

HWC Long-Term Health Condition(s) Project

‘Investigating the impact of Covid-19 on
people with new or existing conditions.’

- September 2021-



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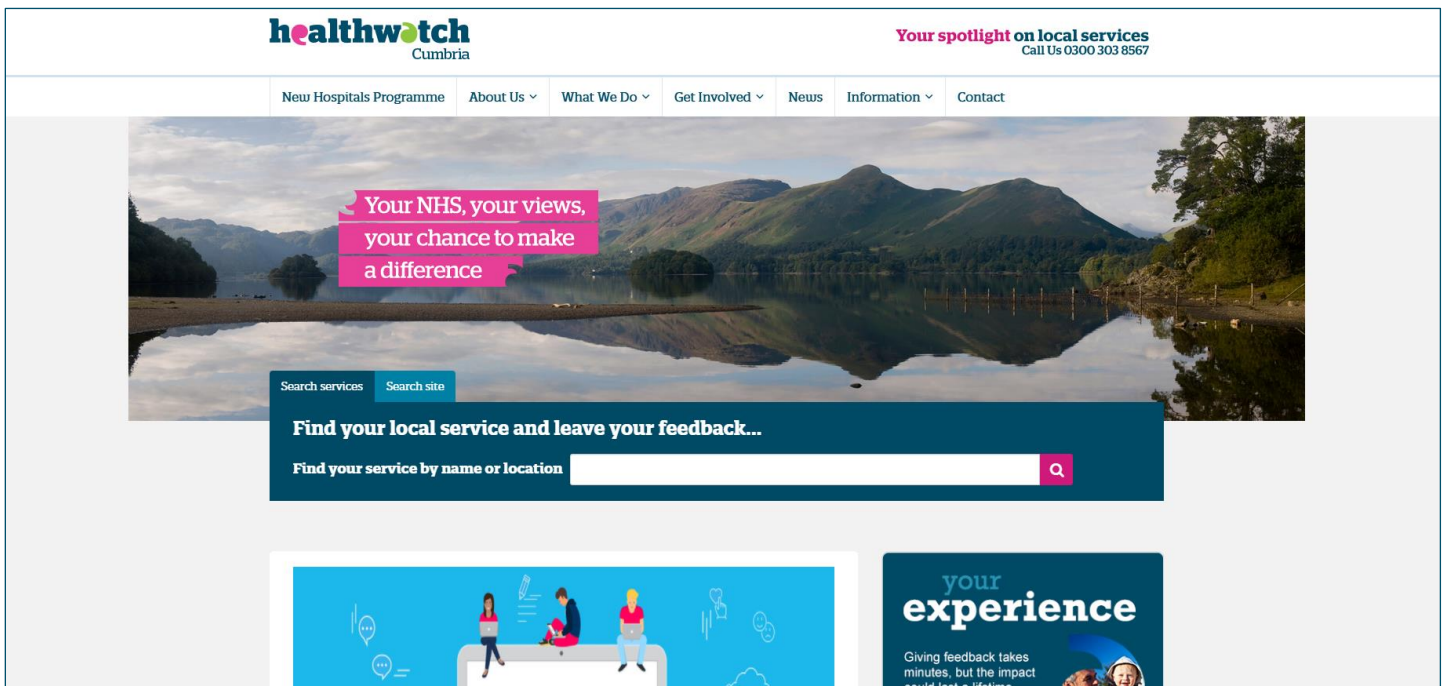


About Healthwatch Cumbria

Healthwatch Cumbria (HWC) was established in April 2013 as part of the implementation of the Health and Care Act 2012.

Healthwatch England acts as the national consumer champion for all local Healthwatch organisations, enabling and supporting HWC to bring important issues to the attention of decisions makers nationally.

A key role of HWC is to champion the views of people who use health and care services in Cumbria, seeking to ensure that their experiences inform the improvement of services. HWC are constantly listening, recording and reporting on the views of local people on a wide range of health and care issues, ensuring that people in the county are able to express their views and have a voice in improving their local health and care services.



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Executive Summary

The original survey was launched on Survey Monkey on the 13th April 2021 and ran until the 23rd August 2021, the shorter version ran from the 19th July 2021 to the 23rd August 2021. There was a total of 32 survey responses. Also, as part of this project there was 4 case studies done and 1 focus group held which were completed throughout August.

- Most common categories respondents' conditions were under gastric and pulmonary.
- The majority of respondents have felt a bit worried or anxious about their medical condition(s) during the last 18 months.
- The biggest concern that made respondents anxious about their condition during the last 18 months was catching Covid-19. Other significant worries included being able to access support for their condition, and their medical condition(s) worsening.
- 69% of respondents required treatment for their pre-existing condition during the last 18 months.
- The top 3 health services used by respondents in the last 18 months (other than for their pre-existing condition) were:
 1. GP
 2. Dentist
 3. Hospital
- More respondents had appointments cancelled or postponed than those who did not. More respondents had appointments postponed than cancelled.
- Usually, respondents were kept informed of any changes to pre-existing or new appointments/treatments in relation to their medical condition(s) during the last 18 months.
- The most common methods of communication to receive information for respondents about their medical condition was by letter or by phone calls.



Rationale for Research

What is the project?

Healthwatch Cumbria have been investigating the impact of the Covid-19 pandemic on people with new or existing health conditions in the local area. This has been done through engagement work with local support groups, the public reached through social media and one to one conversations with members of the community. This research project took place because of the findings from the Healthwatch Together Coronavirus Survey version 1 which took place in March/April 2020 highlighted that there was a lack of insight into the lives of those living with new or existing health conditions. Specifically, on how COVID-19 had impacted their condition in terms of ongoing treatment, appointments, and surgeries.

Why have we done this?

The Covid-19 pandemic has had an enormous impact on health and social care in England. The Healthwatch Together (HWT) Coronavirus survey identified issues with a current lack of available treatment, postponed or cancelled consultations and people who are too anxious to attend their appointments. In order to address this Healthwatch Cumbria (HWC), with the support of the HWC Board, decided that there was a need to focus on the particular impact for people in Cumbria living with new or existing health conditions (such as, but not limited to, mental health issues, long-term medical conditions and cancer tests or treatment).

The findings from the Healthwatch Together Coronavirus survey version 1 can be found in the below report:

<https://healthwatchcumbria.co.uk/wp-content/uploads/2020/05/HWT-C19-v1-report-March-April-2020-Version-2.pdf>

Healthwatch Cumbria noted the lack of responses from those living with a long-term condition and additionally, the lack of responses from male participants. The demographics were predominantly white females in a particular age group. From this, two things were done. Firstly, we tailored remaining Coronavirus surveys (version 3 and 4) to ask questions aimed at developing an understanding to why those with pre-existing medical conditions did or didn't get medical support during the pandemic.

Version 3: <https://healthwatchcumbria.co.uk/wp-content/uploads/2020/09/HWT-Coronavirus-survey-v3-August-2020-final.pdf>

Version 4: <https://healthwatchcumbria.co.uk/wp-content/uploads/2021/06/HWT-C19-v4-Final-1.pdf>

Secondly, we designed a new project and created a survey as a complimentary piece of work to the Coronavirus surveys. With the aim of this survey being to capture how members of the community, living with a long-term condition, have been affected by the pandemic, with a focus on increased engagement with the male population. This report '**investigating the impact of Covid-19 on people with new or existing conditions**' is the accumulation of this project and showcase's our findings.

"The respondents to the 'How are you coping with the Coronavirus (COVID-19) pandemic? Survey' series, have been mainly from the white/white British, heterosexual, female and over 45, demographic categories." **Quote from HWT coronavirus survey 12 month overarching report;** <https://healthwatchcumbria.co.uk/wp-content/uploads/2021/07/HWT-12-month-combined-report-Final.pdf>

"It should be noted however, that over ¾ of the respondents were female and over half were between 35-64 years old and nearly all identified as white, which will skew the data towards the concerns of this demographic." **Quote from HWT coronavirus survey findings v1:** <https://healthwatchcumbria.co.uk/wp-content/uploads/2020/05/HWT-C19-v1-report-March-April-2020-Version-2.pdf>



Methodology

There was a total of 32 survey responses, 4 case studies done and an additional 1 focus group held (with 7 participants), in relation to this project.

There were 3 parts to the engagement of this project:

- Survey long version
- Survey short version
- Focus group/ Case studies

Survey - long version

This version of the survey was launched on Survey Monkey on 13th April 2021 and ran until 23rd August 2021. There were 20 respondents.

Anyone living in Cumbria was eligible to complete the survey online. A link to the survey was on Facebook and Twitter and was also distributed to a number of support groups in the Cumbria area to be passed onto local contacts and members of the public. A paper copy of the survey was also taken along to any Face-to-Face engagement events Healthwatch Cumbria attended in this period (in-line with government Covid guidelines) so that members of the public could fill it out and leave it with a team member during the event.

There was a total of 22 questions asked in the survey.

The survey itself was limited to 15 questions to ensure it was relatively easy to complete and not too time consuming for the participant. The majority of questions were multiple choice to add to the ease of completing. The survey also included some 'open questions' to allow respondents to share personal stories and opinions, which resulted in highlighting further (unprompted) themes. The HWT COVID-19 survey hinted at appointment cancellations, concern around cancer treatment and mental health services being unavailable, thus these themes were the basis of some questions of this survey.

After the 15 questions, an optional additional 6 questions were asked in relation to demographics of the respondent, which allowed a focus in-depth analysis of how specific demographics of those with long term conditions had been impacted by the Coronavirus pandemic.

The final survey question provided the participant with the option to leave personal information in order to be contacted by a member of the team if they wished to participate as a case study. Those who chose not to leave their contact information were assured of their anonymity but were informed that we may use their (anonymous) quotes in our reports. Those who left contact details were informed that they would remain anonymous in any published documents. For these individuals we asked, these individuals were asked for their; name, email address and contact number so that we could get in touch with them.

These respondents were assured that their information will be handled in line with General Data Protection Regulation and Data Protection Act 2018 and that their information would only be used for the purpose of this survey.

The full set of questions that were asked in the long version of the survey can be found in appendix A.



Methodology

Survey - short version

This version of the survey was launched on Survey Monkey on 19th July 2021 and ran until 23rd August 2021. There were 12 respondents.

A link to the new version of the survey was shared Facebook and Twitter and was also distributed to a number of support groups in the Cumbria area to be passed onto local contacts and members of the public.

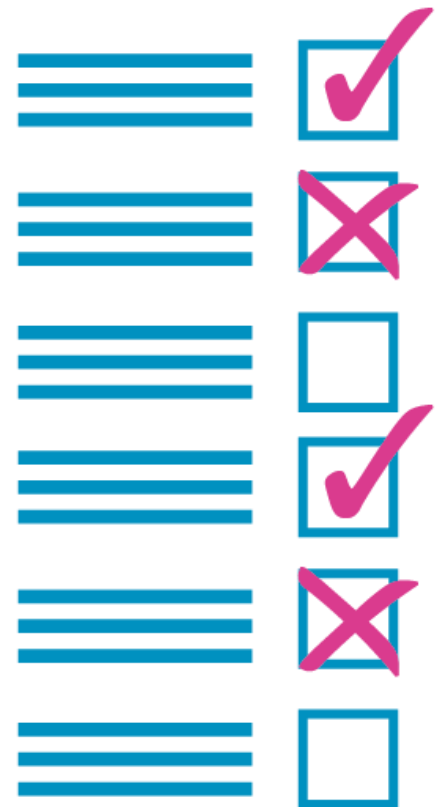
It was identified that there was a lack of responses to the original survey. In response to this, a new version of survey was created to encourage more responses. This new survey was shorter than the original version of the survey. The total number of questions were reduced to 14 from 22. The 14 questions were made up of 9 survey questions, 4 demographic questions and 1 contact detail question.

This new version also removed any direct mention of Covid-19 and replaced with the phrase ‘last 18 months’ which covered the pandemic period. This decision was made because it was made apparent from other work Healthwatch are and have been involved in (attending meetings/forums, engagement, public feedback) that the general attitude of the public was that they were tired of being asked about Covid-19/pandemic. Therefore, a simple rephrasing of the question meant that the same question could be asked but without the off-putting mention of Covid-19/pandemic.

The benefit to revamping the survey was that it asked nothing new and kept as many questions as possible the exact same to the original survey (minimal rephrasing and ensured that the meaning of the question was the exact same). This meant that any responses to the shorter survey could be accumulated with the long survey and analysed together.

This version of the survey also gave respondents the option to leave their contact details if they were interested in taking part in a case study for the project, with the same procedure as the original (longer) version of the survey regarding anonymity.

The full set of questions that were asked in the long version of the survey can be found in appendix B.





Methodology

Focus group/case studies

As part of this project there was 4 case studies done and 1 focus group held.

7 respondents left their contact details, of which 4 agreed to proceed and take part in a case study for the project. These case studies were done throughout August. These case studies varied in length depending on how much the participant wanted to share. The case studies were done in a semi-structured interview style, with a list of questions prepared to inspire discussion, but predominately led by the participant.

Questions

- 1) Background: could you tell us more about your personal experience/situation?
- 2) What were your main worries concerning your health condition during the pandemic?
- 3) Did any aspects of the process change as a response to the Covid pandemic?
- 4) What has your experience of waiting times over the pandemic period been?
- 5) What impact, if any, have any cancelled/postponed appointments/treatment had on you?
- 6) Where did you hear about this survey/project?
- 7) Is there anything else you would like to tell us?

Healthwatch facilitate a support group/ forum for over 55's called 'What Matters To You'. Healthwatch Cumbria (in partnership with colleagues at Healthwatch Lancashire) advertised that if there was interest, that one of these meetings would be used as a focus group for the long-term condition project. Sufficient interest was shown and on the 4th August 2021 the focus group went ahead with 7 participants. There were no pre-prepared questions for the focus group, the project was explained to the group which was then followed by an open discussion amongst the participants.





Survey Demographics

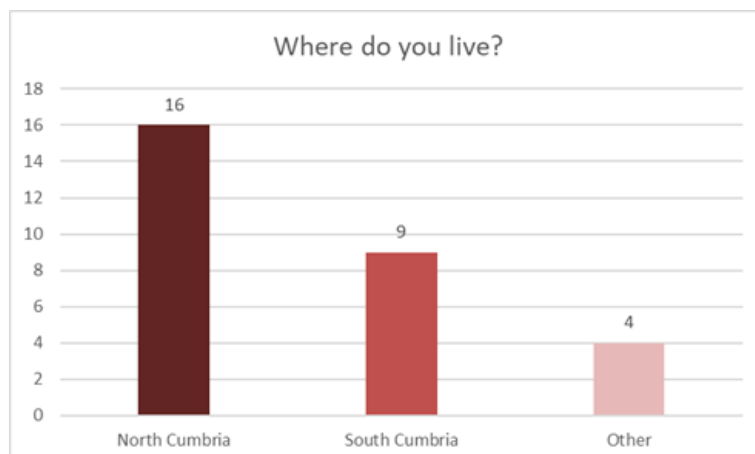
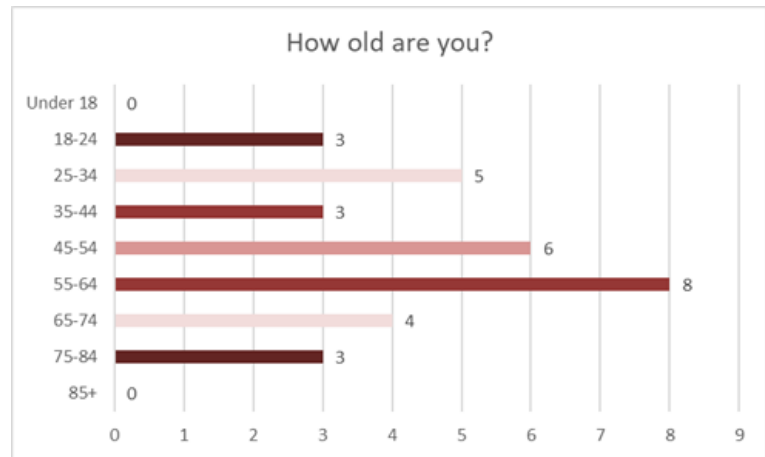
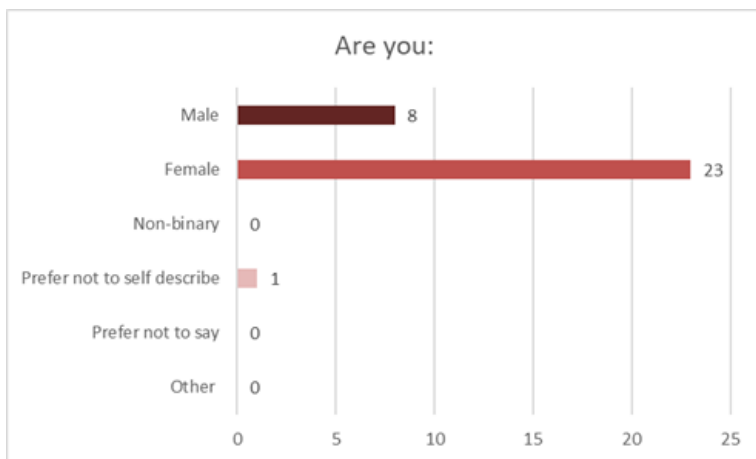
Reflective Overview of Survey

The original survey was launched on Survey Monkey on the 13th April 2021 and ran until the 23rd August 2021, the shorter version ran from the 19th July 2021 to the 23rd August 2021. There was a total of 32 survey responses (which will be combined and analysed together).

(Question response rates - Postcode: 29 answered, Age: 32 answered, Gender: 32 answered, Ethnicity: 32 answered)

The respondents to the survey have been mainly White/White British, female's, over 45 from the North of Cumbria.

- 100% White/White British
- 71.9% female
- 65.6% Over 45
- 55.2% North Cumbrian

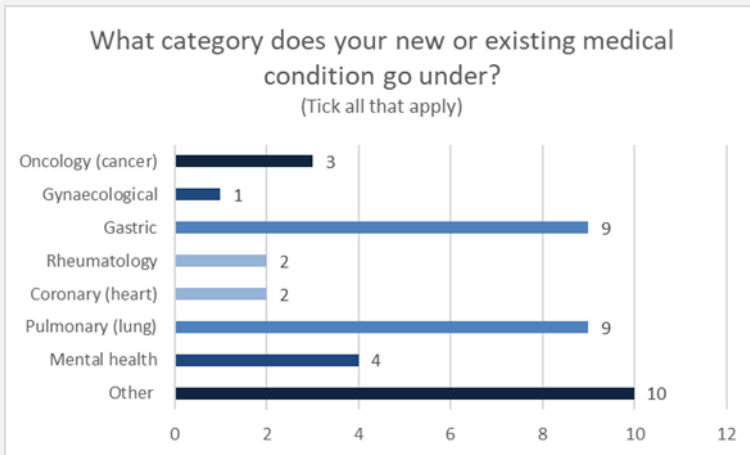




Medical condition category

Reflective Overview of Survey

To give some context to the long-term conditions that the respondents were living with, we asked them to tell us what medical condition category their condition went under. All 32 respondents answered this question.



Some listed under 'other' included:

- Glaucoma and macular degeneration
- Diabetes
- Blood disorder
- Ovary Cyst
- Neurology
- Renal

28.1% of respondents shared that they have long-term conditions that are classified as gastric conditions, also 28.1% of respondents declared that they have long-term conditions that are classified as a pulmonary condition. More respondents stated that their medical condition was listed as a gastric and/or pulmonary condition than any other medical condition category.

The other medical categories that appeared to be more common with respondents were mental health and oncology (cancer). 12.5% of respondents mentioned that they have long-term mental health condition(s), while 9.4% shared that they had a long-term oncology medical condition.





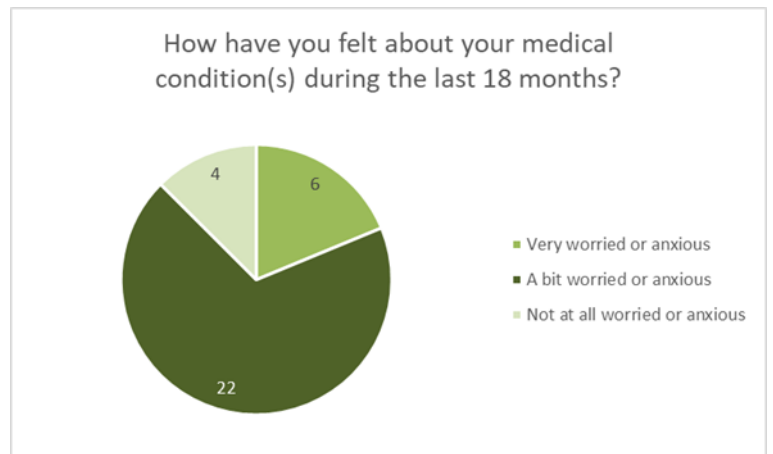
Feelings (specifically concerns)

Reflective Overview of Survey

To gauge how people were feeling about their medical condition(s) over the last 18 months/during the pandemic, respondents were asked how worried/anxious they were regarding their medical conditions (32 answered), and what (if they had any) their specific concerns were (31 answered).

The majority (68.75%) of respondents stated that they have been 'a bit worried or anxious' about their condition.

Also, more respondents said that they were 'very worried or anxious' (18.75%) than 'not at all worried or anxious' (12.5%) about their long-term condition during the specified period.



“Worried in case something did happen and needed urgent treatment, but okay day-to-day.”

“The medical conditions have been more of an inconvenience.”

“Been feeling healthy, normally would have caught colds and flues but as been forced to remain indoors this has been avoided.”

“Treatment to manage my condition put me in the Clinically Extremely Vulnerable category, which caused panic and anxiety, and still does. Seriously considered stopping my treatment, but in the end decided a flare up and COVID would be worse.”

“Asthma and worried about what would happen if I caught Covid.”

“Shielded from 9 March 2020, still do not go into shops, cafes, etc.”

“Worries about long-term Covid have increased as I have got better. Diabetes has been hard to manage as cannot exercise and because of gastric problems.”

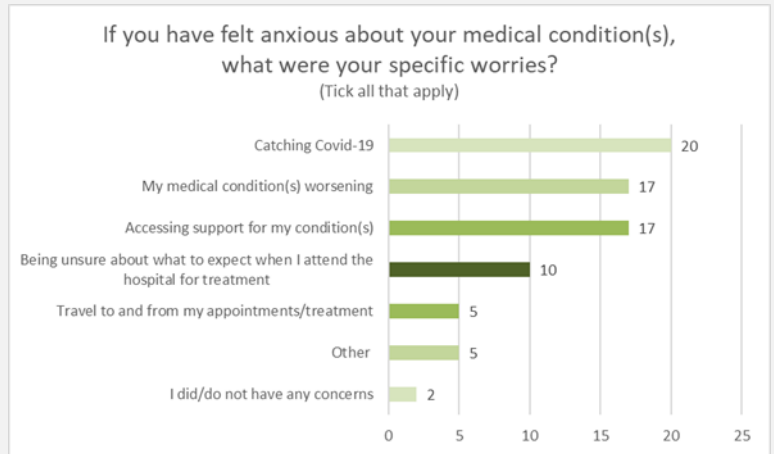


Feelings (specifically concerns) cont.

Reflective Overview of Survey

The top concerns were:

1. Catching Covid-19 (64.5%)
2. Accessing support for their condition(s) (54.8%)
2. Their medical condition(s) worsening (54.8%)
3. Being unsure about what to expect when they attend the hospital for treatment (32.2%)



‘Other’ concerns that respondents shared included:

- Impact on their families

“Impact on my family if they become very poorly...”
“...impact on child’s mental health...”

- Around shielding

“...stringent shielding measures and impact on child’s mental health because of this.”
“Shielding so long I have experienced agoraphobia - something I was prone to in the past and came back with a vengeance.”

- Impact on healthcare resources

“Support not being the same as most appointments were over the phone and getting appointments was hard due to back logs.”
“Not had annual check-up due August 2020.”
“All the staff from rheumatology were redeployed to Covid.”



Required treatment and health services used

Reflective Overview of Survey

To explore respondents, need for treatment and medical services during this period, they were asked if they required treatment for their long-term condition (32 answered) and what services they had accessed if they had (32 answered).

Most of the respondents (68.75%) required treatment during the last 18 months/pandemic for (at least one of) their pre-existing health conditions.

Some respondents shared further details of the treatment during this period:

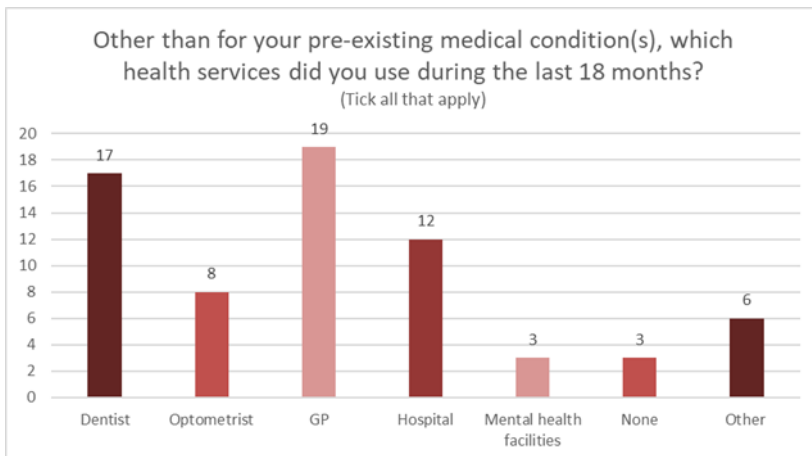
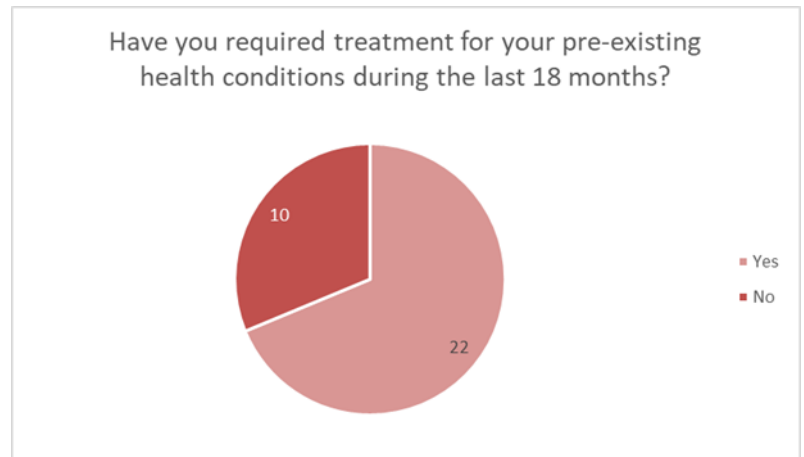
“Ulcerative colitis flare up, started Sept 2019 and is still active. Due for surgery. During time of lockdowns in 2020, I had several appointments with consultations, nurses and GPs to try and get me into remission, but it hasn’t been possible. Due to surgery in June 2021 now.”

“I need 8 weekly infusions to manage my condition plus regular blood tests.”

“Total hip replacement - Jan 2021”

“Opticians for existing conditions.”

“Every 8 weeks I travel out of county for treatment and have b12 injections every 12 weeks at my GP.”



The health services that were accessed by the most respondents were:

1. GP
2. Dentist
3. Hospital

The ‘other’ services used by respondents included:

- Pharmacist
- Cancer treatment
- Maternity services

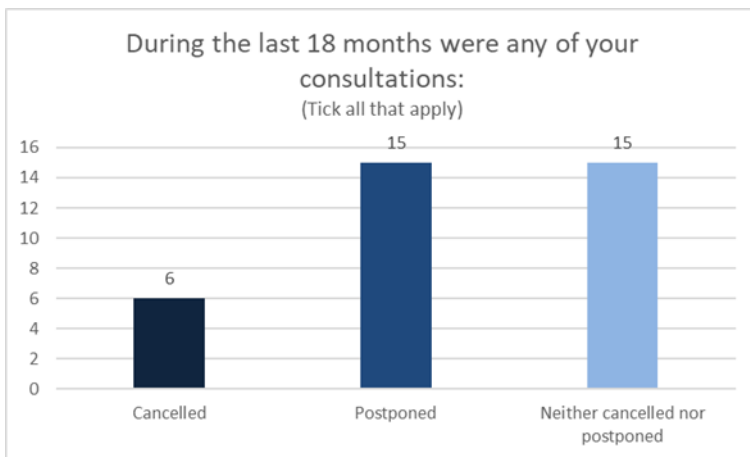
Some respondents did also share that they have not used any services. One respondent indicated that despite needing to go to see a medical professional they have not done so because they are worried - *“Still not braved an eye test!”*



Consultations and communication

Reflective Overview of Survey

Issues had been raised over the ability to get medical appointments and subsequent levels of communication between the health system and the patients during the pandemic. To investigate these issues from the viewpoint of those with a long-term condition, the respondents were asked if any of their consultations had been cancelled/postponed during the period (32 answered), if any changes had been effectively communicated (32 answered), and the methods of communication that have been used (32 answered).



In the last 18 months, 46.9% of respondents neither had a consultation cancelled nor postponed. Meaning that over half of the respondents had a consultation cancelled or postponed.

Out of the 17 respondents that had their consultations either cancelled or postponed. 88.2% of them (15) had an appointment postponed, while 35.3% (6) had a consultation cancelled. (As respondents could have experienced both a postponed consultation and cancelled consultation).

Therefore, overall:

- 18.8% of respondents had a consultation cancelled.
- 46.9% had a consultation postponed.
- 46.9% had neither a cancelled nor postponed consultation

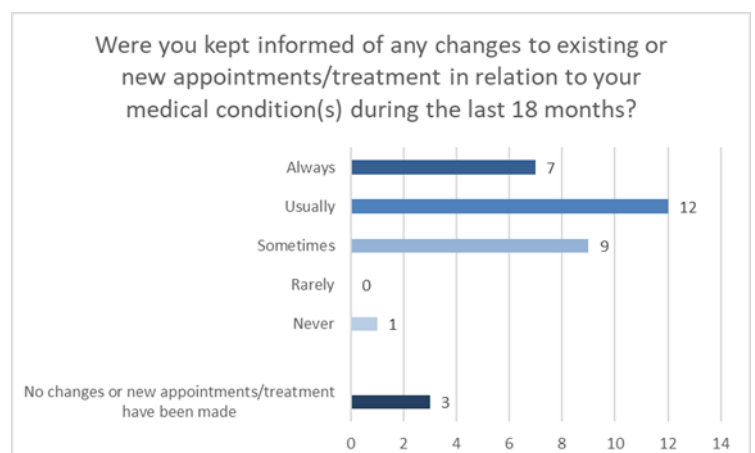
“Eye operation connected to heart problem was cancelled with no notice.”

“Had problems getting retinal appointment in Cumbria, so went privately to Spire Hospital, Blackpool.”

“Consultant postponed, was reallocated and happened during lockdown by way of phone consultation.”

37.5% of respondents (12) felt that they were usually kept informed of any changes to existing or new appointments/treatment in relation to their medical condition(s) during the last 18 months.

21.9% felt that they were always kept informed, while 3.1% shared that they never were.





Consultations and communication cont.

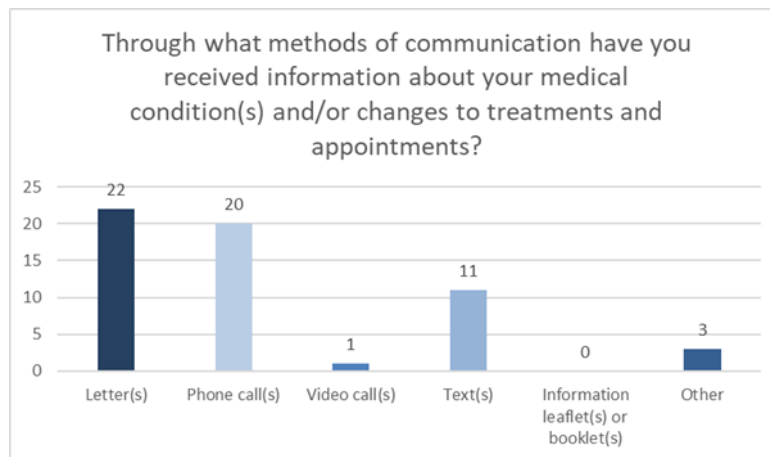
Reflective Overview of Survey

“They didn’t tell me new appointment had been made and I was sent a letter saying that it had been cancelled. I spoke to someone at the hospital, and they re-instated it.”

“I didn’t know they had actually booked an endoscopy for me, as never got the appointment letter.”

“Dentist’s appointment - wasn’t told it was cancelled and very difficult to get through to. I had guessed it would be, but it would’ve been great to have it confirmed.”

“There were one or two issues around postponed appointments. Last minute cancellation of Hep B vaccination. The delay lasted 7 months so almost had to start the whole programme of jabs again.”



The top 3 methods of communication that respondents have received information about their medical condition were:

1. Letter(s)
2. Phone call(s)
3. Text(s)

The ‘other’ methods used included in person and via email.





Anything else?

Reflective Overview of Survey

12 respondents answered this question. 3 prominent themes emerged from the additional comments made by respondents:

- Communication issues

“Communication wasn’t great from Carlisle last autumn.”

“There have been stressful issues around getting past the receptionist to get telephone appointments with my GP or for blood tests at the practice.”

“Received NHS letter on 27th May telling me I needed to make appointment with three option locations in Cumbria. Tried to book appointment with West Cumberland retinal unit. Told I would hear by letter or phone call but hadn’t heard anything so booked a private appointment at Blackpool as I was afraid, I may also lose peripheral vision in my left eye.”

- Issues with Gastroenterology department at Cumberland Infirmary

“Gastro dept in complete disarray. Apparently, only dealing with those patients who ended up in hospital.”

“Staffing at the Gastroenterology dept at Cumberland Infirmary needs sorting fast, it’s not acceptable.”

(Also mentions that the rheumatology department was also struggling during this period -

“Struggled to get in touch with Rheumatology and even now when you leave a message staff struggle to get back due to workload any my last appointment, I had to contact consultations secretary many times just to get an appointment as no one got back to me despite leaving several messages on answering service.”)

- Praises for the NHS staff

“I am grateful for the care and support I receive through the NHS and very much appreciate it. NHS staff should be better appreciated by some sections of the community who are rude and ungrateful.”

“Huge compliments to many NHS professionals...- fantastic work by so many.”





Focused analysis on male respondents

There was an attempt to increase the amount of engagement with (and consequently response rate of) the male population as it was identified as a demographic that had been underrepresented in previous projects. Out of the 32 respondents 8 were male which is 25%. This figure is lower than what was desired, however, there were still some interesting points that came from having a more in-depth look at the survey responses from the male demographic. The male survey respondent results are summarised in the bullet points below:

- 50% of male respondents shared that they had a long-term condition that is categorised under oncology (cancer) and 37.5% said they had a long-term pulmonary condition. These were the most common categories that male respondent's conditions were categorised as.
- The majority of male respondents have felt a bit worried or anxious (75%) about their medical condition(s) during the last 18 months.
- The main concern that made male respondents anxious about their condition during the last 18 months was catching Covid-19 (62.5%).
- 62.5% of male respondents required treatment for their pre-existing condition during the last 18 months.
- The dentist was the top health service used by male respondents in the last 18 months (other than for their pre-existing condition).
- No male respondents had an appointment/consultation cancelled, but 4 had appointments postponed. (4 male respondents had neither a consultation cancelled nor postponed).
- Male respondents felt that they were sometimes kept informed of any changes to pre-existing or new appointments/treatments in relation to their medical condition(s) during the last 18 months.
- The most common method of communication to receive information for male respondents about their medical condition was by letter.

The following table provides a clearer comparison of the male respondent's answers and the female respondents who made up 71.9% of the total number of responses. (The remaining 3.1% of responses were by individuals who preferred not to self-describe - but have not been included to this table as 3.1% corresponds to just one individual, thus doesn't provide a useful comparison in this case).

	Male	Female
Most common classified category for long-term condition to go under	50% pulmonary	39.1% gastric
% that were a bit anxious or worried about medical condition last 18 months	75%	65.2%
% that felt anxious about catching COVID-19	62.5%	68.2%
% that required treatment for pre-existing condition in last 18 months	62.5%	73.9%
Most used health service during last 18 months (other than for pre-existing medical conditions)	Dentist (37.5%)	GP (69.5%)
% of respondents that had cancelled consultations	0%	26.1%
% of respondents that had postponed consultations	50%	47.8%
... kept informed of any changes to existing or new appointment/treatment for medical condition	Sometimes	Usually
Most common method of communication to receive information about long-term condition	Letter (62.5%)	Letter (69.6%)

This table indicates that whilst the male respondents were more worried about their medical condition in the last 18 months, female respondents were more anxious about catching COVID-19 than the men. It also shows that whilst men had more postponed appointments, women had more cancelled appointments during the pandemic. The table also reveals that female respondents required more treatment for their pre-existing condition during this period than the male respondents.



Reflective Overview of Focus Group/Case studies

As part of this project there was 1 focus group held and 4 case studies done.

Focus group

On the 4th August 2021 a focus group was held with 7 participants (the focus group was held with the over 55's forum 'What Matters To You'). There were no pre-prepared questions for the focus group, the project was explained to the group which was then followed by an open discussion amongst the participants.

The focus group raised multiple issues that the participants had been facing themselves or have become aware of during the pandemic and wanted to share. 3 dominate themes emerged from the conversation, these were:

- Waiting times
- Access to GPs
- Hybrid appointments

It was expressed by participants that they want the NHS to become even more patient focused and orientated after the pandemic: *“you have to have systems in place to make sure it works for the people and the way that people want it.”*

Waiting times

It is already a well-known that one specific impact of the COVID-19 pandemic has been an increase in patient waiting times and lists. Therefore, it was not a surprise that it was an issue that was raised by participants in the focus group discussion. The delays in appointments and treatments have caused participants stress, concern and worries about their long-term conditions. The following are shared by participants about their health conditions and waiting times during the pandemic:

“The one thing that was delayed a lot was my course of Hep B vaccinations because I am at risk of getting liver cancer if I get Hep B. I had the first 2 in a timely manner, the last one was 7 months late so I'm on the edge of having to start the whole programme again.”

“I am a cardiac patient, and I am pacemaker dependent, my appointment was cancelled in May 2020 because of COVID and my next scheduled appointment is November 2021. So I think services like that should be looked at because that's an important service for people to make sure their batteries and pacemakers are functioning well.”





Reflective Overview of Focus Group/Case studies cont.

Access to GPs

There was a general consensus amongst the focus group participants that it has been a struggle to get GP appointments during the pandemic. The two main reasons highlighted by participants for this was due to a reduction in the number of available appointments and staff members as a consequence of the impact of COVID-19.

“The biggest problem is they’ve cut all their lists back and said we are not available for these appointments, we are doing other things, we are giving out jabs and stuff like that so all the appointment slots just disappeared but hopefully they should be coming back now.”

“You try and phone up these offices and they say most of them have staff off because of COVID and you could take a week to get through to someone.”

Participants also shared that in some GP surgeries booking systems were altered or were more difficult to access during the last 18 months. It was discussed that in some GPs that the online system they had were temporarily stopped to allow the GPs the chance to control the number of patients in accordance with their resources, it was emphasised that some of these systems are still not running. Closing these online booking systems also added further pressure onto the already over-demanded GP phone lines. It was acknowledged that the phone lines often posed a problem for participants prior to the pandemic, especially in GPs which relied solely on their phone lines as a way for patients to book appointments.

“The 8 o’clock thing though you could actually be on the phone line with it engaged for the full hour and still not get through so that’s only got a limited usage as well.”

A big issue raised by participants was the role of GP receptionists in the appointment booking process. There was a feeling that receptionists have become an additional barrier in accessing the GP appointments, thus hindering more than facilitating the process. Participants pointed out that they call the GP to seek medical advice from a doctor not from a receptionist.

“I have found it very difficult throughout the whole pandemic dealing with the receptionists at our practice.”

“We ring the doctors up because we are ill or we need medical advice and receptionists aren’t trained but at the minute they are making the decisions.”

“In many instances they are not actually qualified to make the decisions they are making, and I find that very concerning.”

“The pandemic has empowered them to be gate keepers again.”





Reflective Overview of Focus Group/Case studies cont.

Hybrid appointments

During the pandemic face-to-face appointments were discouraged and hard to obtain, due to safety measures that were enforced. Appointments and consultations were instead done online or by phone. Online (video conferencing) appointments were more favourable than phone appointments for the participants. As it was discussed that for some individuals and often for doctors as well video appointments worked rather well, as it allowed patients and doctors to see each other but also maintained the benefits (speed and safety) of a phone call.

“Telephone didn’t work very well but video conferencing did if people were having problems with their inhalers and things like that, they could actually go online with them. Seeing a person and talking to them is much easier. They were very successful, and it has improved the service because it might take them 30/40 minutes in these work areas to get from one patient to the next where as they can see a lot more patients with a lot better results in a very short period of time.”

But participants did emphasise that phone and online appointments are not always ideal and, in some situations, so not work for people.

“It doesn’t work for everything, it has to be different things for different people and maybe in different conditions.”

“Somethings can’t be done over the phone, they can’t be done on the internet, so how can they improve this going forward?”

Participants were very concerned about those who do not have the digital skills or resources to be able to have an online appointment. This could be a bigger concern due to their demographic (over 55) and thus have more interaction with those individuals who are challenged as a consequence of digital limitations.

“About 20% of people don’t have access to things like the internet, they’ve only got the telephone, or they can only walk in and speak to them.”

“We are working to get more people online but not everyone wants to be online and that’s the thing that people don’t understand, it’s alright saying include them and give them a tablet but if you are a 90 year old lady trying to book a GP appointment on a tablet you don’t want to be bothered with that if you are feeling ill, you want to pick up the phone and speak to someone.”

“It’s a big thing...not everyone can use technology and going forward there has to be that mixed blend for people.”

Therefore, the participants reached the conclusion that in the future there should be a type of hybrid model of appointments, depending on patients’ needs and their situation. Thus, giving patients the option of having an online, phone or face-to-face appointment.

“A hybrid model going forward is the right way, but it has to come from the patients and what they need.”

“Who should have the option to say which one they want? I think it has to be the patient.”





Reflective Overview of Focus Group/Case studies cont.

Case Studies

The survey asked respondents to leave contact details if they were interested in being involved in doing a case study for this project. 7 respondents left their contact details, of which 4 agreed to proceed and take part in a case study for the project. The case studies were done in a semi-structured interview style. These were done throughout August.

The 4 case studies highlighted a range of different challenges faced by people with long-term conditions during the last 18 months. They show that everyone has their own experience and story. By asking a set of prompt questions there were 4 distinct themes that the information and experience the participant shared could be divided into. These are, worries and concerns, changes experienced due to COVID-19, waiting times, and cancelled/postponed appointments.

Background

The case study participants shared the long-term conditions that they have been living with. Some of the ones that were mentioned during the conversations included:

- Type 1 diabetes
- Eye conditions
- Gastro conditions
- Heart problems (resulting in multiple heart attacks)
- Rheumatoid arthritis/ arthritis
- Fibromyalgia
- Depression
- Blocked artery
- Hypertension
- Chronic Pain

Worries and concerns

There were a variety of worries shared by participants during the case study conversations. The following list bullet points the main concerns raised by individuals involved:

- Different medical departments do not share information effectively, as often symptoms are focused on as individual problems rather than a collective complete bigger picture.
- Doctors don't always listen to their patients and their individual stories/situation/experience (before reaching a conclusion).
- If someone doesn't look ill then others make assumptions of your level of health and/or treatment.
- Waiting times gives time for conditions to further deteriorate.
- Participants were not asked about their mental wellbeing at any appointment during the pandemic.
- Struggled to get in touch with their GP and obtain appointments/consultations/treatment/medication.
- Went weeks without medication (due to delays) which increased pain levels.
- Financial concerns - unable to work during this period because of long-term medical conditions.
- High risk of catching COVID-19 (and the consequent impact on themselves, their family and their condition would/could have been huge).
- Worried about their long-term condition(s) worsening.





Reflective Overview of Focus Group/Case studies cont.

Changes experienced due to COVID-19

3 main changes were identified from the case study conversations, which showed the impact of the pandemic had on those with long-term conditions.

The first change was appointments/consultations being done via the phone rather than face-to-face. While participants recognised and understood the need for the method of appointments to be altered, they also expressed a desire for regular face-to-face appointments to return. It was shared that phone calls feel less personal as it just a voice on the end of a phone. One participant mentioned that they sometimes struggle to communicate with doctors by phone.

The second change identified was that there were staff shortages in some medical departments and GPs. Participants suspected this was due to COVID-19 and there being a need to redeploy staff to deal with the pressures of the pandemic. These staff shortages had an impact on participants accessing appointments and treatment for their long-term conditions.

The final change identified was increased waiting times. The participants mentioned that during the COVID-19 pandemic it was hard to obtain treatment and appointments linked to their long-term conditions.

Waiting times

As predicted an increased waiting times was an issue for participants. It is well-known that a big impact of the pandemic was that the waiting lists have got longer, and the time individuals have to wait for treatments/appointments have increased. Participants expressed that waiting times would add to worries/concerns that they already had.

A participant shared that they made the decision to get treatment done privately during the pandemic to avoid the long waiting lists in the NHS. Though other participants shared that they couldn't afford to go private but would if they could.

One participant shared that they had issues with obtaining their medication due to not being able to get an appointment. This resulted in their pain, caused by their long-term condition, increasing and becoming more difficult to live with.

There was a shared desire from the participants to have their regular check-ups again. It was mentioned by one participant that they have not had an official appointment since before the pandemic. Another said that their diabetes annual check up has been delayed a year.





Reflective Overview of Focus Group/Case studies cont.

Cancelled and postponed appointments

Participants mentioned that having appointments postponed/cancelled has sometimes caused issues for them and has left them frustrated.

A participant shared that having appointments postponed caused them to be in more pain due to not being able to get the medication they needed. They shared that they felt that pain relief should still be considered as a priority, especially if it is caused by a long-term condition which impacts their daily life significantly.

Participants mentioned that a big issue with the postponed/cancelled appointments have been down to the poor levels of communication received from the medical system. One mentioned they received apology letters because of delayed appointments but they were not sure which department was sending these letters to them. Another mentioned that communication only improved once they had complained about not receiving a phone call on the day, they were told they would.

There was a clear, strong desire amongst participants for communication and appointment availability to return to levels they were prior to the pandemic.

Anything else?

The following are some additional points made by participants during the case study conversations:

- Concerned about the effect of the pandemic on young children and teens (mental health, anxieties, returning to schools during pandemic).
- Increase in germ phobias and anxieties linked to the COVID pandemic.
- Catching COVID would have had a huge impact on their personal situation as primary carer for a relative.
- A need to have appointment bookings stage more closely linked to the medical department.





Summary of Entire Project

There was a total of 32 survey responses, 4 case studies done and an additional 1 focus group held (with 7 participants), in relation to this project.

There were 3 parts to the engagement of this project:

- Survey long version - This version of the survey was launched on Survey Monkey on 13th April 2021 and ran until 23rd August 2021. There were 20 respondents.
- Survey short version - This version of the survey was launched on Survey Monkey on 19th July 2021 and ran until 23rd August 2021. There were 12 respondents.
- Focus group/ Case studies - There was 1 focus group held and 4 case studies done. On the 4th August 2021 a focus group was held with 7 participants (the focus group was held with the over 55's forum 'What Matters To You'). The survey asked respondents to leave contact details if they were interested in being involved in doing a case study for this project. 7 respondents left their contact details, of which 4 agreed to proceed and take part in a case study for the project, which were done throughout August.

The project raised many new interesting points as well as provided further supporting evidence to issues that have already been highlighted at national and local level. The following are some key points that can be taken away from this project and its findings:

- The majority of respondents have felt a bit worried or anxious about their medical condition(s) during the last 18 months.
- The biggest concern that made respondents anxious about their condition during the last 18 months was catching Covid-19. Other significant worries included being able to access support for their condition, and their medical condition(s) worsening.
- It was common to receive treatment for their pre-existing condition during the last 18 months.
- The top 3 health services used by respondents in the last 18 months (other than for their pre-existing condition) were:
 1. GP
 2. Dentist
 3. Hospital
- The most common methods of communication to receive information for respondents about their medical condition was by letter or by phone calls.
- It has been a struggle to get GP appointments during the pandemic (and most people have experienced having an appointment postponed or cancelled in the last 18 months).
- Some patients believe that GP receptionists hinder rather than facilitate the appointment booking process.
- In the future the option of a hybrid model for appointments is wanted, with the method (online, phone or face-to-face) being chosen by the patient.
- A strong desire to return to regular check ups for long-term conditions.
- Long waiting times and poor communication have been highlighted as big issues during the pandemic.



Conclusion and Recommendations

The ‘Investigating the impact of Covid-19 on people with new or existing conditions’ project has allowed those individuals with a long-term condition the opportunity to share their experience of the COVID-19 pandemic and the impact it has had on them and their condition(s). It has given them the chance to communicate and be listened to, and in the process, it has raised many interesting points. As well as highlighted issues that are being experienced by this group that go beyond the impact of the pandemic but have also been escalated due to COVID-19.

Healthwatch Cumbria would like to thank all the people who participated in completing the survey and for sharing their experiences with us during the Covid-19 pandemic. Also a huge thank you to those who allowed us to contact them for further insight into their circumstances by being involved in our case studies, as well as those who attended our focus group.

We would also like to thank the groups we engaged with in order to gain further knowledge around long-term conditions and how the community may have been affected by the pandemic. These groups include:

- Barrow Men’s Group
- Parkinson’s UK
- Millom Prostate Cancer Group
- Furness Prostate Cancer Group

Recommendations

The information and insight gained from the project; the following recommendations have been made:

1. Complete additional work to gain further focused insight into those individuals with Pulmonary and Gastro long-term conditions.
2. Give patients the option of what form of appointment they would like to have - face-to-face, phone or online (video).
3. Improve communications between system and patients, in particular concerning cancelled/postponed appointments and those who are on the waiting lists.
4. Doctors to return to having planned regular appointments with patients about their long-term conditions.
5. A revaluation of the booking process of GP appointments, especially the role of non-medical professionals in the triage decision.



References

List of How are you coping with the Coronavirus (COVID-19) pandemic? Survey series published reports:

Version 1: <https://healthwatchcumbria.co.uk/wp-content/uploads/2020/05/HWT-C19-v1-report-March-April-2020-Version-2.pdf>

Version 2: <https://healthwatchcumbria.co.uk/wp-content/uploads/2020/07/HWT-C19-v2-report-June-2020-final.pdf>

Version 3: <https://healthwatchcumbria.co.uk/wp-content/uploads/2020/09/HWT-Coronavirus-survey-v3-August-2020-final.pdf>

Version 4: <https://healthwatchcumbria.co.uk/wp-content/uploads/2021/06/HWT-C19-v4-Final-1.pdf>

12 month Overview: <https://healthwatchcumbria.co.uk/wp-content/uploads/2021/07/HWT-12-month-combined-report-Final.pdf>





Appendix A

Survey Questions - long version

- 1) Do you have a new or existing health condition?
- 2) What category does your new or existing medical condition go under?
- 3) How have you felt about your medical condition(s) during the pandemic?
- 4) If you have felt anxious about your medical condition(s), what were your specific worries?
- 5) Have you required treatment for your pre-existing health conditions during the COVID-19 pandemic?
- 6) Other than your pre-existing medical condition(s), which health services did you use during the pandemic?
- 7) During the pandemic were any of your consultations cancelled or postponed?
- 8) Did you decide to use private healthcare instead of the NHS during the pandemic?
- 9) Were you kept informed of any changes to existing or new appointments/treatment in relation to your medical condition(s) during the pandemic?
- 10) Through what methods of communication have you received information about your medical condition(s) and/or changes to treatments and appointments?
- 11) Overall, how would you rate your experience of communication between yourself and your health provider during the pandemic?
- 12) Overall, how would you rate your experience of your treatment for your health condition(s) during the pandemic?
- 13) What was done well in relation to your treatment?
- 14) What could have changed to make your treatment better?
- 15) Is there anything else you would like to tell us?
- 16) What is the first line of your postcode?
- 17) How old are you?
- 18) Are you: (Male, female, non-binary, other...)
- 19) Is your gender identity the same as on your original birth certificate?
- 20) What sexual orientation do you identify as?
- 21) What is your ethnicity?
- 22) OPTIONAL: Please leave your contact details if you are interested in taking part in a case study for this project.



Appendix B

Survey Questions - short version

- 1) What category does your new or existing medical condition go under?
- 2) How have you felt about your medical condition(s) during the last 18 months?
- 3) If you have felt anxious about your medical condition(s), what were your specific worries?
- 4) Have you required treatment for (if you have multiple, at least one of) your pre-existing health conditions during the last 18 months?
- 5) Other than for your pre-existing medical condition(s), which health services did you use during the last 18 months?
- 6) During the last 18 months were any of your consultations cancelled or postponed?
- 7) Were you kept informed of any changes to existing or new appointments/treatment in relation to your medical condition(s) during the last 18 months?
- 8) Through what methods of communication have you received information about your medical condition(s) and/or changes to treatments and appointments?
- 9) Is there anything else you would like to tell us?
- 10) What is the first half of your postcode?
- 11) How old are you?
- 12) Are you: (male, female, non-binary, other...)
- 13) What is your ethnicity?
- 14) OPTIONAL: Please leave your contact details if you are interested in taking part in a case study for this project.



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