



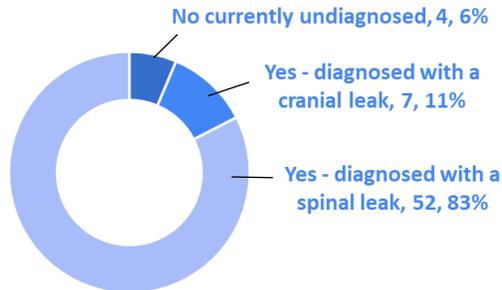
CSF Leak Covid19 Impact Survey Report

December 2020

Authors

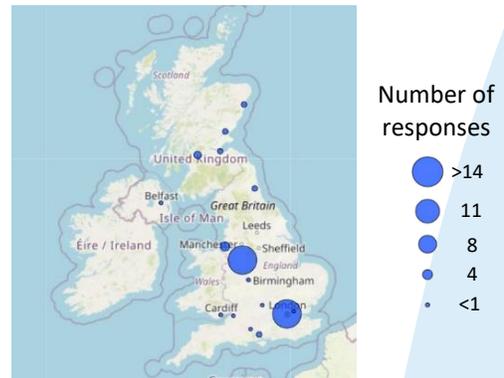
Dr Jenny Pople & Clare Sargeant

The CSF Leak Association want to better understand the impact the Covid-19 pandemic has had on the care and treatment of patients with diagnosed or suspected CSF Leaks. To do this we devised an anonymous survey which was open from 7th September 2020 until 30th September 2020. The survey received 93 responses, 63 responders from the UK and 30 from the rest of the world.



Of the UK responders
 52 were diagnosed with a spinal leak
 7 were diagnosed with a cranial leak
 4 were currently undiagnosed

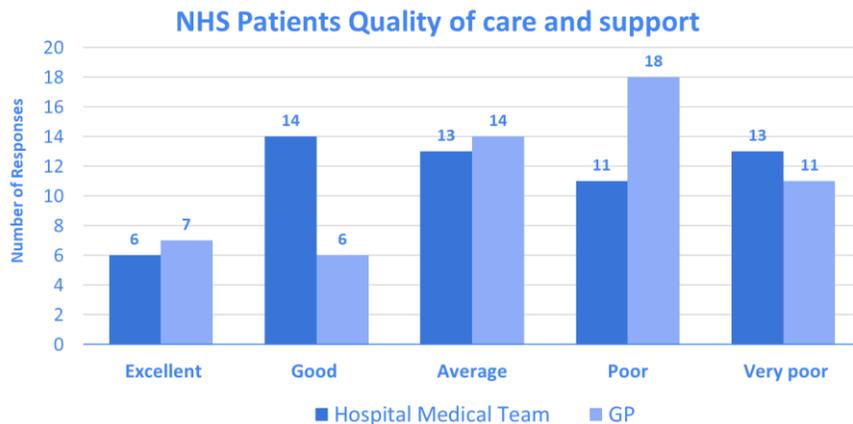
We received survey responses from patients receiving care for their CSF leak at NHS hospitals across the UK. The highest number of responses was received from patients receiving care at University Hospital of North Staffordshire (19 responses), The National Hospital for Neurology and Neurosurgery, London (14 responses, 4 receiving private care) and The Walton Centre, Liverpool (4 responses). We also received a further two responses from patients receiving care at other private providers.



“I felt abandoned with deteriorating pain; it’s been difficult”

“Covid19 prolonged my symptoms and resulted in A&E admissions”

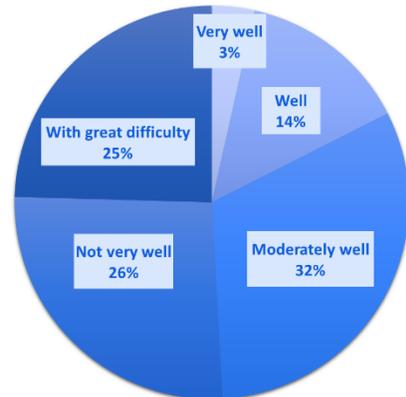
We asked the 57 survey respondents receiving NHS care to rate the quality of the care they received regarding their CSF Leak from both their Hospital medical team and from their GP. 36% (20) rated care from their NHS hospital team as good or excellent for GP’s this was 23% (13). Just over half the respondents (52%, 29) rated their GP’s quality of care as poor to very poor for NHS hospital care this was 42% (24).



Almost half (51%, 29) of the survey responders receiving NHS care felt they were not coping very well or were having great difficulty in coping during the COVID-19 pandemic. 18% (10) of responders reporting difficulty in accessing their regular medicine.

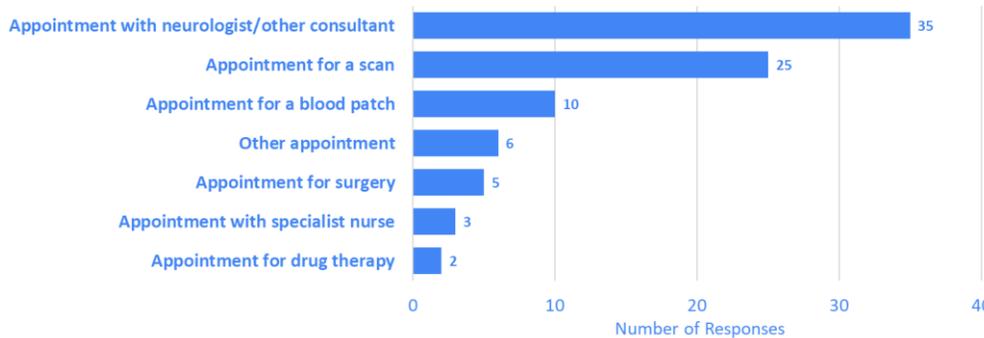
The vast majority of respondents (81%, 46) receiving NHS care had appointments delayed or cancelled due to the pandemic.

How have you been coping during the covid-19 pandemic?



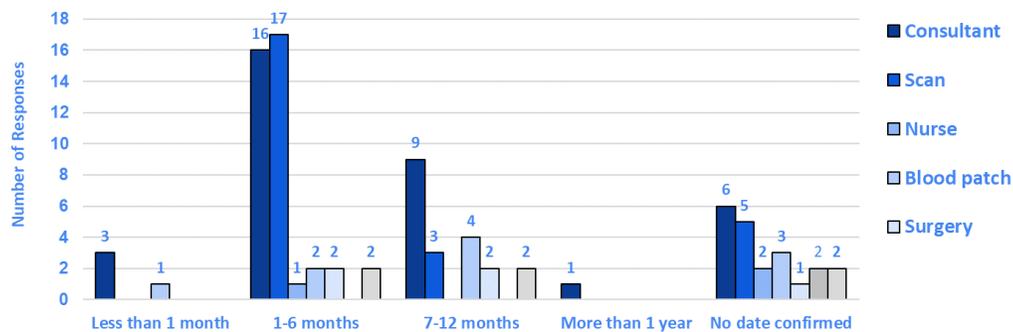
“It feels like everything has stalled”

Which appointments have been delayed or cancelled:



The 57 UK respondents receiving care from the NHS reported a total of 86 appointments cancelled due to the pandemic. The majority of respondents had delays in an appointment with a neurologist or other consultant (35) and appointments for scans (25). The majority (40) of the cancelled appointments were delayed by 1-6 months. Almost a quarter (21) of the respondents reported that their cancelled appointments had not been rescheduled at the time of the survey.

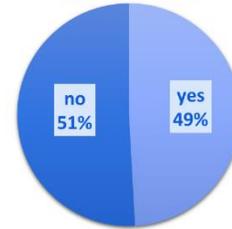
For how long has each appointment been delayed?



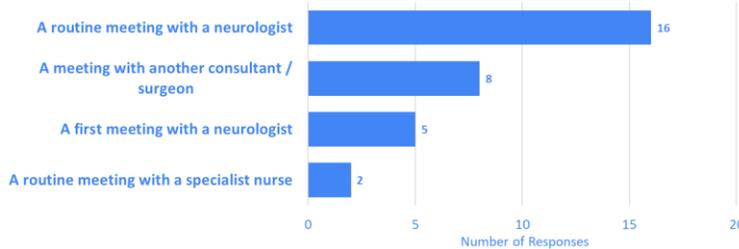
“There's been no communication from the hospital I have to chase them”

Almost half (49%, 28) of the 57 UK NHS respondents had been offered virtual consultations with some respondents having more than one virtual consultation. Of the total 31 virtual appointments reported the majority were delivered by phone (25 responses) and video (5 responses). The majority (16) of the virtual appointments were for a routine meeting with a neurologist. 64% of survey responders rated the virtual consultations as either very effective, effective or as effective as a face to face consultation.

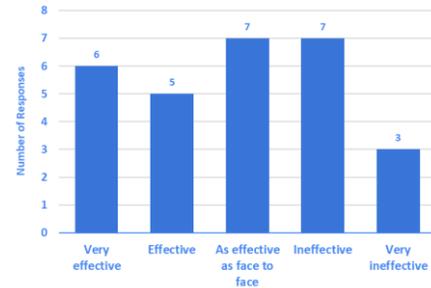
Have you had any 'virtual' consultations ?



Was your 'virtual' appointment concerning your CSF Leak:



How effective were the 'virtual' consultations?

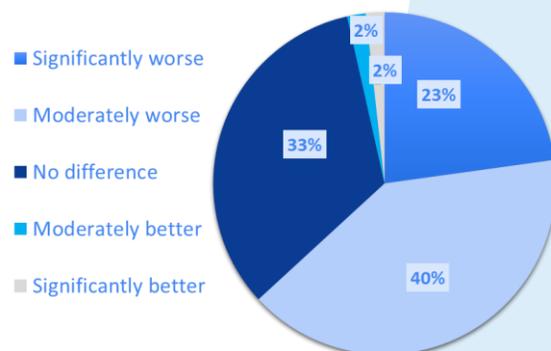


We asked the survey responders who reported their CSF Leak has been made worse during the pandemic the reasons for this. 75% said COVID-19 delays and/or cancellations to their treatment and support had affected their health with 72% stating this had resulted in them experiencing increased or prolonged symptoms. 64% reported not being able to access services had caused increased stress and anxiety and 25% said it was because they had not been able to see friends and family. 25% said their CSF leak symptoms remained the same but the added stress and isolation had resulted in increased mental health challenges and they were coping with their symptoms less well. Only 14% felt the risk of contracting Covid19 whilst visiting hospital or receiving treatment was too high so had chosen not to pursue medical care. Two responders mentioned they were receiving less support at home with everyday tasks which had worsened their CSF leak symptoms.

“My leak symptoms have severely worsened, my appointment didn't happen & the hospital will not give me a new date”

Overall, the pandemic has had a negative impact on survey respondents with the majority 63% (36) saying they felt their CSF leak was moderately or significantly worse.

How do you feel your CSF Leak has been affected by the pandemic?



“Treatment and care for those with CSF leaks was poor and slow before, as NHS services are being restored it seems CSF leak patients are way down the list of priorities”

We asked for additional comments, a word cloud was generated from these responses



Survey responders from the UK receiving private medical care made up a small proportion of survey responses totalling 6. Four of these responders reported they were coping well in the pandemic. 50% of these responders said they had experienced delays or cancellations to appointments for their CSF leak, their delays averaged 1-6 months. Four of the responders rated the care they receive from their hospital team as excellent, one as very good and one average. Three of these responders rated their GP care as excellent and two as very poor. 50% of these survey responders had virtual consultations these were delivered by video or telephone. Half of these responders felt their CSF leak had been made moderately worse by the pandemic the remainder reported no difference. All the responders in this group who felt their CSF leak was made worse was due to delays / cancellations in their treatment and care.

Survey responders from outside the UK answered a subset of survey questions. 36% of non-UK survey responders reported their CSF leak had been made moderately worse by the pandemic and 10% significantly worse, these figures were considerably better than for UK responders. Those who reported their CSF leak has been made worse during the pandemic gave the following reasons for this; 85% reported not being able to access services had caused increased stress and anxiety, 57% said COVID-19 delays and/or cancellations to their treatment and support had affected their health, 71% said it included not being able to see friends and family. 43% said their CSF leak symptoms remained the same but the added stress and isolation had resulted in increased mental health challenges and they were coping less well. 21% felt the risk of contracting Covid19 whilst visiting hospital or receiving treatment was too high so you had chosen not to pursue medical care. 50% of responders had a virtual consultation, 73% of these were with another consultant/surgeon, 13% of these were a routine appointment with a neurologist and 6% a first meeting with a neurologist.

Survey Findings Summary

We received 93 responses to this survey, 63 from patients from across the UK and 57 receiving care from the NHS. 36% of the responders rated the care from their hospital team as good or excellent. The majority of responders receiving NHS care reported not coping well. 81% of patients receiving NHS care had appointments cancelled or delayed due to the pandemic, mostly commonly an appointment with a neurologist / other consultant or for a scan. The majority of the cancelled appointments were delayed by 1-6 months, but a quarter of respondents reported appointments had not been rescheduled. Nearly half of UK NHS responders had virtual consultations and the majority rated these as being effective. 63% of patients who responded to the survey reported their CSF Leak had been made worse by the pandemic the majority due to delays and cancellations in treatment / care affecting their health. Only a small number of these patients report concerns about contracting Covid19 in hospital for not pursuing care & treatment.

