

15th National IBD  
Nurse Forum 2021

**EVER INCREASING CIRCLES  
THE EVOLUTION  
OF THE IBD  
NURSING ROLE**

**FERRING**

PHARMACEUTICALS



# Changes to Inflammatory Bowel Disease (IBD) Advice Lines During the Pandemic

**Pearl Avery**

Patient Safety Practitioner, Dorset County Hospital Foundation Trust, Dorchester

# Disclosures

- Ferring, Tillotts, Janssen and Dr Falk and MD Education Speaker and consultancy fees



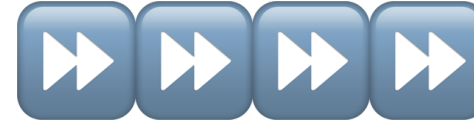


# IBD Nursing has a history with telemedicine

- In 1995 Sheila Phillips in Weymouth and district hospital started one of the first Inflammatory Bowel Disease specialist nursing services anywhere in the world.
- One of the key tools available to people with IBD in this new service was a telephone advice line with access to a then brand new IBD nurse specialist.

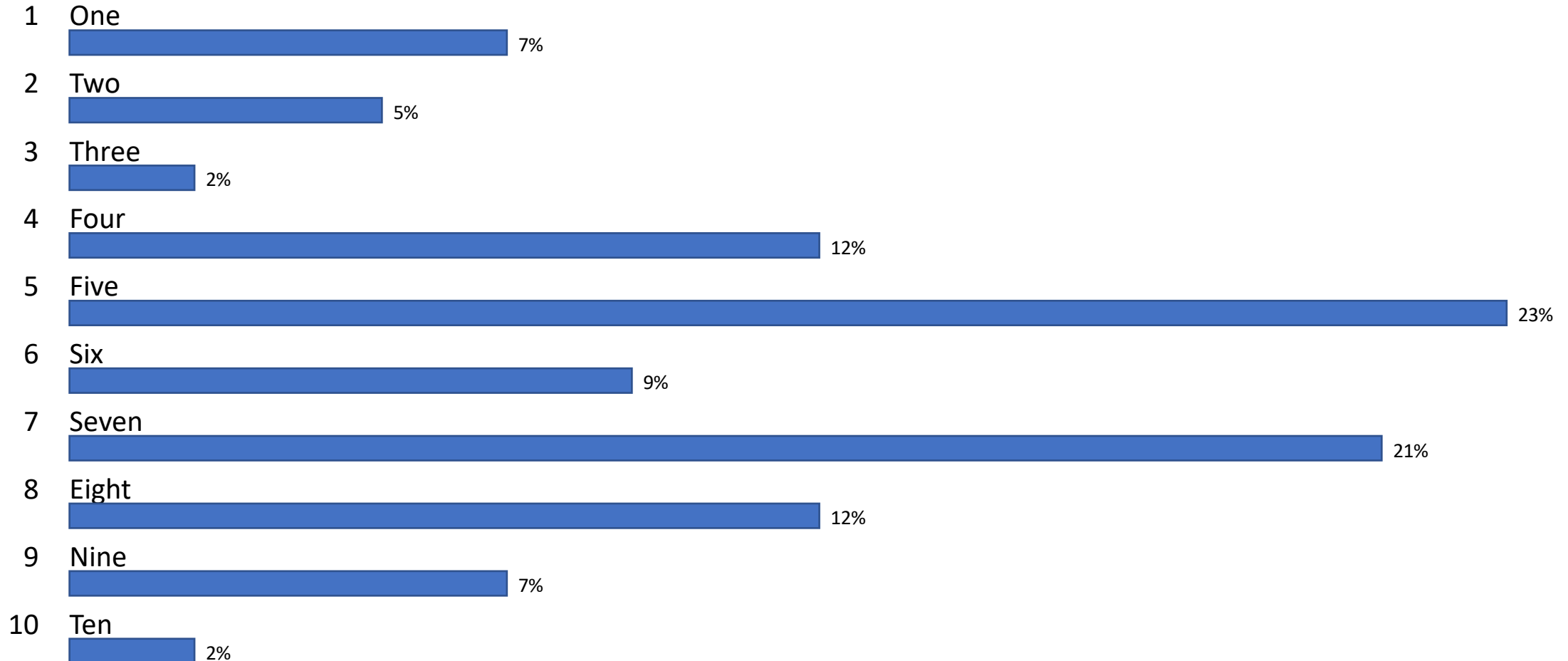
Phillips,S. (1995)





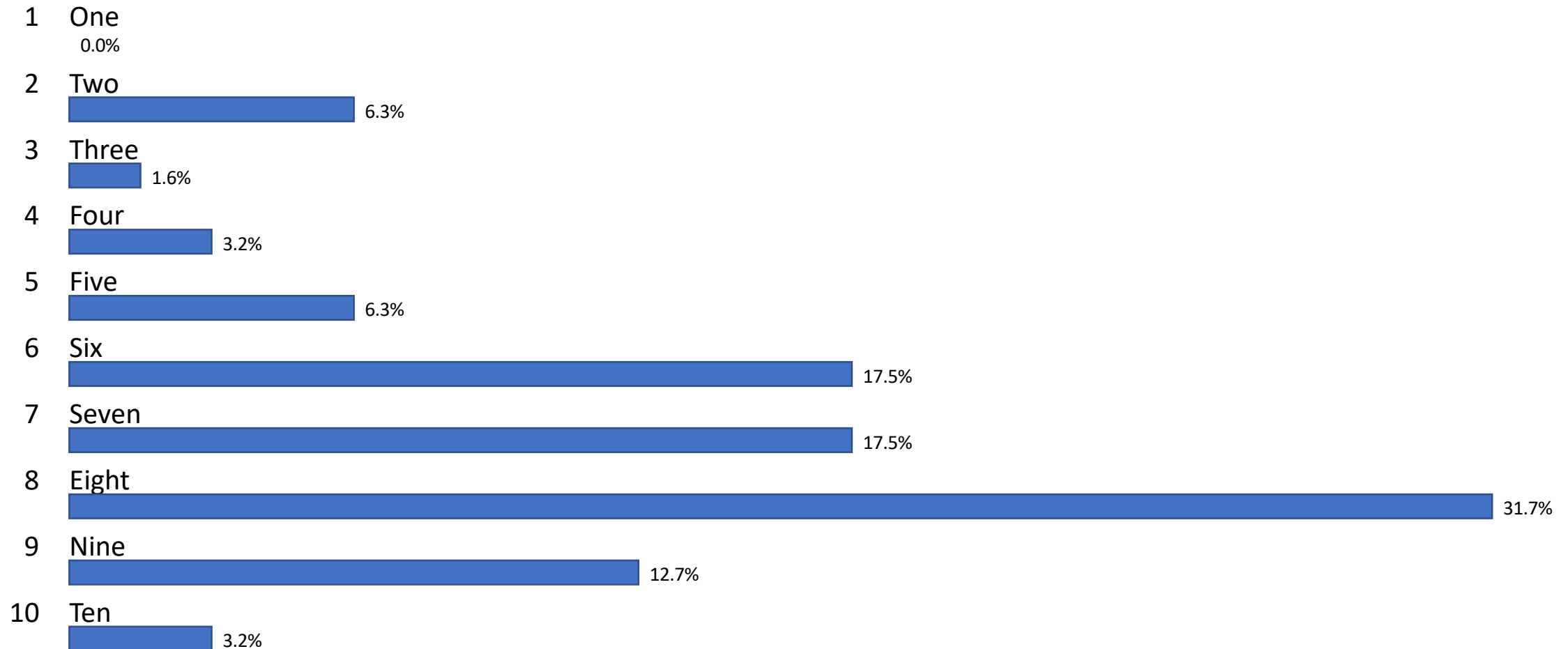
- Advice lines have grown from simple advice and guidance to the first port of call for people in flare
- in 2021 they are now way bigger than just telephone service with digital portals and email being offered to people with IBD .

On a scale of 1 to 10, how confident did you feel about the support from your leaders pre- pandemic?



On a scale of 1 to 10, how would you have rated your ability to support your patients pre-pandemic?  
1 being no confidence at all and 10 being extremely confident

Enter  
Number(s)  
and Press  
Send



Question



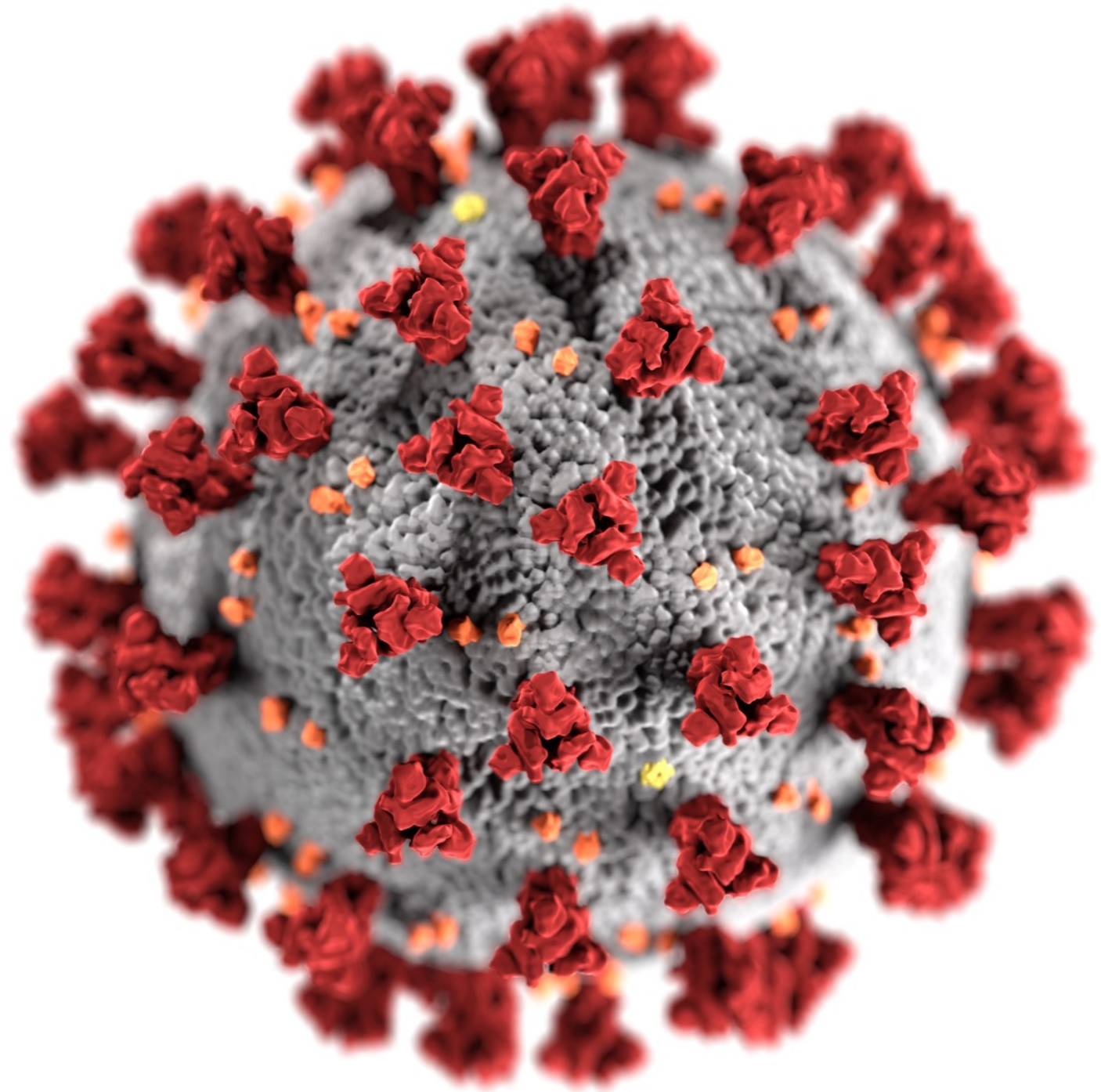
# COVID-19 Arrives 2020

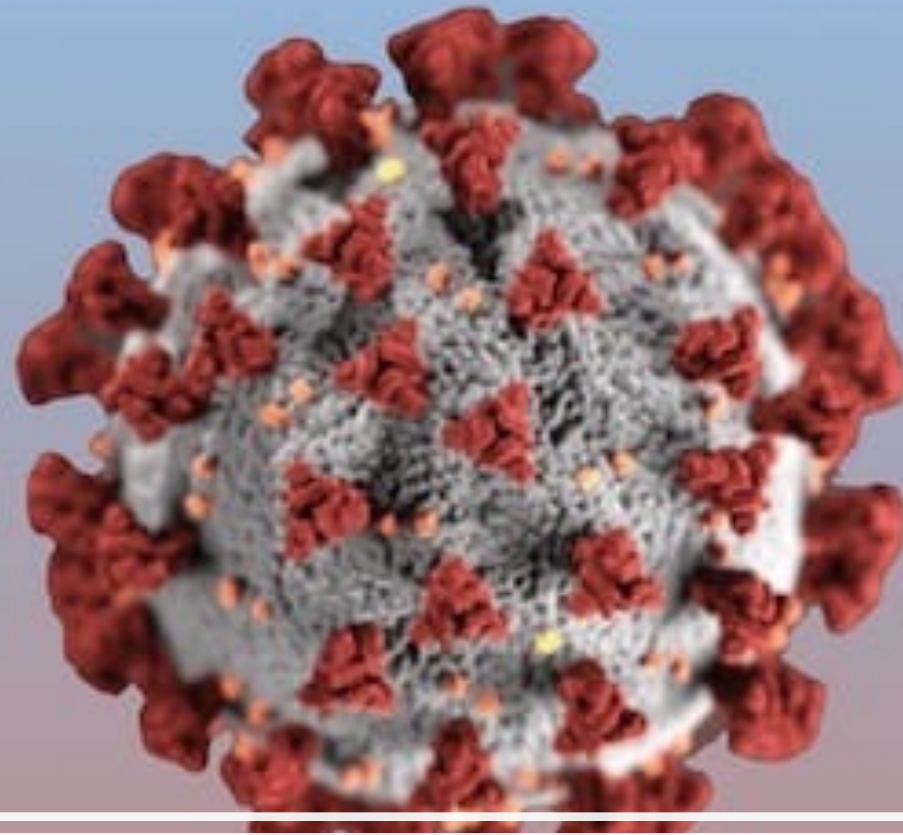
---

Along with COVID-19 came an overnight change in delivery of healthcare and in outpatient care In particular.

IBD teams felt this !

Kennedy et al (2020)

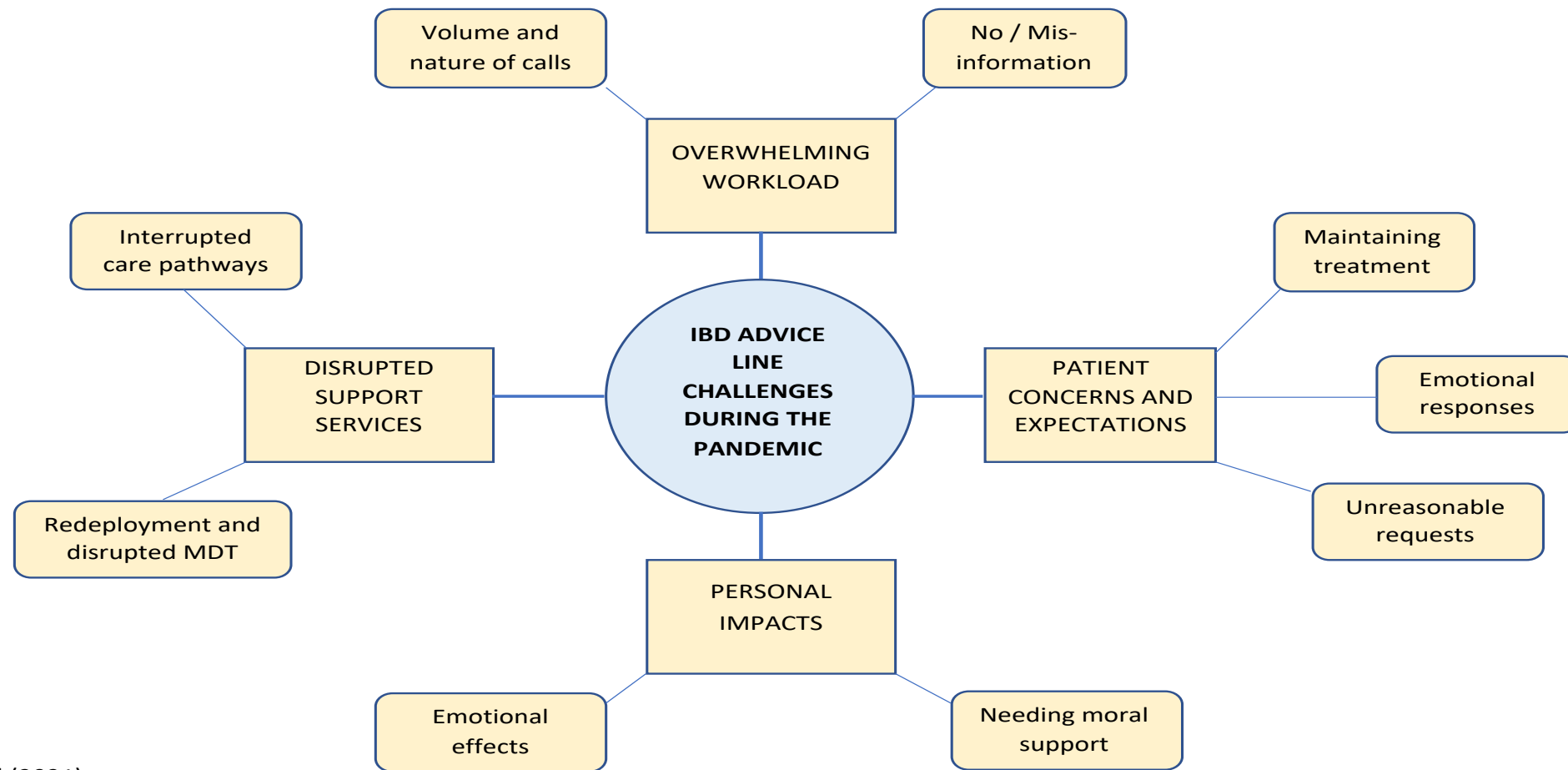




Normal follow up stops

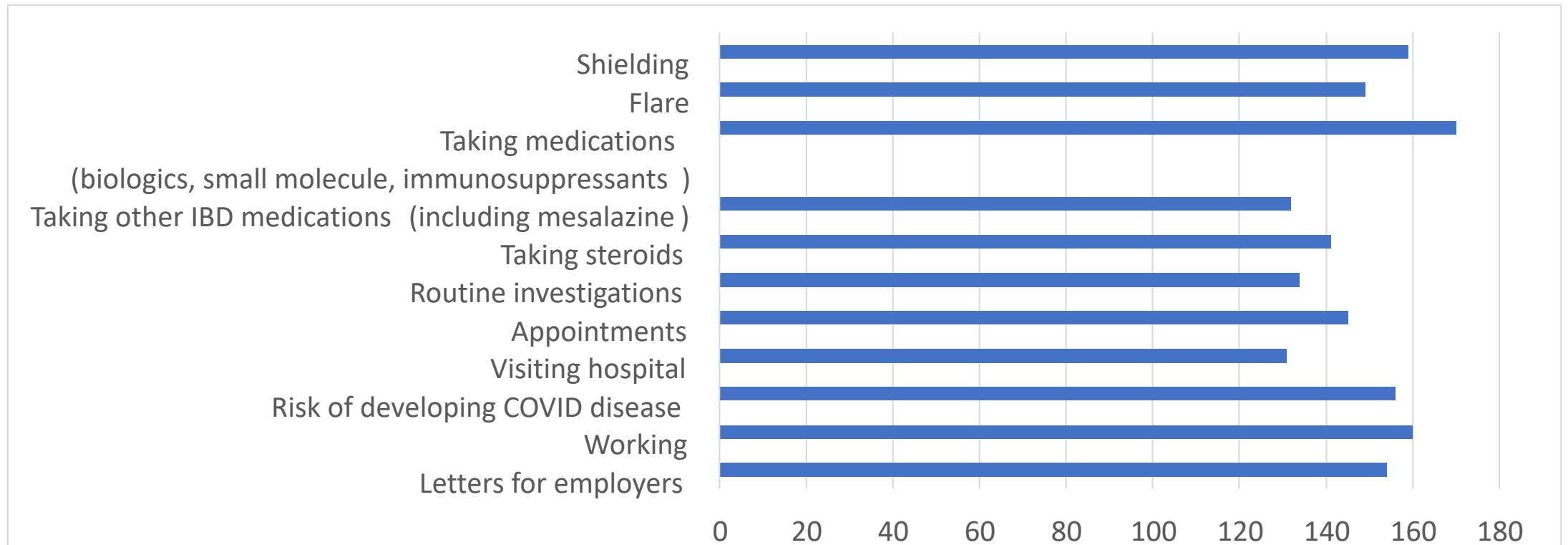
# Wholesale change overnight

Figure 2: Challenges of managing an IBD Advice Line during the pandemic





# There was also a change in the reason for contact from people with IBD



# Despite this care continued

- All IBD services that completed the survey in Avery et al 2021 managed to maintain an advice line service
- IBD Clinical Nurse Specialists had the skills to manage this
- There was a toll
- On people living with IBD
- On Health care professionals and IBD nurses were not immune.

# Personal impact on IBD nurses

---

COVID, so a lot of decision-making was put on myself. We had no multidisciplinary team (MST) for complex patients, so I went around trying to get consensus answers for management—lots of leg work.'

- The increased workload resulted in many hours over-rostered time, tiredness and increased stress levels. [There was a] sense of failure in not meeting patients' and [organisations'] needs.'

Two small bowel perforations in the last 3 months on account of GP inaction. I cannot contain my fury at this!'

The instructions... changed a lot. So, the instructions you gave in the beginning were different than those you gave a week later. That was frustrating, and patients got confused'.

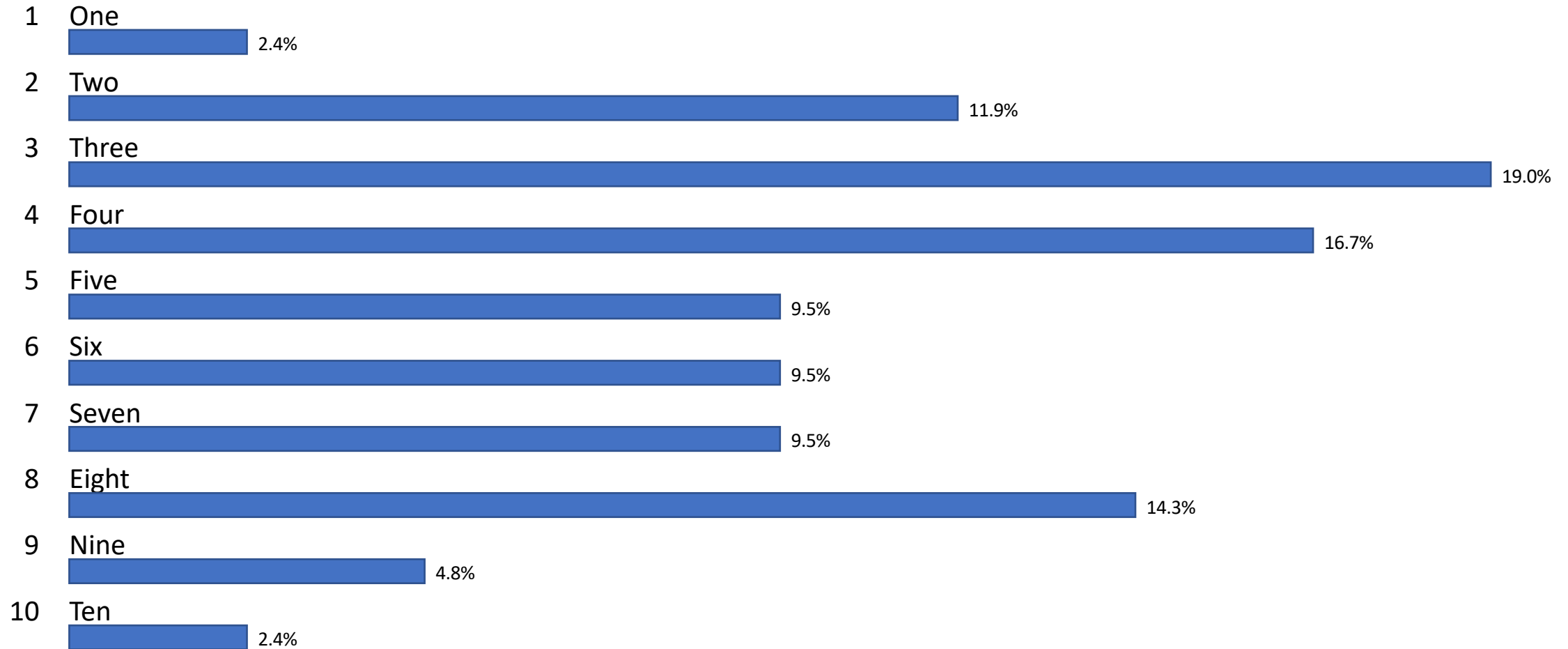
The increased workload resulted in many hours over-rostered time, tiredness and increased stress levels. [There was a] sense of failure in not meeting patients' and [organisations'] needs.'



On a scale of 1 to 10, how manageable would you say your current workload is?

1 being not manageable at all and 10 being No problem, I've got this!!

Enter  
Number(s)  
and Press  
Send

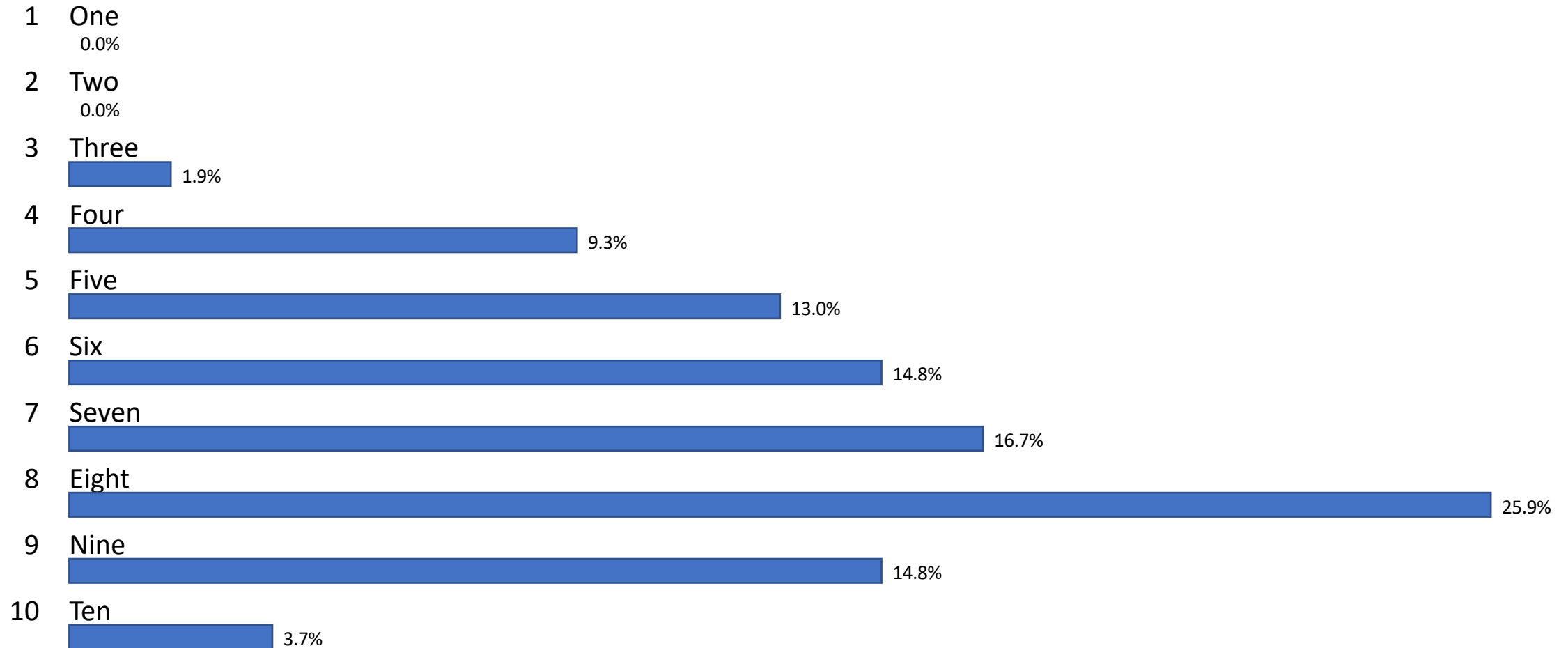


Question

On a scale of 1 to 10, how would you rate your ability to support your patients now?

1 being no confidence at all and 10 being extremely confident

Enter  
Number(s)  
and Press  
Send



Question

# The many headed beast how to handle it

---

Well you told us how to handle it





# Top Tips as Reported by IBD Nurses

Top tips (Total N=171)	Frequency N (%)	Sample Supporting Quote
Messaging and information	117 (68.4)	
Signposting to external sources of information (Government, charity or IBD specialist websites)	82 (70)	<ul style="list-style-type: none"> <li>• set the email to say, 'flare calls only, contact NHS direct about COVID, and admin staff about appointments</li> <li>• signpost patients to guidance via voicemail message and making it clear flaring patients calls will take priority</li> </ul>
Consistency	25 (21.4)	<ul style="list-style-type: none"> <li>• Speak to the team to ensure everyone is in agreement of advice ASAP so it can be relayed to patients/families</li> <li>• Make rules within your team and stick to those</li> <li>• Network to use info others are using so not reinventing wheel.'</li> </ul>
Pre-empting patient need	10 (8.6)	<ul style="list-style-type: none"> <li>• be proactive and contact high-risk pts before problems arise. If they have clear information on hours, schedules, medication, etc, the volume of calls can be reduced</li> </ul>

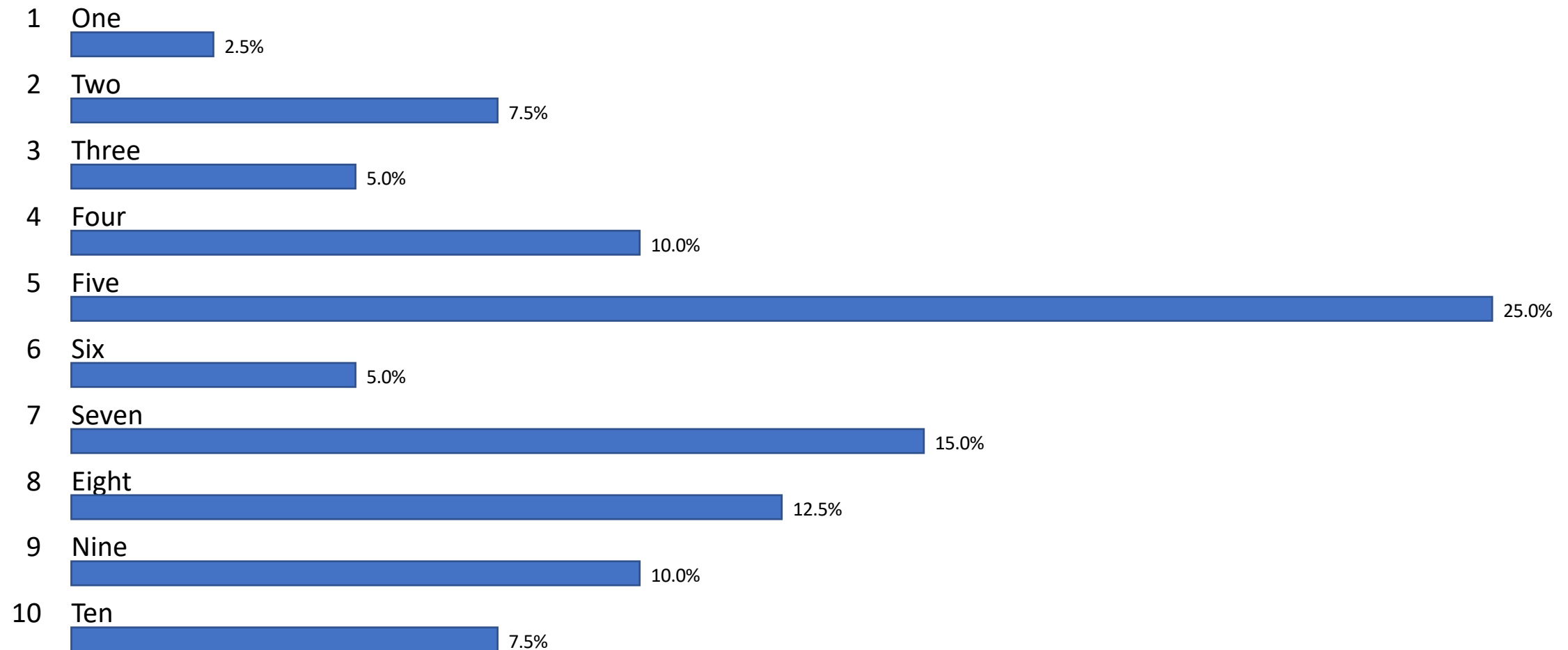
Managing the workload	78 (45.6%)	
Prioritising / triaging	40 (51.3)	<ul style="list-style-type: none"> <li>We have admin [staff] to triage calls and deal with non-clinical [questions]. Admin then add patients with clinical questions to a central 'IBD advice line' clinic template, and we call those patients back after 2pm. This then enables other work to be done around the advice line</li> <li>ask patients to leave information as to why they are calling rather than just their contact details - to help with prioritising who needs contact first</li> </ul>
Maintain the MDT	20 (25.6)	<ul style="list-style-type: none"> <li>to escalate [flare calls] early to a doctor nominated to respond to queries, to 'get help with biologic prescribing' and 'difficult situations /conversations,' and ensure 'better support for nurses for complex advice.'</li> </ul>
Adjust the IBD services	18 (23.1)	<ul style="list-style-type: none"> <li>increased workload was significantly managed better with having REDUCED hours for helpline calls messages - leaving more working hours to manage them</li> <li>We set up a 'Hot Clinic' for face to face with an IBD Consultant twice a week for the very unwell who we couldn't manage remotely</li> </ul>

Nurses' wellbeing	35 (20.5)	
Taking breaks and taking care of the self	14 (40)	<ul style="list-style-type: none"> <li>take small breaks regularly to stretch, get some fresh air, and clear the mind after so many calls with anxious, upset patients ... need to be refreshed as each call is different and often challenging</li> <li>Empathise with your patients but remember not to take that emotional/anxiety baggage with you. Doing this doesn't make you a bad nurse who doesn't care, it stops you from burning out and [helps you] be able to function to look after the many'</li> </ul>
Sharing the load	6 (17.1)	<ul style="list-style-type: none"> <li>To avoid staff getting overloaded by responding to calls all the time 'share the advice line between staff'</li> </ul>
Acknowledge all efforts		<ul style="list-style-type: none"> <li>recognize that not only those working directly with COVID patients have had difficult and busy spring/summer but also those making the rest of the healthcare system work</li> </ul>
Seeking moral support		<ul style="list-style-type: none"> <li>In the UK: 'lean on the IBD Nurse Facebook page'</li> <li>'Working remotely has its own challenges but ... I had members of my family who would take care of me.'</li> </ul>

Managing expectations of patients and of oneself	32 (18.7)	
Managing patient expectations	17 (53)	<ul style="list-style-type: none"> <li>Set expectations - state what you can and can't do</li> <li>Inform [patients] of any redeployment commitment, and keep them aware of the reduced service</li> </ul>
Setting realistic staff expectations	15 (47)	<ul style="list-style-type: none"> <li>accept that it may not be possible to achieve everything as you would have done previously</li> <li>[nurses] should not feel guilty for letting patients wait for non-urgent queries.'</li> <li>important to acknowledge what the huge increase [in calls] from anxious patients, can do to nurses.</li> </ul>
Meeting patient and parent need	14 (8.2%)	<ul style="list-style-type: none"> <li>Even if you don't have the staff for it, you need to open up for the patients; they need much more information and support</li> <li>talk calmly and listen carefully ... to reassure patients as much as possible</li> </ul>
Staffing levels	11 (6.5)	<ul style="list-style-type: none"> <li>Don't agree to full redeployment of your team</li> <li>If redeployment is necessary, back-fill with staff who can't be patient facing and increase administrative support to triage calls appropriately</li> </ul>

On a scale of 1 to 10, how confident do you feel now about the support you are receiving from your leaders?  
1 being no confidence at all and 10 being extremely confident

Enter  
Number(s)  
and Press  
Send



Question



Opening this  
up

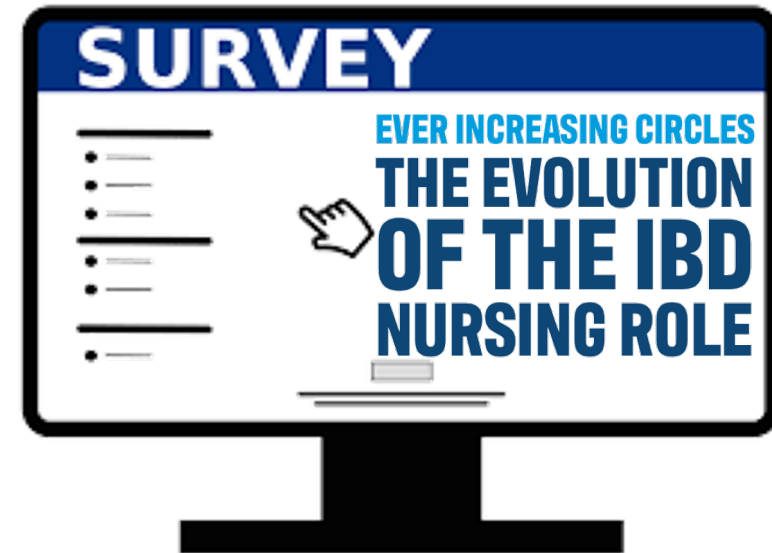
Asking you how you are  
now in your own words



# References

- 1. Phillips S. Gut reaction. Nursing times. 1995;91(1):44-45.
- 2. Kennedy NA, Hansen R, Younge L, et al. Organisational changes and challenges for inflammatory bowel disease services in the UK during the COVID-19 pandemic. Frontline Gastroenterology. 2020;flgastro-2020-101520.
- 3. Avery P. Using e-health tools and PROMs to support self-management in patients with inflammatory bowel disease. British Journal of Nursing. 2021;30(7):394-402.
- 4. Avery P. The cost of treating inflammatory bowel disease: step-up vs step-down, therapeutic drug monitoring and personalised medicine. Gastrointestinal Nursing. 2021;19(4):18-24.
- 5. Naghibi M, Bettey M, Cummings JRF. P564 An innovative information technology tool to promote patient self-care - A web-based 'IBD patient portal'. Great Britain: ELSEVIER SCIENCE B.V; AMSTERDAM; 2014.
- 6. Aziz A, Reynolds R, Ansari A. A population-based model of care for people with inflammatory bowel disease – patient-reported outcomes. Future Healthcare J. 2019;6(1):30-35.
- 7. Avery P. Developments and challenges of e-health strategies for people with inflammatory bowel disease. British Journal of Healthcare Management. 2020;26(3):73-76.
- 8. Avery P, Younge L, Dibley L, Segal J. Inflammatory bowel disease advice lines during the COVID-19 pandemic: a retrospective service evaluation. Gastrointestinal Nursing. 2021;19(3):38-49.
- 9. Walsh A, Travis S. What's app? Electronic health technology in inflammatory bowel disease. Intest Res. 2018;16(3):366-373.
- 10. Crohn's & Colitis UK. How coronavirus has affected people with Crohn's and Colitis - you told us | Crohn's & Colitis UK. 2020; <https://www.crohnsandcolitis.org.uk/news/how-coronavirus-has-affected-people-with-crohns-and-colitis-you-told-us>. Accessed 12th September 2020.

# Ferring IBD Specialist Nurse Forum Meeting 2021 Survey



The slides have been reviewed for off label information by Ferring Pharmaceuticals

September 2021  
UK-GAS-2100131


---

# Disclosures

## Lisa Younge:

- Advisory boards for Janssen, Abbvie, Falk, Galapagos, Takeda & Tillots
- Talks for Janssen, Abbvie, Falk, Ferring, Galapagos, Takeda & Tillots

## Glyn Scott:

- Received speaker fees for conferences and meetings from AbbVie, Ferring Pharmaceuticals and Tillotts
  - Attended Advisory Board meetings for AbbVie, Ferring Pharmaceuticals
- 



# What is the one positive change made to your IBD Service made during COVID-19 that you are going to keep?

15 respondents (28%) answered **patients** for this question.



A word cloud of responses to the question 'What is the one positive change made to your IBD Service made during COVID-19 that you are going to keep?'. The word 'patients' is the largest and most central. Other prominent words include 'telephone clinics', 'communication with our patient', 'flare clinic', 'patients able clinic appointment', 'accessible for well patients', 'Telephone reviews IBD patients', 'Virtual clinics', 'hot clinic', 'biologic clinic', 'face to face', 'patient weather', 'reviews - patients', 'patient lists', 'sickest patients', 'immunosuppression patients', 'telephone consultations', 'clinics for counselling', and 'hot clinic'.

communication with our patient  
accessible for well patients Telephone reviews IBD patients  
Virtual clinics  
hot clinic biologic clinic  
patients  
telephone clinics  
flare clinic patients able clinic appointment  
face to face patient weather  
reviews - patients  
patient lists  
sickest patients  
immunosuppression patients  
telephone consultations  
clinics for counselling



***IBDHOT clinics for  
flaring IBD  
patients***

*I was deployed to the ward and met new colleagues and established positive working relationships with them.*

***Getting a Band 6 Nurse nearer the end of the pandemic to help with the workload***

**Telephone reviews - patients much prefer them, no travelling, no parking issues, no time off work etc. We will still see F2F when required. More patients assessed as a consequence.**

*We started having a "IBD Huddle" in the morning with the on call consultant the same time each day to discuss patients which we continue to do now and also we have an urgent flare clinic where we can see up to 2 patients daily who are needing urgent review but not in surgical assessment for review where we have implemented new biologic starts and switches in treatment*

*Those patients able to swap from IV to subcutaneous biologics have allowed them to have more freedom and take control of their own treatment.*

*Some patients actually prefer telephone appoints as opposed to f2f. If they are 'well' it makes sense to keep the footfall in hospital to a minimum.*

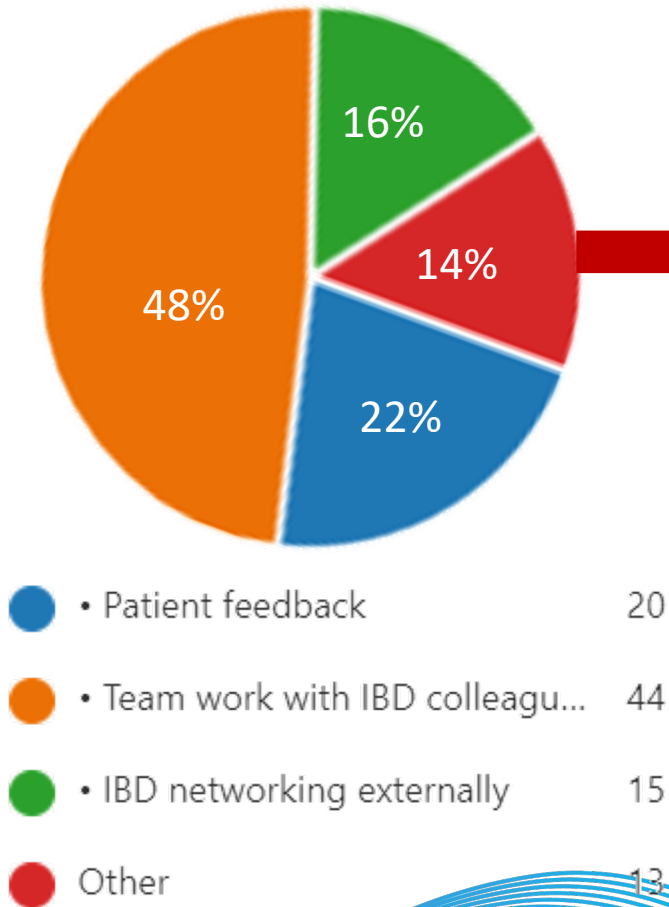
*Better collaboration between Nurses and Consultants, working together to deliver care to the patients in very difficult circumstances*

*Keeping constant communication with our patient which make them comfortable and build a good trust*

*Having a specified infusion day to keep our immunosuppressed pts as separate as possible from other patients*



# What helped you get through this last 18 months of challenges caused by COVID-19?



## OTHERS

- CCUK
- Having a work life balance with outside interests to keep me going
- public support of NHS staff e.g. Thursday clapping
- family support
- My Nursing colleagues and the secretaries have been truly amazing
- BSG guidance, Crohn's and Colitis UK support
- good support from line manager
- None of the above
- support from other community team members as work alone

Would you like to give an example of an experience or event that made a positive impact during one of your working days during COVID-19?

20 respondents (38%) answered **patients** for this question.

patients were frightened

anxiety for patients

infusion patient

patients with questions help line

touch with the patient

patient service

IBD team

clinic

**patients**

IBD nurse

conversation with the patient

patients are so grateful

working

new patients

COVID contact with our patient

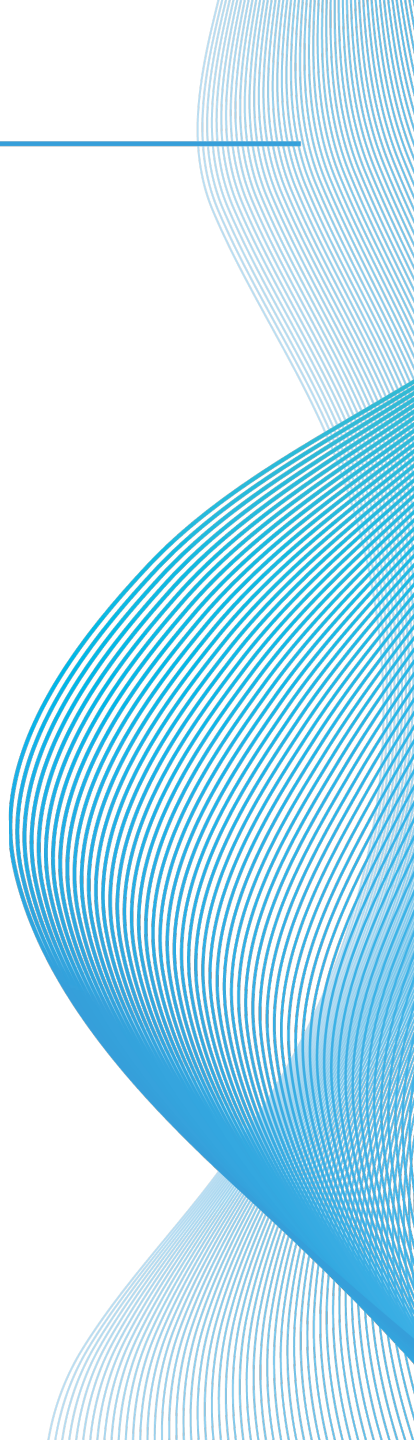
able to see patients

rapport with the patients

patients's expectations

---

**Would you like to give an example of an experience or event that made a positive impact during one of your working days during COVID-19?**





**Being able to provide clinic review via 'near me' - being able to see patients again.**

*Patient contacted IBD help line as was very unwell. Patient had a FCP test and the results just came through the app. showing active disease. A quick conversation with the patient, assessing the symptoms told me that he should come in the hospital. Patient was seen in AEC, admitted and new treatment was started. All the process was quick and smooth. Virtual clinics and telephone assessment gives more time to focus on the help line and other IBD tasks, then the face to face appointments.*

*How grateful patients have been to receive care, and the thankyou gifts from the trust given by the companies.*

*The CCUK pod casts on COVID and immunosuppressive treatments I felt grateful some one was there looking in to it to inform the rest of us*

*Having someone at the end of the line or over email instantly provide support and reassurance*

*We were able to manage patients well by offering them to have their IV Vedolizumab at home or switch to subcut, as many patients were frightened to come into the hospital for fear of contracting COVID.*

*Able to use the decision tree to help patients with questions so we are all giving same advice*

**Being able to also continue my rapid access clinic during the pandemic so suspected new patients could be seen and reviewed- although endoscopy was not available I was still able to assess the patients**

*allaying patients worries during the COVID-19 pandemic and being there for our patients no matter what even if this was just over the phone*

*Patient ringing us on the help line enquiring how we were and if we were ok So Thoughtful.*

*Re-location of the infusion service to a green site meant that there were less distractions whilst infusing. This meant stronger bonds were made with those patients as more time was spent with them. Colleagues from endoscopy also supported this service and therefore gained a better understanding of our roles and the infusion service and built a rapport with the patients.*

**Support from nursing team and hosp. Management team. Working hand in hand with juniors and senior nurses and doctors.**

**Taking time out of the office as a team to talk**



15th National IBD  
Nurse Forum 2021

**EVER INCREASING CIRCLES  
THE EVOLUTION  
OF THE IBD  
NURSING ROLE**

**FERRING**

PHARMACEUTICALS

