I have not been told of any changes and have undergone treatment
- ❖ No, I have not been told of any changes and have undergone treatment but have opted not to have treatment due to concerns about Covid-19
- ❖ Yes my treatment of surgery has been delayed but I have been told when treatment will start
- ❖ Yes my treatment of surgery has been delayed but I have not been told when treatment will start
- ❖ Yes, changes have been made to where I will receive treatment (eg home rather than hospital)
- ❖ Yes my treatment has been changed (eg different drug or type of drug or surgery changed to a treatment)
- ❖ Other (please specify)

12. Have you seen any changes to your follow up outpatients appointments since the outbreak? got

- ❖ Yes, appointments have been delayed or moved
- ❖ Yes, appointment have been cancelled with no alternative offered
- ❖ Yes, the appointment was conducted by phone or video
- ❖ No, my appointments have continued as usual and I have attended these
- ❖ No, my appointments have continued as usual but I have chosen not to attend due to concerns about Covid-19
- ❖ Other (please specify)

13. If you receive regular surveillance to monitor your cancer, such as blood tests or scans, have you been told of any changes? got

- ❖ Yes, appointments have been delayed or moved
- ❖ Yes, appointment have been cancelled with no alternative offered
- ❖ Yes, the appointment was conducted by phone or video
- ❖ No, my appointments have continued as usual and I have attended these
- ❖ No, my appointments have continued as usual but I have chosen not to attend due to concerns about Covid-19
- ❖ Other (please specify)

14. Are you still happy to attend appointments if it means you have to go to a hospital or other medical centre?

- ❖ Yes
- ❖ No
- ❖ Maybe
- ❖ Appointments all paused.

15. What sources of information have you used to find out about your cancer and coronavirus? Choose all that apply

- ❖ Contact with my GP
- ❖ Contact with my hospital cancer team
- ❖ Charity websites/ helplines
- ❖ NHS/government websites
- ❖ Online forums/patient groups
- ❖ Other (please specify)

16. If you have tried to contact your cancer team during the pandemic, were you able to get in contact with them? got

- ❖ I have tried and was successful
- ❖ I have tried and was not successful
- ❖ I have not tried to contact them but do not need their support
- ❖ I have not tried to contact them and do need their support.

17. If you use regular support services to help manage the effects of your cancer (eg physiotherapy, counselling), have you been able to access these services during the coronavirus crisis?

- ❖ Yes, I have been able to access this support as normal
- ❖ Yes, I have been able to access support but it is less frequent or in a different format (eg virtually rather than face to face)
- ❖ No, these services have stopped for the time being but I have been able to access them elsewhere (eg through a charity)
- ❖ No, these services have stopped and I have been unable to find support elsewhere
- ❖ Other (please specify)

18. Are you in a clinical trial (study) or were you dependent on commencing a clinical trial, and if so has the trial:

- ❖ Continued as planned
- ❖ Been altered
- ❖ Been paused
- ❖ Ended
- ❖ I have been removed due to safety concerns.

19. Have you been informed that you are in the extremely vulnerable group, sometimes called the shielding group?

- ❖ Yes
- ❖ No

20. If you were informed you should shield, who told you to do this?

- ❖ Government
- ❖ GP
- ❖ Hospital team
- ❖ Not applicable
- ❖ Other (please specify)

21. If you were informed you should shield, by which method were you first informed that you are in the extremely vulnerable group (shielding group)?

- ❖ Email
- ❖ Text
- ❖ Telephone call
- ❖ Letter
- ❖ Did not received communication but believe I should be in the group
- ❖ Not applicable

22. Are you shielding?

- ❖ Yes
- ❖ No

23. If yes, please tell us your thoughts about shielding including any difficulties you may be facing.

24. What positive changes, if any, has the coronavirus caused to your treatment, trial options and care that you would like the NHS to keep (for example video appointments, home treatment)?

25. What negative changes, if any, has the coronavirus crisis caused to your treatment, trial options and care that you would like the NHS to address?

26. Do you have any ideas on what could have been introduced to make this time easier for you? We cannot promise suggestions can be implemented but we can escalate them.