

OPINION

Exit strategies from the COVID-19 lockdown for children and young people receiving home parenteral nutrition (HPN): lessons from the BSPGHAN Intestinal Failure Working Group experience

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BACKGROUND

In response to the novel COVID-19 pandemic, rapid and unprecedented public infection control measures were undertaken by all four nations of the UK culminating in 'lockdown' with the majority of the population being asked to stay at home other than for a few designated essential activities. In addition, identified vulnerable members of the population were required to participate in 'enhanced social distancing' or 'shielding', remaining strictly housebound, dependent on outside assistance for essential items and isolating from members within their household. This was proposed for 12 weeks in the first instance.¹⁻⁴

Necessity for shielding was considered on the basis of relative burden of chronic disease and known risk factors for severe COVID-19 infection; however, young age conferred a protective association with infection.⁵ Although central government described the principles of enhanced distancing measures, the framework for the degree of measures employed and to which distinct patient groups was largely devolved to national expert bodies. As such, multiple national expert bodies considered adults with long-term intestinal failure (IF) with an ongoing need for home parenteral nutrition (HPN), as significantly vulnerable enough to warrant 'shielding'.^{6,7}

The Royal College of Paediatrics and Child Health (RCPCH), in consultation

with multiple paediatric specialty groups, published advice on the principles of 'shielding' for children. The advice outlined the unique challenges faced by families and carers delivering socially distanced care to dependent children who have specific conditions, and also the impact of 'shielding' on children.⁸ The RCPCH and the British Society for Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) endorsed 'shielding' for a number of key chronic gastrointestinal conditions, with a stratified approach in some conditions such as inflammatory bowel disease. The consensus of the BSPGHAN Intestinal Failure Working Group (BIFWG) was that children and young people receiving HPN should participate in shielding.⁸ The decision was based on the desire to keep key carers well and children safe and out of hospital (given that this population are required to present to hospital with any significant fever). As lockdown exit strategies were described, it was important to consider what social distancing policies patient groups should follow.

The purpose of this document is to:

1. Describe the developments in our understanding of the COVID-19 in the context of children with chronic health conditions.
2. The effects of 'shielding' on young people.
3. We then describe our strategy for ending shielding measures for children receiving HPN, and the move to standard social distancing with their age group unless

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individual considerations modify this approach. This approach may assist other clinicians who have to continue to decide on risk stratification for patients with complex disease.

During the initial lockdown period it was agreed that a new BIFWG stance to shielding for our patient population should be devised on the basis of general advice on children from the RCPCH, published literature, and our clinical experience during the pandemic. We wished to establish what was known about COVID-19 and children with chronic diseases, the effects on lockdown on children and whether any children receiving HPN in the UK had knowingly contracted COVID-19.

What is now known about COVID-19 and children?

While the initial information from China on COVID-19 appeared to suggest a significant protection from

severe infection by young age, what was not immediately clear was how dramatic the reduction in risk was for younger people, in terms of asymptomatic carriage, severe clinical course or risk of mortality. The gastrointestinal manifestations of COVID-19 in children are only apparent after respiratory symptoms and are mild and self-limiting and do not contribute significantly to COVID-19 morbidity in children.⁹⁻²⁰ Children appear to be the index case in family transmission infrequently.²¹ Transmission rates of COVID-19 from children were very low in the early pandemic²² and countries that have reopened nurseries and schools have not experienced institution-related outbreaks.^{23 24} The data for COVID-19 infection in children with chronic gastrointestinal conditions, although limited, are reassuring in terms of relative incidence and severity.^{25 26}

Table 1 Summary of four nations' approach to exit from lockdown

Nation	England ¹	Scotland ²	Wales ³	Northern Ireland ⁴
Lockdown	Lockdown	Phase 0	Lockdown	Lockdown
Step 1	<ul style="list-style-type: none"> ▶ Workers who cannot work from home now travel to work ▶ Unlimited exercise outdoors ▶ Non-household meetings one-on-one outdoors ▶ Travel to outdoor spaces ▶ Vulnerable limit contact outside household ▶ Continue 'shielding' 	<ul style="list-style-type: none"> ▶ Unlimited local outdoor exercise ▶ Contact with other household outdoors ▶ Reopening of workplaces for work that cannot be performed at home ▶ Outdoor-limited retail 	<ul style="list-style-type: none"> 'Red' ▶ School remains for key workers and vulnerable ▶ Seeing one member out with household for care only ▶ Unlimited local outdoor exercise 	<ul style="list-style-type: none"> ▶ Schools remain for key workers and vulnerable ▶ Workers who cannot work at home travel to work ▶ Outdoor non-contact sports activities ▶ Groups of 4-6 non-household members can gather outdoor
Step 2	<ul style="list-style-type: none"> ▶ Phased reopening schools ▶ Other households contact 'bubbles' to be announced ▶ Shared childcare in two households 	<ul style="list-style-type: none"> ▶ Larger outdoor gatherings ▶ Indoor meeting with other one household ▶ On-campus laboratory work ▶ Playgroups and sport courts reopen ▶ Registration offices for high priority 	<ul style="list-style-type: none"> 'Amber' ▶ Schools open for priority groups ▶ Exercise with other individual or group, non-contact team sports ▶ Travel for leisure and non-essential retail ▶ Museums and galleries open ▶ Limited cultural events 	<ul style="list-style-type: none"> ▶ Schools open to wider definition of key workers ▶ Non-food retail resumes ▶ Gatherings of up to 10 individuals outdoors ▶ Resumption of team sports training
Step 3	<ul style="list-style-type: none"> ▶ Opening of, public worship and self-care retail ▶ Museums, galleries, indoor gyms and cinema open thereafter ▶ Wider outdoor public gatherings, weddings, sports and cultural yet thereafter 	<ul style="list-style-type: none"> ▶ Indoor meeting with multiple households ▶ Longer distance travel ▶ School reopen for part-time face to face ▶ Museums, galleries, indoor gyms and cinema open 	<ul style="list-style-type: none"> 'Green' ▶ All children and students access education ▶ Meeting small groups for socialisation outdoors ▶ Unrestricted travel ▶ All sports and cultural leisure open ▶ Pubs, restaurants, non-essential indoor retail open 	<ul style="list-style-type: none"> ▶ School open to priority cohorts ▶ Phased return to office work ▶ Gatherings of up to 30 people ▶ Resumption of non-contact sports ▶ Museums and galleries open
Step 4		<ul style="list-style-type: none"> No time frame set ▶ Further relaxation of face-to-face gatherings ▶ Full opening of childcare, schools and universities ▶ Resumption of sport and mass gatherings 		<ul style="list-style-type: none"> ▶ Schools open for all pupils part-time ▶ Competitive sports resume behind closed doors, leisure centres open ▶ Wider range of social gatherings
Step 5				<ul style="list-style-type: none"> ▶ School extended to full time for early years ▶ Extended social group gatherings ▶ Resumption of contact sports ▶ Spectators attend live sports and concerts

Data from severely immunosuppressed children, even in high-level pandemic areas, are that of low overall infection rate with low level need for hospitalisation.²⁷ Black Asian and minority ethnicity (BAME) does incur greater risk of severe disease and mortality in UK adults²⁸; paediatric data have suggested BAME to be a risk factor in UK children but the relative risk is harder to quantify.^{29 30} To date, significant morbidity and mortality from COVID-19 in children appears limited to the idiopathic paediatric multisystem inflammatory response, for which pre-existing chronic disease does not appear a major risk factor.^{31 32}

We did not identify any data reporting severe complications of short bowel syndrome, IF or HPN from COVID-19, both in the adult and paediatric literature. Through corresponding members of BIFWG and eBANS, we established that to date none of the 400 patients <16 years receiving HPN in the UK have knowingly contracted COVID-19.

What is now known about children, lockdown and shielding?

The consequences on the mental health of children required to take quarantine measures are well described and include anxiety, distress and increased risk of major mental health disorder.³³ The effects are disproportionately isolating on our adolescent patients, for whom friendship groups are already difficult to establish due

to chronic disease.³⁴ The effects of prolonged interruption of formal education for a population already at significant risk of poorer social and educational attainment needed to be considered in ongoing risk assessment. There had been a significant reduction in children's presentation to accident and emergency departments and face-to-face paediatric consultations. Children's presence in society had declined in general, particularly for those with chronic health conditions. These children as such were 'vulnerable' and the risks of this ongoing social invisibility were amplified and needed to be considered when weighing up the potential benefits of social distancing measures.^{35 36}

Leaving lockdown and shielding

The initial period of shielding ended for many vulnerable patients. What happens thereafter is determined by the individual's health condition, local protocol on social distancing across the four nations and local emergence status. We outline our new strategy for children receiving HPN based on the available evidence and our cumulative experience. The pandemic has proved to be a unique and bewildering time for children and families, and for the clinicians who have to determine what to recommend individual patients from the synthesis of emerging science, population measures and local infection rates. Supporting families moving from shielding to increasing emergence

Table 2 BSPGHAN NIFWG framework for considering individualised lockdown exit strategy for children receiving HPN

Group B		Group C
Most vulnerable patients to consider whether they may continue to re-enact shielding when appropriate^{8 38}	No return to 'shielding' but consider 'other enhanced social distancing'	Enact social distancing as per local population measures
Circumstances that may recommend MDTs and families to re-enact shielding when appropriate*	Circumstances to consider group other enhanced social distancing measures†	Circumstances that would recommend patients to act with general population‡
<ul style="list-style-type: none"> ▶ Children at risk of severe infection due to immunodeficiency induced by their disease or drug therapy ▶ Other significant conditions or other organ involvement (renal, haematology, cardiac, GI, respiratory, diabetes mellitus, severe metabolic disease, children with severe neurological disease, severe lung disease requiring continuous or overnight supplementary home oxygen) ▶ Decompensated liver disease. Receiving post-transplant immunosuppression or on transplant waiting-list ▶ Social cofactors (eg, heavily reliant on support from healthcare professionals/carers) 	<ul style="list-style-type: none"> ▶ Any of first column factors not severe enough to merit 'shielding' ▶ 7/7 PN ▶ Under 1 year of age ▶ Difficult contingency arrangements for prime carer illness ▶ High output ileostomy ▶ Parental anxiety ▶ BAME ethnicity 	<ul style="list-style-type: none"> ▶ No immunosuppression ▶ <7 nights PN ▶ Normal neurodevelopment ▶ Easy contingency arrangements for prime carer illness

*No children or young people with chronic gastrointestinal conditions automatically fulfil highest risk 'Group A' by revised RCPCH criteria.⁸ However a proportion of HPN patients may have severe multiple risk factors that may give consideration to enacting as 'Group A'. These families will represent a small minority of the total PN population and likely most risk factors will emerge from other organ dysfunction. However, it maybe that cardiorespiratory or neurodisability in combination with IF may lead to a decision of 'continue shielding' with less severe disease than would indicate shielding in isolation, and discussion with relevant other specialist team may assist with decision-making.

†Potential strategies are the following: (1) Transition to local social distancing protocol with other age group peers; (2) temporal transition to local social distancing protocol, such as 2 weeks behind age group peers; (3) remain a 'step' behind age group peers; (4) remain in lockdown but not 'shielding'.

‡If an MDT considers that the mental health risks to the individual or family OR if the potential safeguarding risks for the child are significantly high enough, they may wish, in conjunction with the families or social services, to make a case for ongoing nursery or school placement even with lockdown resumption. However, we recommend some form of peer review for this extraordinary decision.

BAME, Black Asian and minority ethnicity; BSPGHAN, British Society for Paediatric Gastroenterology Hepatology and Nutrition; GI, gastrointestinal; HPN, home parenteral nutrition; IF, intestinal failure; MDT, multidisciplinary team; NIFWG, Nutrition and Intestinal Failure Working Group; PN, parenteral nutrition.

and schooling requires effective test and trace enforcement, rapidly available local infection data, responsive local public health and personalised approach from clinicians and multidisciplinary teams (MDTs) which could involve local knowledge of very small community clusters or individual schools distancing effectiveness. The clinical team must remain agile to help enact and reverse emergence measures rapidly. We know that the risks to children from COVID-19 disease are much lower than in the adult population; however, absolute quantification of risk for our patient group is unknown and will remain obscure.

BIFWG strategy for lockdown emergence, re-enactment of enhanced social distancing and recommencement of schooling

Depending on geographic location in the UK, the social distancing status of the general population may vary from 'ongoing lockdown' to primary or secondary phased relaxation of lockdown measures.¹⁻⁴ These conditions will continue to advance or regress locally depending on local infection rates. Clinicians' and MDTs' understanding of local (national) emergence from lockdown framework is essential to inform decision-making (UK variations in phase re-emergence are summarised in [table 1](#)). A member of the MDT should regularly conduct a face-to-face or virtual consultation with each family to discuss the family's current status and potential need for re-enactment of 'shielding' or not and strategy for ongoing social re-emergence.

The following principles should inform each discussion:

1. The majority of families can discontinue shielding and transition to the current local social distancing protocols. Only patients who are in the highest risk should have the need for re-enactment of 'shielding' when local public health recommends ([table 2](#)).
2. Some patients may have risk factors additional to IF, but these are insufficient to warrant re-enacting shielding; families and MDTs may wish to agree some enhanced distancing measures above current local protocols (such as remaining a step behind [table 2](#)). These measures are primarily in place to help encourage families who may continue to be anxious or reluctant to engage with re-emergence and resuming face-to-face education.
3. Where there has been local regression of local social distancing measures, the MDT and the family may wish to consider a more cautious approach to such as remaining in lockdown for additional 2 weeks ([table 2](#)).
4. If an MDT considers that the mental health risks to the individual or family OR if potential safeguarding risks for the child are significantly high enough, they may wish, in conjunction with the families or social services to make a case for ongoing nursery or school placement even with lockdown resumption. However, we recommend some form of peer review for this decision.

A summary of potential strategies for emergence from lockdown are summarised in [table 2](#).

Resumption of face-to-face education

The plans for resumption of school education are complex and diverse across the four UK nations at the time of writing. However, again, an initial discussion will aid in making individual decisions on re-engagement with education. As per the RCPCH guidance, the following principles should guide discussions:

1. Children should only stay away from school if they are considered as part of 'ongoing shielding' at times that shielding is to be enacted
2. The majority of patients should be having a balanced conversation about returning to school.
Many families will be understandably anxious and may wish to take a tailored approach (such as following in 2 weeks behind their peers to assure that initial logistics of social distancing are being followed well, or initially following a reduced timetable).
3. Where there is reluctance to re-engage with face-to-face education, the MDT may need to consider what impact this may have on a child's social invisibility and resultant vulnerability.

Key messages

- ▶ Children and young people receiving home parenteral nutrition (HPN) were advised to 'shield' when lockdown commenced in March 2020.
- ▶ It is now apparent that gastrointestinal manifestations of COVID-19 in children are mild and self-limiting.
- ▶ We have not identified any reports of severe complications of COVID-19 in short bowel syndrome, intestinal failure or HPN from COVID-19 in the adult and paediatric medical literature.
- ▶ Mental health of children required to take quarantine measures is well described with anxiety, distress and increased risk of major mental health disorders.
- ▶ HPN children should no longer be considered 'extremely vulnerable' since negative social and developmental effects would appear to outweigh protection.
- ▶ Shielding has ended and the majority* of families can transition to the current local social distancing protocols.
- ▶ If there is resumption of lockdown due to a second virus peak, we propose that the majority* of families only follow social distancing policy and do not resume 'shielding' again, even if adult HPN populations do so.
- ▶ Patients* and families should have a balanced conversation about returning to school. They may wish to take a tailored approach, such as following in 2 weeks behind their peers to assure that initial logistics of social distancing are being followed.

*If a child has coexisting disease, for example, cardiorespiratory, neurodisability, immunodeficiency, inflammatory bowel disease or is on certain immunosuppressive treatment that would not in itself be severe enough to warrant shielding, clinicians may wish, in conjunction with other specialty teams and families consider that the patient should continue to enact shielding when appropriate from cumulative multiorgan risk.

4. Siblings of extremely vulnerable children should attend school as per local social distancing protocols.
5. Where there are positive contacts in school 'social bubbles', patients will need to isolate as per whole group.^{37 38}

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Vignettes

1.

Millie, a 10-year-old girl, has intractable diarrhoea due to Tricho-hepato-enteric syndrome, caused by a mutation in the gene TTC37. She receives Home parenteral nutrition 4 nights per week, and takes a milk free diet supplemented by oral nutritional supplements. She has a cardiac anomaly, (aortic insufficiency) and mild bilateral hydronephrosis.

In infancy she had recurrent otitis media and has immunodeficiency, with low serum concentrations of immunoglobulins in infancy which improved with age and has had a poor immunological response to childhood vaccination (Hib and pneumococcal titres remain low). She developed bloody diarrhoea in later childhood and at colonoscopy, histology shows an IBD-like distal colitis, currently treated with prednisolone 5mg alternate days.

The clinician, MDT and parents discuss the child's situation. She has major organ failure (Intestinal Failure) in combination with additional risk factors (immune dysregulation, cardiac anomaly, renal anomaly, IBD-like illness). Although she hasn't had a severe infection for a number of years, her cardiac and renal anomaly are stable, and her rectal bleeding appears to be in remission on treatment with low dose steroids, it is agreed that it would be prudent to continue to '**continue shielding**' (move to Group A) at home.

The team also advised that her sibling age 15 attends school (as her local school in England has reopened) as stringent social distancing can be offered at his school, however, her younger sister will stay at home as is unable to understand and follow instructions on social distancing and is supported to learn at home. Millie's parents elected to stay at home as can work in the home.

2.

Stephen is a 3½ year old only child. He was born prematurely at 28 weeks and had severe NEC resulting in resection of significant amounts of small bowel and colon, he has an ileostomy and is on 5 nights a week PN. In addition he had chronic lung disease of prematurity and only came out of oxygen over-night 6 months ago. He also had IVHs and has some periventricular leukomalacia and cystic changes, he is ambulant but walks with a supportive frame and has a marked left hemiplegia. Dad has to work out of the house hold, he assists with hanging his PN.

The clinician, MDT and the family had a long discussion about the next move; Stephen has a few risk factors that don't fulfil 'shielding' individually. However his mum and dad were keen to get back to normality as much as possible and go back to nursery. They agreed to '**remain a step behind**' and they first would take Stephen into 'lockdown' measures, and then (as per Scotland moving into step 2) allow Stephen and family to meet up with 1 other-house hold after 2 weeks.

Dad will continue to go out and work but the MDT emphasised to continue change clothes and shower before engaging with the rest of the household when they get in. They agreed they would hold another consultation before discussing Stephen's nursery placement and that if it did open, they would at let the nursery be open for 2 weeks to check the logistics of social distancing were being enforced well practically.

3.

Ella is 14. She had congenital gastroschisis as an infant and has an ileocolonic anastomosis with continuity. She eats on top of enteral feeds but still requires 3 nights PN a week. She has no neurological impairment and, prior to lockdown, was starting to socialise a lot with her peers in the evenings she was off PN, including being a keen footballer with a local team. She has had no central line infections for several years and is growing well. She has 3 siblings all are well

The clinician, the MDT and the family discussed. Mum was very anxious about coming out of lockdown, and always engaged in extended hygiene measures within the house and for visitors prior to lockdown. Despite their hometown in Northern Ireland soon moving to step 2 (groups of up to 10 individuals meeting outdoors) mum has kept Ella inside. There was clearly tension between mum and Ella in the consultation although she is always quite when mum speaks.

After a long consultation agreement was made that Ella would engage in a **'temporal transition'** with 2 weeks between lock-down, Step 1 and then step 2. The Clinical Nurse specialist was going to keep in close touch to encourage the family to engage in emergence for Ella, getting to meet friends in groups and re-integrate with her outdoor sports when it becomes possible.

Ella and her siblings should return to school when it starts for Northern Ireland in September, although it may be reasonable for Ella to wait out the first week to check that the local High school is coping with social distancing protocols.

4.

Marcus is 2 years old, he has intestinal aganglionosis. He has a high ileostomy which can put out >1litre some days and he's on minimal feeds with 7 nights of PN a week. Marcus's mum Alicia is a single parent as there was domestic violence within the household and Marcus's dad has no contact with the family anymore. Alicia has a history of major mental health problems and has follow up regularly with a CPN. Alicia has assistance from her own mother for PN hanging and to help with Marcus's older sister who is 4, but she also has to work during the day. Marcus has had 3 central line infections in the past 18 months but is quite well currently

The Clinician, the MDT and Mum had a discussion about coming out of lockdown. Alicia became tearful very quickly as under the current plans, in Wales, nursery places will not to open up again as yet. Her CPN who had joined the call stated that he was concerned about how exhausted is with having the children at home all the time and that she hasn't been sleeping well.

After a discussion everyone agreed that the team would try to make a case for Marcus to be considering a 'priority group' for returning to nursery as his additional needs during shielding were starting to take a strain on mum. Alicia was very grateful when the IF team social worker suggested she make contact with the local education authority to see what could be arranged.

APPENDIX 1

Dear Parent

The team were pleased to meet with you all today to discuss plans for social distancing for _____ today. As of 12th of June the initial stage of 'shielding' will end and the Royal College of Paediatrics has advised that beyond this, most patients on home parenteral nutrition will come out of shielding and move to the same measures as children their own age. We met to discuss what this would mean for _____

We discussed that currently that shielding has meant for (family members/employment status/ who has had to isolate from patient).

We discussed risk factors for _____ and factors demonstrate 'lower risk'

We therefore all agreed together that from June 12th _____ will

- Continue to 'shield', but discuss what enacting 'shielding' will now involve
- A plan to transition over ___ weeks to match the rest of the country
- To remain 'a step behind' until further review
- To immediately move to the local protocol
- To commence discussion with education about the resumption of nursery/school

This plan is in-line with advice from the British Society of Paediatric Gastroenterology Hepatology and Nutrition Intestinal Failure working group and we will keep you up to date on any planned changes as they develop.

Yours