

## IMMUNODEFICIENCY UK SURVEY ON REMOTE CONSULTATIONS 2021

The aim of the survey was to explore the experiences of remote consultations by members of the immunodeficiency community. Since the start of national restrictions due to the coronavirus pandemic, many consultations have moved from face-to-face to remote (telephone video or online) both in general practice and hospital specialties.

This survey asked members of the Immunodeficiency Community for their experiences of remote consultations with their Immunology Teams. The survey ran from 13<sup>th</sup> May to 7<sup>th</sup> June 2021 and was made available via social media, Immunodeficiency UK's newsletter, and an emailed member invitation. Immunodeficiency UK would like to thank those who took part.

### Key findings

- **91% of respondents who were offered a remote consultation since April 2020 were not offered a face-to-face consultation as an alternative**
- **83% of respondents were happy to be offered a remote consultation but 84% of respondents would prefer at least some face-to-face consultations in the future**

*'Unsure what to expect, never had a telephone appointment before'*

*'Very good communication and consultation. I did not require a physical examination so remote was very good for me.'*

*'It was just as useful as a face-to-face appointment, which I would not have even considered at the time'*

*'Did not have the usual physical examination. I missed having face to face contact.'*

*'I live 130 miles away from the hospital, so it was helpful to have the consultation on the phone. I would prefer a video consultation than a phone one with alternate face to face consultations.'*

*'You can't fully explain over phone u need to be in person'*

*'Useful to have telephone appointment for occasions when my son does not need to be present for a physical exam or tests...eg if it is just a discussion. Means he does not need to miss school.'*

- **8% of respondents had a disability which affected communication**  
*'Hard to make out all that she was saying due to hearing problems'*
- **47% (less than half) of respondents were completely confident that their medical needs had been properly assessed**

*'If I hadn't taken the initiative and got my GP to arrange the bloods before the consultation, I wouldn't have had a full review. At the time I wouldn't have wanted to go to the hospital for the bloods, but there's no reason why they can't be done in the community, in advance of the consultation. I know it was not an emergency, but a bit of thinking and coordination would have helped a lot.'*

- **The main positive points which people highlighted were not having to travel to the hospital by car or public transport, not being exposed to the risk of contracting Covid-19, and the convenience of being at home.**

*'Didn't have to drive for 1 hour to get to the hospital so much more convenient. Had the opportunity to ask several questions that I have written down to ask the doctor.'*

*'I didn't have to make a 180 mile round trip to the clinic and home. Didn't have to wait with strangers to see the consultant.'*

*'Not having to go to hospital where there is still some additional risk of picking up a COVID infection'*

- **The main negative points were the lack of a physical examination and access to investigations, poor rapport including lack of visual contact, being rushed, communication difficulties and lack of follow up.**

*'Blood tests, lung function tests and abdomen ultrasound not available'.*

*'I feel face to face is best. Usual physical checks are important'.*

*'No eye contact/non verbal communication. Also Tel consultation meant I couldn't have physical examination (re immunoglobulin treatment/stomach, lungs -(asthma, Bronchiectasis etc); & couldn't have the more complex/specific blood tests which I usually have 6 monthly (my GP did do basic blood tests on behalf of the hospital)'.*

*'The doctor was very late calling so I was worried that we had been forgotten about or issues with getting through etc. I telephoned the clinic to be told they are running behind but perhaps it would have been considerate to telephone those who were waiting so they didn't need to worry.'*

*'I've heard nothing since the call, no follow up, no info on what happens next. Basically, left in limbo feeling my problem wasn't urgent enough so I'm now reluctant to make another appointment in case I'm seen as wasting appointments'.*

*'Need to ensure that you cover any issues you may want to raise by writing a prompt sheet beforehand'*

*'It is less personal not being able to see the consultant. It feels like you need to be very well prepared beforehand to get the best from the discussion. It is perhaps less easy to resolve any difference of opinion if not face to face. Still had to travel to the hospital for blood tests.'*

*'I am finding it extremely difficult to contact the hospital at present, (name of centre) they don't answer phones or emails, so it would be helpful when we have a meeting, there was a way to ensure we cover everything. My GP surgery has the same problem with them'.*

## **Recommendations for medical teams**

1. Maintain traditional models of care alongside remote consultation methods of care (in person, telephone, email, video) and support people to ensure the most appropriate type to meet their needs.
2. Provide a clear expectation to patients about what will be involved in a remote consultation.
3. Ensure people with support or access needs are not disadvantaged when accessing care remotely.
4. Prepare for the consultation and don't ask patient for information that you already have access to.
5. Be proactive and work with patients to learn about their preference of remote consultation methods.
6. Make time for the patient to ask questions.
7. Make clear what will be happening next and who is responsible for next stages of care.
8. Always provide patients with contact details of whom they can contact in case of enquiries or in an emergency.
9. Seek feedback of a patient's experience of care and use this to improve the service.

## **Recommendations for patients**

1. Let your health care provider know how you prefer to talk by phone, video or in-person.
2. Take some time to prepare in advance, consider what you want to say and key questions you would like to ask.
3. Ask your health care provider to summarise the next steps at the end of the appointment.
4. State your preference of what method of remote consultation you would prefer.
5. Ask for help and support if you need it concerning use of technology or information on how the consultation will work.
6. Not all appointments are suitable for remote consultations, if you would like to see someone in-person please say so.

## Analysis of results

117 people completed the survey and a further 24 people looked at the survey but did not proceed beyond the first question. 109 (93%) people responded on behalf of themselves, 5 for their child and 3 as a carer.

All except one of the consultations had taken place since April 2020.

Not every respondent answered every question.

For answers to the demographic questions 1-3 and information the conditions that participants reported please see the appendix.

### Question 4. What type of consultation was offered?

Category	Number of respondents
Phone	101
Video	10
On-line	1
Face-to-face	4
<b>Total</b>	<b>116</b>

86% of respondents were offered a telephone consultation

### Question 5. Were you offered a face-to-face consultation as an alternative?

Reply	Number of respondents
Yes	7
No	107
Not sure	3
<b>Total</b>	<b>117</b>

91% of respondents were not offered a face-to-face consultation as an alternative to a remote consultation

### Question 6. Were you happy to be offered a remote consultation?

Reply	Number of respondents
Yes	96
No	8
Not sure	12
<b>Total</b>	<b>116</b>

83% of respondents were happy to be offered a remote consultation

### Question 7. Do you have a disability which affects communication? (For example, vision, hearing or speech problems)

Reply	Number of respondents
No	108
Yes - Hearing	5
Yes – Hearing and vision	1
Yes – Speech (breathless)	1
Yes – speech (ataxia)	1
Unspecified	1
<b>Total</b>	<b>117</b>

8% of people had a disability which affected communication

### Question 8. Do you require assistance with sign language?

No-one required assistance with sign language.

**Question 9. Is English your first language?**

Reply	Number of respondents
Yes	113
No	4
<b>Total</b>	<b>117</b>

3% of respondents did not have English as their first language

**Question 10. If no, did you require an interpreter?**

No-one required an interpreter.

**Question 11. If your consultation was by video or online, did you receive adequate training on using this method?**

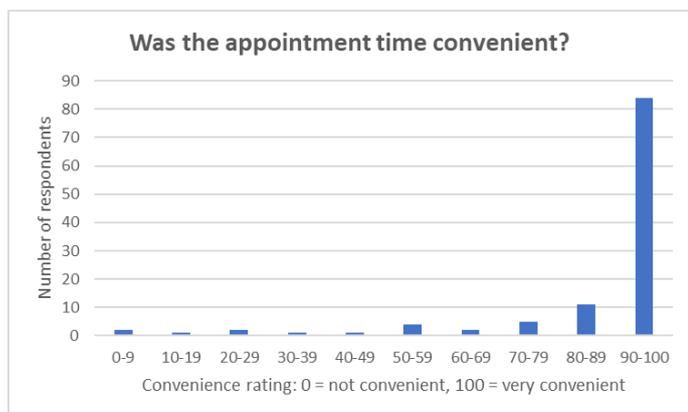
Of the 11 respondents who were offered a video or on-line consultation, 2 people received adequate training and 9 people did not require any training.

**Question 12. Had you met the clinician previously?**

Reply	Number of respondents
Yes	79
No	36
Unsure	2
<b>Total</b>	<b>117</b>

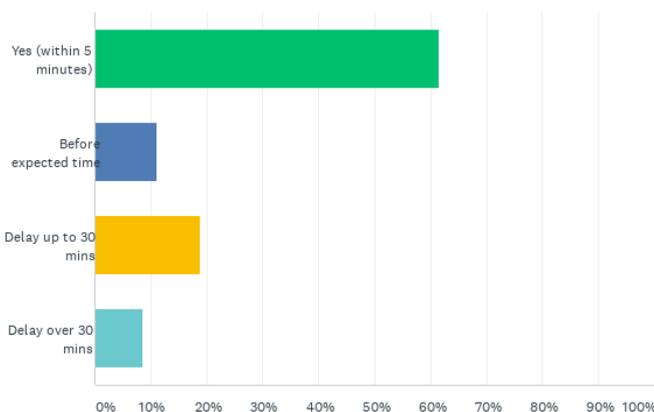
68% of respondents had met the clinician before.

**Question 13. Was the appointment time convenient?**



Of 113 respondents, 84% scored over 80 for convenience of the appointment time.

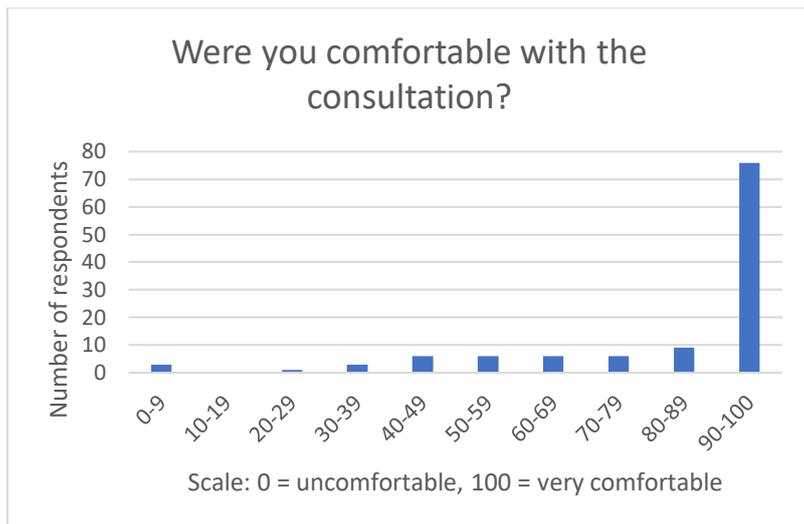
**Q14 Did the consultation happen at the expected time?**



Reply	Number of respondents
Yes (within 5 minutes)	72
Before expected time	13
Delay up to 30 minutes	22
Delay over 30 minutes	10
<b>Total</b>	<b>117</b>

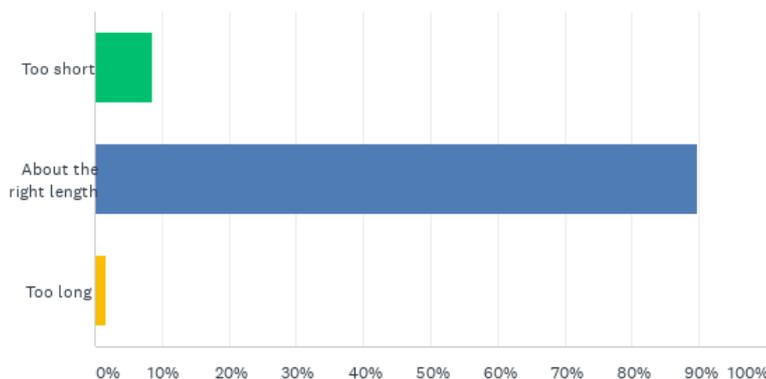
62% of respondents said the consultation happened at the expected time but 9% of respondents experienced a delay of over 30 minutes

**Question 15. Were you comfortable with the consultation?**



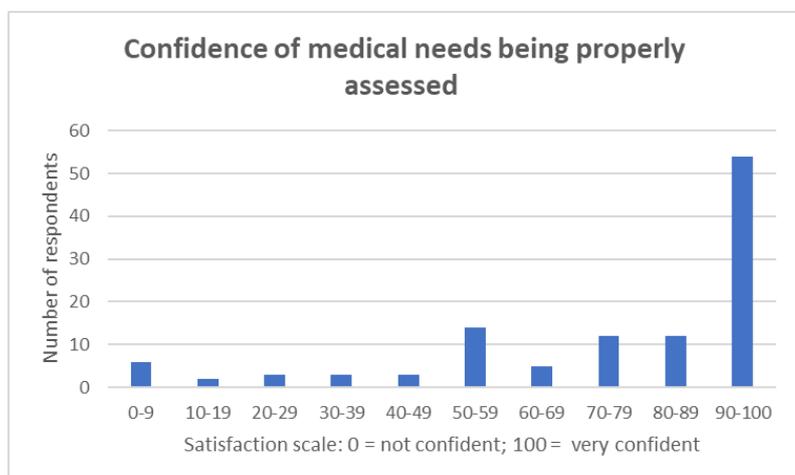
Of 116 respondents, 73% scored over 80 for comfort but 11% of respondents scored less than 50.

**Question 16. About the duration of the consultation**



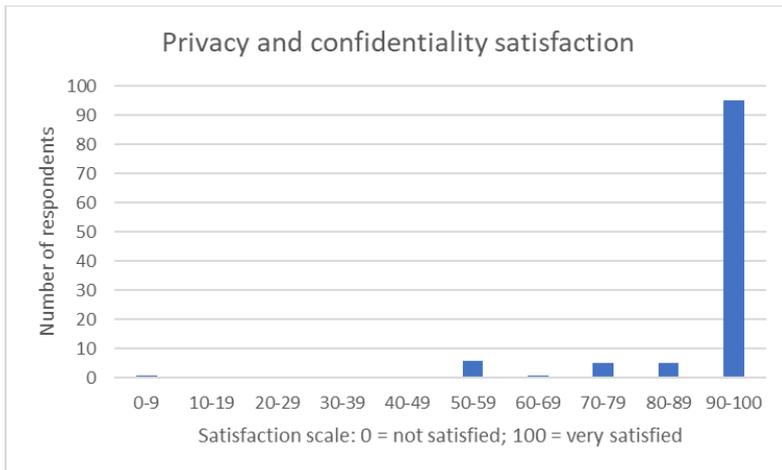
90% of respondents said that the duration of the consultation was the right length.

**Question 17. Were you confident that your medical needs were properly assessed?**



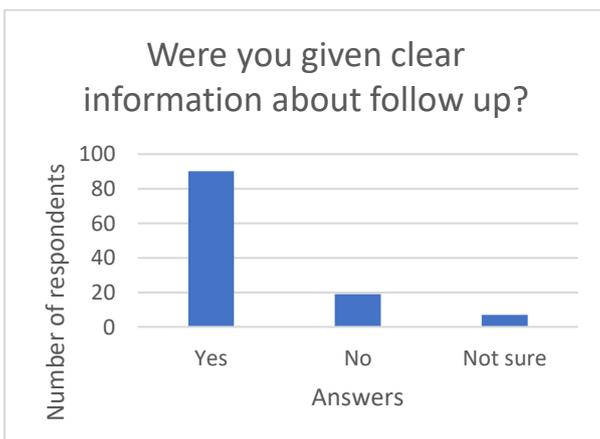
57% of respondents scored over 80 on this scale.  
 47% of respondents scored over 90 and 15% of respondents scored less than 50.

**Question 18. Were you satisfied that privacy and confidentiality were maintained?**



Of 113 respondents, 84% scored over 90 on this scale indicating high satisfaction.

**Question 19. Were you given clear information about follow up? (Future appointments and who to contact in an emergency)**



Of 116 respondents, 78% said they were given clear information about follow up.

**Question 22. If you could choose which type of consultation to have in the future, what would you choose? (Some people answered more than once)**

Category	Number of respondents
Face-to-face	44
Telephone	5
Video	15
Mixture (e.g. alternate Face-to-face / telephone)	59
<b>Total</b>	<b>123</b>

84% of respondents would prefer face-to-face consultations in the future although 48% of respondents would be happy with a mixture of face-to-face and remote consultations.

## Appendix

### Contents

- **Demographic questions** - Questions 23, 24, 25 and 26.
- **Question 20. What was positive? [free text]**
- **Question 21. What was negative? [free text]**
- **Question 27. Any other comments [free text]**

### Gender of respondents

Gender	Number of respondents
Male	33
Female	84
<b>Total</b>	<b>117</b>

### Ages of respondents

Age	Number of respondents
Under 16	0
16-29	5
30-49	27
50-64	46
65-79	39
Over 80	0
<b>Total</b>	<b>117</b>

### Ethnicity of respondents

Ethnicity	Number of respondents
White/ Caucasian	111
Celtic	2
Black	1
Asian	1
Prefer not to say	2
<b>Total</b>	<b>117</b>

### Main condition for which you see your Immunologist

Condition	Number of respondents	Condition	Number of respondents
CVID	53	Primary immune dysregulation disorder	1
CVID and related issues	1	Polysccharide antibody deficiency	1
CVID, GLILD, Recurrent infections Aftercare following MAC	1	Acquired C1 immunity deficiency	1
CVID and lung and stomach problems	1	Hypergammaglobulinaemia	1
CVID and history of autoimmune diseases	1	SAD, previous CVID	1
Hypogammaglobulinaemia	8	Primary and secondary immune deficiency	1
Agammaglobulinaemia	1	Multiple and complex immune deficiencies And recurring cancers	1
Possible CVID, hypogammaglobulinaemia	1	CGD / BMT	1
Specific antibody deficiency	3	Hypogammaglobulinaemia + MGUS + Myeloma	1
Good's disease	3	Secondary Immunodeficiency Lymphoplasmacytic Lymphoma	1
Combined immunodeficiency	2	Non Hodgkin's Lymphoma	1
IgM deficiency	1	Rare primary immunodeficiency affecting normal killer cell function	1
IgA deficiency	2	COPD	1
IgA deficiency and MBL deficiency	1	Chronic mucocutaneous candidiasis	1
MBL deficiency	1	PID and allergies	1
Specific antibody deficiency, selective IgA deficiency CD40 ligand deficiency, mannose binding deficiency	1	Low IgA, low IgM, investigations For GI issues	1
XLA	4	Antibody deficiency	1
IgG deficiency (inc subclass deficiency)	3	Complement deficiency (son)	1

**Question 20. What was positive? [free text]**

Not having to go to hospital where there is still some additional risk of picking up a COVID infection.	Things explained, questions answered Follow up instructions given and explained
That some issues were addressed and appropriate prescriptions and actions were followed up.	Didn't need to travel, being immunodeficient didn't want to risk travelling on public transport
Not having to visit the hospital.	Continuity of care
Not having to travel to the appointment	Was given follow up appointment, but did not receive copy of letter following consultation
Dr gave comforting responses & I didn't have to drive 50 miles!	We covered all my questions, and the consultant was as honest and reassuring as possible
Everything was discussed and not having to drive an hour and a half for my appointment	The entire process
Everything	Maintaining contact
Didn't have to drive for 1 hour to get to the hospital so much more convenient. Had the opportunity to ask several questions that I have written down to ask the doctor.	Going to send out some blood forms...after I pointed out that it had been nearly 2 years since I last given any bloods for analysis.
Prefer to be face- to-face	Didn't feel rushed
Being able to stay at home. Not having to travel to hospital.	No need to travel to the hospital which involves a 2hour drive or 2 different trains.
All issues were discussed fully	I could ask questions
Everything	Assurance of medical needs
They didn't try to blame everything on the coronavirus	Nothing really as I'm still waiting for blood tests
Saved travelling while shielding	Convenience
Very positive. Always is. I have a great immunology consultant and nurse	I had a follow up appointment and bloods taken which are now being looked into
Spoke with Consultant who knew me + I knew him. Didn't feel rushed. I had list of questions & had every question answered.	All queries address for both of us. Not having to travel for 2and a half hours to hospital
Did not have to travel & challenge of public transport or parking in pandemic while shielding	Very happy with my blood result and hopefully have and appointment at hospital in September
Assessment of Covid risk	She finally agreed to see me face to face
I prefer not to attend hospital at the current time.	My consultant listened to what I said and discussed with me.
It was just as useful as a face-to-face appointment, which I would not have even considered at the time.	I was concerned about the efficacy of a recent change of immunoglobulin for me and asked about changing it again. The request was met with approval and agreement and changes were made.
no travel or expense to get to the hospital	I was relieved not to have to travel to London from Sussex.
Active discussion, by both the consultant and myself, about my condition and medication and how to proceed in the event of difficulties.	My specialist is a two-and-a-half-hour flight from me, I am free to WhatsApp him anytime and he answers immediately on WhatsApp and an email within 12hrs. Communication is an absolute pleasure and so much safer than flying to see him. He is also in contact with my physician on a regular basis and only a phone call away. These two men are absolutely amazing and put patient care as a priority. I have also used Skype for a consultation
Nice to be checked up on. Blood forms sent etc.	Easier to talk to consultant. Low risk. No need to travel over an hour to hospital
All of the process.	The resident did not seem in a rush and tried to answer questions.
Not having to go into the hospital	Doctor gave me someone helpful information about co-vid vaccination.
Being able to check in with the clinical team even when meeting in hospital was deemed too dangerous. Felt much better than the alternative of simply continuing to wait until coronavirus is no longer in circulation.	The Professor I saw was able to explain everything clearly and demonstrated using the screen to explain my results. He also sent me a good follow up letter
Speaking to a consultant for a first appointment	Very good communication and consultation. I did not require a physical examination so remote was very good for me.
Not having to travel around bus trip of 3 hrs	No need to travel to appointment. No rush & plenty of time for questions.

Seemed the same as in the room	Unsure of question
Having an appointment	That the advice continued
Everything also consultant followed up with instructions to my gp. Excellent consultation	At the time it felt good to be able to ask questions/explain my problem
Mostly all was. However, there was one or two questions I forgot to ask. My fault.	Good to have contact with a doctor during the pandemic
It is convenient to have the consultation at home (no travelling).	The whole experience was very helpful and positive. I am a COVID patient. This was a consultation with the Respiratory Specialist Team
Listens to me and answers questions.	Having access to a needed fairly urgent immunology appointment.
Confidentiality	clinical plan
Not sure	I felt safe not having to go to the hospital. This was for my November 2020 appointment
This appointment was actually the most thorough I've had in a long time but was with a Nurse rather than Doctor.	Caught up with my son regarding school and future plans
Felt at ease and confident with physician, who was caring and had time for my questions and concerns. Felt like they will give me plenty of support in the future.	Everything about my condition was gone through and I felt really happy with the appointment
nice doctor who seemed to have time to speak, listen and answer questions. didn't seem harassed. but even though this was supposed to be a monitoring and review consultation, there was no attempt made to get blood tests in advance. fortunately, I had been able to get my GP to add the blood test on to a routine community test a few months earlier, and the doctor was willing to look at those and discuss them with me.	I didn't have to make a 180 mile round trip to the clinic and home. Didn't have to wait with strangers to see the consultant.
They were polite.	That I can be referred back to the service
Got blood tests results	Reassuring to speak to a consultant I know
The doctor went above expectations and did what she said she would do, calling back later that day with the information	Questions answered fully and advice given
Being able to ask questions about vaccinations and shielding for me and also my family.	Knowing someone still there
No different to face to face - still have access to clinical nurse if need urgent help in between.	Not having to endure a long journey to the hospital
On time, covered everything I needed to	Felt listened too and several Problems solved
That I had self-medicated correctly	No travelling to a tertiary centre less disruptive to work Even though had to wait could get on with work
1. It was much better than a telephone appointment. 2. Probably lasted much longer than a usual face to face consultation at hospital.	(Doctor's name) knows me very well, and this appointment was particularly detailed as he wanted to reduce my dose by a ml. He is always clear and I trust him
Not a lot! No knowledge on development of vaccine for PID. No rapport as haven't met the Doctor before.	Didn't have to travel to the hospital which is an hour away.
Always a good experience with the immunology team	It was on time. They agreed to send a pack to do my own blood tests at home which saves me a lot of money on train fares to the hospital.
Having contact with consultant during this trying time, to talk through any worries that I had	Appointment time was kept No travelling No delays Quiet environment for talking
The consultant and her responses to my questions	Didn't need to travel to the hospital. The doctor was friendly

### Question 21. What was negative? [free text]

31 people said there was nothing negative and 1 person said that everything was negative.

#### Additional comments below

I needed to go in anyway a week later for blood tests so might as well have had a face-to-face consultation in the first place.	Unsure what to expect, never had a telephone appointment before
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I was always told I would need to be seen every three months. So, in the phone conversation of course there was no physical examination.	Not having a full examination. Felt rushed & forgot to ask important questions.
I felt not really being taken serious about my anxiety and risk a I have not only PID but also secondary lung damage	Just not seeing the consultant and having to arrange for blood sample to be taken at another time. But nothing major, felt safer staying at home.
Appointment in work time so difficult to answer the phone	Nothing, this time. My last three consultations were by phone. The previous one with this department was not so good, but the registrar has now moved on.
Have been losing weight and feeling nauseous after eating, plus keep getting mouth ulcers, but informed would follow up in 4 months' time	Due to finding a gene mutation through the 100,000 genome project, I would have preferred a face-to-face appointment or video consultation
I've not had an Immunology appointment since August 2019	Lack of visual contact
The doctor was very late calling so I was worried that we had been forgotten about or issues with getting through etc. I telephoned the clinic to be told they are running behind but perhaps it would have been considerate to telephone those who were waiting so they didn't need to worry. Obviously not face to face so unable to do any blood tests etc this time. Felt rushed towards the end as I had a few questions to ask and he was clearly trying to catch up with his delayed calls.	No eye contact/non verbal communication. Also Tel consultation meant I couldn't have physical examination (re immunoglobulin treatment/stomach, lungs -(asthma, Bronchiectasis etc); & couldn't have the more complex/specific blood tests which I usually have 6 monthly (my GP did do basic blood tests on behalf of the hospital).
Better face to face chat with doctor	Not completely clear what tests have now been ordered
Doctor had checked in with the dna sequencing....but no feedback as yet as to a possible reason for my condition.	Hard to make out all that she was saying due to hearing problems
No physical examination	You can't fully explain over phone u need to be in person
She didn't have a copy of all the paperwork I had sent it previously to help with the history of my problems	Had to get blood test done at surgery and not sure if they have looked at results
I had a follow up appointment and bloods taken which are now being looked into	Inability to be examined
Missed face to face but positives outweighed negative	See previous comments regarding discharging me with a diagnosis of primary immunodeficiency and specific antibody deficiency with no personal understanding of my condition
All queries address for both of us. Not having to travel for 2and a half hours to hospital	It seemed a bit fragmented
Nothing particularly. Only the enforced phone consultation due to the pandemic. I wouldn't want to have phone consultations on a permanent basis.	Blood tests, lung function tests and abdomen ultrasound not available.
I feel face to face is best. Usual physical checks are important.	There is no way to ask follow up questions -or to contact the person who called. Messages to the department and a letter were unanswered (although that could have been done by phone or text or email.)
Difficult for consultant to access my test results organised by local GP but we got round this as I have online access to my records	It was difficult/impossible for certain things to be evaluated. For example, the doctors were not able to properly see areas of alopecia areata and hair whitening, listen to my lungs, or take blood (of course).
No bloods could be done	Did not have the usual physical examination. I missed having face to face contact.
Consultant unable to read/find the information and test results that had been done elsewhere and sent to the secretary prior to the appointment. Consultant fixated on only test results done at that hospital being accurate.	I've heard nothing since the call, no follow up, no info on what happens next. Basically, left in limbo feeling my problem wasn't urgent enough so I'm now reluctant to make another appointment in case I'm seen as wasting appointments.
Not having to travel a round bus trip of 3 hrs	Unable to get bloods & physical exam taken
Student present but that could have been the same regardless	Unsure of question
Not able to do blood tests on same day as would usually do	Difficult to build rapport with a new clinician. Unnerving that investigations such as trough levels not being measured
Waiting beyond my appointment time, however, I was able to wait, and I understand this is a mixture of the need for the service and resources. I am prepared to wait. I feel lucky to have this service available to me	Although I had 2 meetings, they were very similar and it was tricky because I didn't know the doctor

It is less personal not being able to see the consultant. It feels like you need to be very well prepared beforehand to get the best from the discussion. It is perhaps less easy to resolve any difference of opinion if not face to face. Still had to travel to the hospital for blood tests.	Didn't remember when his BMT was, didn't know when he had bloods done last, didn't remember where in the country we live, contradicted previous advice because he didn't remember. Very dismissive of any covid concerns and told us to break the rules and have friends over. Generally very dismissive of any concerns re immunity and on the one hand said that his immune system is very young and naive, then went on to say that T cell numbers were fine if you use the adult parameters.
No blood test, so no idea what bloods are doing.	Too short, felt rushed, didn't feel like I had the opportunity to talk about concerns
not having any face-to-face rapport	Phone conversations don't work
I'd rather have spoken to a doctor.	Admin is very slow, taken months for results, not had any in writing yet. Had to contact them for follow up appointment after there had been no progress for 3 months. Would be good to have online access to view results myself in absence of communication as with GP surgeries. Tests were done over 2 months results were 4 months later with no contact for 6 months. Get told to contact office via email after tests but they mostly go unanswered.
If I hadn't taken the initiative and got my GP to arrange the bloods before the consultation, I wouldn't have had a full review. At the time I wouldn't have wanted to go to the hospital for the bloods, but there's no reason why they can't be done in the community, in advance of the consultation. I know it was an emergency, but a bit of thinking and coordination would have helped a lot	No structure to the telecon, they appear not to have read my notes or consulted with other medical units with an interest. No follow-up letter.
Would have liked a face-to-face consultation to show the clinicians swollen lymph nodes	Blood test hadn't been viable but we were not told so a second test was required which added delay
Didn't feel as easy to explain my situation as it would have been face to face. At a face to face I would have had blood tests and an x-ray with results reviewed the same day	If we're to go much longer by phone I would be happier to go a video consultation.
Didn't speak to a doctor	Lack of clinical facilities
Would have preferred video so i could see the consultant's face	Would prefer video to see consultant
That she had been the person who had advised me to come off the antiviral medication, thus causing a flare up. My GP had put me on the medication and wasn't aware that I'd come off it...	1. No ability to undertake any physical examination. 2. No ability to take blood samples.
Just the journey, as always! But my husband got me there absolutely fine, again, as always. I wouldn't go so regularly if he didn't take me.	See above. Have had no support at all from Unit since Feb 2020 other than 2 telephone consults and wouldn't have had any input at all from Immunology nurses since early January 2020 until June 2021 had I not said I didn't want to attend the hospital then.
No physical examination, which has been done at previous check-ups.	Maybe a bit too short and sweet
Not face to face	The remote. Intact is not the same Need to ensure that you cover any issues you may want to raise by writing a prompt sheet beforehand
No facilities for examination or blood tests	

### Question 27. Any other comments [free text]

I have a very long standing and good relationship with the immunology team and am on home therapy so I do not find remote consultations a problem. They are responsive when contacted.	I feel I could contact the immunologist if necessary, or if I had problems. Have always felt well supported by this group.
Excellent service received so far.	I am aware that my immunology team is doing their utmost
I feel I could contact the immunologist if necessary, or if I had problems. Have always felt well supported by this group.	No immunologist in my area so see a haematologist

Poor service from department, occasional check ins from nurse specialists	Always get a great service from the team at {name of centre}.
Useful to have telephone appointment for occasions when my son does not need to be present for a physical exam or tests...eg if it is just a discussion. Means he does not need to miss school.	I live 130 miles away from the hospital, so it was helpful to have the consultation on the phone. I would prefer a video consultation than a phone one with alternate face to face consultations.
I think I would have had a better response in person however with Covid I would not have wanted to go to the hospital	I would love follow up care with the same consultant each time for consistency and understanding
Would welcome feedback Re outcome of survey. Thank you.	Treatment on UK NHS is free and very good
My consultation was with an Immunology Nurse	Thank you for all you do for PI patients
My usual consultant had left the hospital and I hadn't met the new one in person. I would have preferred to see / know who I was talking to, but this was just unfortunate timing, due to the circumstances.	There was no opportunity to ask questions relevant to COVID such as 'Will we be tested for antibodies after being vaccinated'? If we do not have antibodies, what should we do? Or find out the answers to other questions that have arisen since our last appointment. Much of this could be done with a general letter to patients with similar problems (as does PIUK).
Telephone appointment allowed me to avoid using public transport and having to attend a very busy hospital that was concentrating on the care of Co-vid patients.	I have been a CVID patient for 50 years - diagnosed at 26 and now 76 and on home therapy. I have always found the immunology team/service extremely helpful and professional
First appointment 6 months previously was simply cancelled with no alternative phone appointment offered.	I hate the remote consulting! it's so disatisfying, anxiety provoking and feels unsafe.
You didn't mention email consultation. For some appointments I'd be happy with an email prompt to get bloods, and then an email (if it came from a doctor I'd met) with results and next steps. obviously only for simple reviews and as an option, but why not>	I am finding it extremely difficult to contact the hospital at present, (they don't answer phones or emails, so it would be helpful when we have a meeting, there was a way to ensure we cover everything. My GP surgery has the same problem with them.
I'm not suggesting that telephone appointments are ideal nor an appropriate substitute for face-to-face consultants, but given the extreme circumstances, personally, I have felt well-supported by the Immunology team throughout the pandemic.	Although I answered that I would prefer video consultations, once it is perfectly safe to do so, I would prefer to return to face to face consultations.
Seen as multi-disciplinary team for chest condition.	I was shielding for 54 weeks alone. I didn't see any friends or relatives and relied at first on Government food parcels. Now have VIP access to supermarket deliveries. I haven't seen my Mother since 1st Jan 2020, but hope to fetch her to my house after next lockdown easing. She lives 100 miles from my home. It has been an awful time, and I'm now very anxious when I have to go to have my bloods taken every few weeks. Thankfully I've had both vaccinations now.
Taking bloods isn't as straightforward as it should be. As I live in a different NHS Region from my hospital (I am in North Yorkshire and my hospital in South Yorkshire) obtaining test results and getting them to my consultant is messy.	I have had two telephone consultations and one face to face since lockdown began. The telephone ones work fine because my immunologist knows me so well; face to face is very reassuring and probably necessary when you are a new patient.
Very poor communication from immunology Department. Feel doing home therapy means you are practically forgotten until they are required to go through the motions of making contact to fill in paperwork. GP support and knowledge is non-existent, at least attending hospital as Day Patient you have access to a Doctor regularly if needed.	Have a greater feeling of isolation now that I am doing my infusions myself at home rather than intravenously at the hospital than not having face to face appointments. Fully understand the need for this though
I've had a lot of health problems over the last 12 months, with COVID it's been particularly scary and challenging, my care takes place between my GP, lung specialist, haematology dept, skin specialist, and cardiologist with several local A&E visits. How long will it be before different hospitals and gp's will be properly connected? I have spent so much time going over and over my problems and the drugs I take, no one seems to communicate with each other. My last hospital stay near killed me due to exhaustion, my Immunologist was uncontactable for me, due to being an inpatient at a different hospital, but they had agreed with haematology I wouldn't be released until my platelets etc reached a certain level, which the hospital team took as red, meanwhile I'm getting poorer and poorer due to lack of proper rest and proper food, and keeping my mask on 24/7 due to being terrified even though I couldn't breathe properly. No one considered my mental health, I've come home a	

shadow of my former self, thinking may not survive because I feel so I'll. My temp dropped to 32c because of exhaustion, but no one was looking at the whole picture, just my bloods because a team Miles away who couldn't see the state I was in, deemed that was the most important thing. I feel so very angry, I've been left a shell, my husband was terrified when he came to collect me, I walked into A&E 6 days previously with a high temp, I came out 3 lbs lighter, unable to walk and shaking because no one actually looked at the big picture and allowed me to get into that state