



British Society of Paediatric Gastroenterology Hepatology and Nutrition

We want your opinion - Survey from Sue Protheroe BSPGHAN members survey:

NHS response to Covid - second phase

SURVEY FEEDBACK

Thank you very much for your response to the survey- 56 responses in a short time with the majority completed within the first few hours. It's a helpful snapshot to see what's on your mind when planning recovery, restoration of paused services and supporting families as the lock down eases.

Respondents:- 65% consultants, 13% trainees, 10% dieticians, rest – AHP's (nursing, psychology, pharmacy).

Themes

1. Well-being of ourselves and our patients

- 90% worried about their own health and their patients' health.
- More respondents state that they will worry a lot after the lockdown is eased than they did prior.

2. Opportunities

On the positive side, some service delivery and operational aspects have worked well, and members think that they should continue.

- Patients have generally been proactive and contacting the team for advice if unwell
- Virtual clinics have improved access for urgent cases
- Virtual clinics worked well when there is an established relationship with the family,
- Some families prefer remote monitoring and "talking therapy" from home
- Reduced waiting time to enter the service for sick patients as less activity
- Patients have benefitted from more use of EEN than steroids for Crohn's disease
- Decrease in "unnecessary investigations"
- IT advancements allow working remotely
- Tests at home should be developed eg home FCP kit

3. Concerns about service delivery during recovery phase

- Recovery will be a long haul
- Covid mortality may increase as screening not done/ unreliable/lack of guidance about screening
- Increased waiting times - difficult to prioritize as so many waiting

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- Delayed interventions eg diagnosis of IBD, Coeliac Disease, Insertion of feeding device,
- As a specialty we will not make use of the lessons learnt over the past few weeks - especially with regards to new ways of working
- Remote counselling of patients very difficult when they are new to the service and you are having to explain complex concepts by telephone to people who don't know you. Even harder with interpreters!

4. Concern about staff

- Risks to health from Covid
- Not screening patients/parents for Covid before we see
- Lack of sufficient PPE for some of NHS staff
- Having patients wear facemask also means health care professionals get protected. When we get consent from patients/ parents for their elective procedure, we are in very close proximity with them. We do not know whether they are carrying coronavirus and it is better if they wear facemask to prevent spilling coronavirus onto us. Thank you.
- The risks to staff remain significant- there is likely to be a drive to reopen services without adequate protection in place for all staff concerned-
- The increased risk to BME patients of exposure within the healthcare setting
- Anxiety is rising again now lockdown is eased
- Mental health problems
- Training opportunities. I would strongly support gastro trainees to be allowed to make their own decisions along with educational supervisors/trust about undertaking Endoscopy when it resumes

5. Concern about patients

- More at risk from delayed treatment of condition than getting ill from Covid
- Potentially huge impact of delay in care
- Unknown or hidden morbidity - delayed presentation, treatment suboptimal, outcomes are time dependent eg – eg identifying biliary atresia, delayed/ incorrect diagnosis and treatment if IBD, CD, EoE , delayed presentation with sepsis, delay weaning from HPN, reduced surveillance of liver disease & IBD, missed drug monitoring,
- Delayed diagnosis also increases the likelihood of surgery or more expensive treatments and if left untreated can cause more serious complications
- Families are nervous about coming to see us.
- Patients will still stay at home and be sicker when they present
- Families may not wish children to attend school /hospital after lockdown eased
- Missing their chance of a good education
- Social exclusion
- Safeguarding opportunities lost
- Lack of research

6. Concern about Covid infection

- It will be a long fight against Covid
- Covid infections will increase as schools/ clinics open
- We won't make use of lessons learnt
- New Inflammatory condition

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- Covid-19, generally, does not directly affect children. An average of 1600 people die, every day of the year in the UK. Hard as it seems, we need to, sometimes, look at the outbreak in these terms

7. Protecting people

- Our country has not taken the correct first steps - i.e. early lockdown, stopping flights from coming in, quarantining new arrivals to the UK, universal facemasks, efficient contact tracing etc. The government has done too little too late. Now the government is itching to ease the lockdown. I can see why my hospital is saying that the fight against coronavirus is a 'marathon' and not a 'sprint'. When public health measures for pandemic are not carried out properly, the fight against the pandemic is going to be a long protracted one
- Government have better monitoring, so lockdown can be tightened if cases increase,
- Contract tracing, universal use of face masks, reduce flights into UK etc
- The risks to staff remain significant- there is likely to be a drive to reopen services without adequate protection in place for all staff concerned-
- Screening not done /unreliable/lack of guidance about screening
- Access to tests and medicines safelyvia a cold route in hospital
- My greatest concern from COVID-19 is for staff or parents who are elderly or have underlying health issues. We have had as many symptomatic cases of COVID-19 in children as we have those who have been asymptomatic and have been picked up through inpatient screening
- The risk of nosocomial COVID infections when attending for healthcare appointments- especially in light of poorly applied and inconsistent distancing / shielding and PPE guidance and practice within / between institutions

8. PPE

- PPE availability at work
- Please can you knock some sense into the government and get the top guys up there to introduce universal face coverings / face mask before they ease the lockdown

9. Recovery plans

- Supporting families when they unshielded
- Plans to resume endoscopy, banding programmes
- Restart specialized radiology
- We shouldn't reopen without adequate PPE
- Offering training opportunities – trainees should decide what they do
- Starting up research

10. Shielding - general comments

- Rename - stringent or strict social distancing
- Letters from the government or NHS have been unhelpful
- Acknowledge the limited data in children - rare case reports of Covid in children has led to people unnecessarily delaying medical appointments
- Confusion about their risk status and whether they should be "shielding".
- Some children will still be kept off school unnecessarily when schools open

- Lack of guidance from the government and subspecialty groups regarding additional precautions to be taken for this high-risk patient group

Current shielding criteria are too tight – majority view

- Shield those with chronic heart, lung or diabetes
- Uncertain about patients on high dose steroids and perhaps they should be considered to remain shielded in the first instance
- BSPGHAN should revise its guidance for patients. Data shows treatment with immunomodulator (including anti-TNF and steroids) in IBD patients do not put them at any higher risk of COVID related complications compared to general population. Shielding is not needed for these children; strict social distancing will be needed.
- As many patients as possible. Patients on immune mediated drugs should not be considered as at risk or immunosuppressed c/w those truly immunosuppressed on chemotherapy. There is a reasonable amount of literature which suggests these patients are not at higher risk in children on all immune mediated medications. The jury remains uncertain about patients on high dose steroids and perhaps they should be considered to remain shielded in the first instance
- All except the most immunocompromised e.g. newly post-transplant, just starting high dose steroids or biologics
- There is a compelling scientific argument to unshield all of our patients. There is no indication that any of the medications we use or conditions we treat increase the risk of infection/morbidity/mortality in the paediatric population (with the one possible exception of high dose corticosteroids in IBD). The risks from ongoing social exclusion (vs socially distanced children, as they start to return to school) outweighs benefits.
- Do all patients on PN need to be shielded especially if PN started for neonatal complications and child now much older?

Stay the same - hesitancy to relax due to the limited data – minority view

- I do not think we are ready as a nation to unshield our patients who are being shielded at the moment. Other countries' coronavirus numbers/death/infection rate are nil or way lower than ours before they ease their lockdown.
- We follow the BSG and CCUK guidelines
- No comment - team decision
- Not sure yet
- I'm not sure. We need to work out, collectively, are immunosuppressed children at risk or not? Then, we should all agree how best to advise

It is clear we need a culture of learning from what has happened.

Some bullet points to consider as we move forward.

Theme	BSPGHAN RESPONSE	TO CONSIDER in recovery plans
<u>Well-being of our patients</u>	BSPGHAN statements. Rapid sharing of BSG and other consensus & research articles. NICE guidance for children and for gastrointestinal disorders. Helping prepare and share advice from charitable partners	Plans to focus on needs of patients rather than waiting lists. Build in time to consider the impact on each patient.
<u>Well-being of ourselves</u>	BSPGHAN survey. Guidance on PPE in endoscopy recovery plan. We highlighted that organisations must regard people from BAME backgrounds; risk assess staff at potentially greater risk from Covid, such as older, or pregnant staff, or those with health problems and make appropriate arrangements accordingly.	Looking after ourselves. Be mindful of everyone's concerns so staff feel safe and be compassionate towards each other. Bspghan can respond to requests support staff to feel safe & support each other and write guidance. SIGNPOST TO wellbeing Apps for NHS staff on mindfulness, meditation, sleep improvement.
Harness opportunities	BSPGHAN survey identified areas of good practice Remote working Wherever suitable using telephone and video technology.	Obtain feedback from families when in virtual clinic. Improve access /waiting times / experience for some. EEN v. steroids for Crohn's? Review practice - are all investigations warranted?
<u>Service delivery and plans for recovery phase</u>	Actively plan recovery of activity. Increasing "ordinary" healthcare is a key priority to avoid increase in severity of illness for patients who have been unable to access care or who are frightened to do so. Triaging patients with urgent care needs, supporting those with uncontrolled or flaring disease.	Decide where we need to be at end of phase 2. We have asked for the BSPGHAN/ RCPCH QIULAITY STANDARDS audit to be adapted to include furthest questions on service restoration when it is unpaused in September.

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Unshielding	<p>Consistent , clear national guidance for children, young people and families.</p> <p>To be publicized with RCPCH to guide PHE about risk status. To be decided case by case by lead clinician in partnership with family.</p> <p>There needs to be better coordination between government/NHS communications and patient charities and specialist clinicians to avoid the anxiety caused in people who received the confusing information.</p>	<p><u>Which patients should we decide to unshielded?</u></p> <p>a. certain patients on immunosuppression- high dose steroids and recent transplant (how long?) current guidance.</p> <p>b. HPN – here the views mixed</p> <ul style="list-style-type: none"> • Guidelines should be consistent, and families should agree • Covers schooling, siblings and parental work • Personal contact from specialist to give specific advice and help families to feel safe .
Sharing information	<p>Rapid information sharing</p> <p>New Covid Information hub on BSPGHAN website/bulletins.</p>	<p>Rapid sharing of guidance. Avoid patients receiving incorrect or conflicting advice.</p>
Engagement with charitable partners, stakeholders and families	<p>Shared work and support for rapid guidance – CCUK, CICRA, CLDF, Coeliac UK , BSG, ESPGHAN, Liver</p>	<p>Working in partnership with stakeholders to continue.</p> <p>Letters of thanks to charities.</p>

Sue Protheroe
President BSPGHAN
9th May 2020

