Overview:

Right of reply is due on Monday June 26th. It will be sent to me and I will be alerted when this comes in – including if it comes in next week.

The right of reply will be comprehensive – and long. They will outline their story with details and give us the opportunity to dispute the facts they are presenting us with.

They plan to give us two weeks to respond – but are willing to allow us more time if we can make a case for that.

They believe they have a strong – and watertight – case against us.

ITV's lawyers are handling this for them on the legal front.

Certain consultants may be named individually but they would not confirm names. They will be given separate rights to reply in their own right.

They are working in partnership with the Bureau of Investigative Journalism. Amazing Productions are focussing on the documentary and the Bureau will be seeking to place articles to support the documentary.

They are keen to get someone on camera to respond and have assured me we will be given time to evaluate how we respond (David Hicks name was mentioned by them).

They are respectful of GOSH's status as a leading centre of clinical expertise and a respected institution.

Details:

They are only going to focus on gastro.

They are focusing on EGID. Their premise is serious over-treatment.

The Croydon Serious Case Review is likely to be the hook for the documentary.

They will definitely not be looking at FII but cannot guarantee that the Bureau will not be exploring that route.

They have families speaking directly about their experience of GOSH – some anonymously.

Likewise they have consultants from other hospitals criticising us.

They will be disputing our numbers on cases investigated. Their position on the 14 cases is that we reviewed around 20 out of 40 cases and that these were so bad that we did not go further – and instead only went into any more depth on 14 cases.

They are accusing GOSH of a serious lack of candour and transparency with staff and with patients / families / other hospitals. They dispute that a letter was sent to 1,400 patient families and have people stating they were never communicated with.

Their focus will be on over-treatment and will dispute the GOSH position that there have been no long-term consequences as a result of that treatment.

They may look at the consequences to other hospitals of GOSH's decision to stop admitting patients.

There seems to be some room for accepting that we are trying to make things better.

Actions:

Careful review of reports by the College – extracting key evidence.

Evaluate the numbers

Find proof of communications with patient families and internal / external comms

Urgent action needed on the FOIs from Amazing and the Bureau of Investigative Journalism

[redacted]

From: [redacted]
Sent: 16 June 2017 10:14
To: Peter Steer; [redacted]; [redacted]; David Hicks; [redacted]
Subject: Gastro Documentary Details
Attachments: Amazing summary.docx

Dear All

I spoke to [redacted] of Amazing Productions last night and he agreed to give me a sense of the direction that they are going in with their documentary. It is not good news – but we expected that.

I attach a document where I have written up the details he gave me. They believe they have a very strong case – and it will be damaging - supported by oral testimonies and written evidence. I am hopeful that we can counter much of it. The focus will be over-treatment of patients with EGID.

Right of reply is due in on Monday 26th June and we will be given – initially – two weeks to respond.

I feel bad to dump this on you as I depart for other shores but I think it is better to let you know now than wait for my return. At least I know I leave you in good hands with [redacted], with [redacted] supporting him in the press office.

Should we book a time in the diary now for late in the afternoon of Monday 26th June - in anticipation that we will have received their right of reply by then - so that we can review and plan what needs to be done?

Finally there are two outstanding FOI requests and I know [redacted] is away. I would encourage you to find a way to respond and not wait for her return. She did suggest hiring an independent lawyer to go through them in her absence.

Please do not hesitate to call me at any time while I am away if you would like clarification on any of this.

Best wishes

[redacted]
Great Ormond Street Hospital Children's Charity

[redacted]

[redacted]

From: [redacted]>
Sent: 28 June 2017 21:50
To: David Hicks
Subject: Re: Gastro Documentary: Quick Update

Good additional argument to give.

Get Outlook for iOS

From: David Hicks <David.Hicks@gosh.nhs.uk>
Sent: Wednesday, June 28, 2017 9:43:14 PM
To: [redacted]
Cc: Peter Steer; [redacted]
Subject: Re: Gastro Documentary: Quick Update

this would allow the RCPCH to complete their visit/analysis and therefore would be good I feel,

Best Wishes,
David
Sent from my iPad

On 28 Jun 2017, at 20:01, [redacted]> wrote:

> Dear All
>
> The unexpected news from the ECHR yesterday has meant that we have not been able to make the hoped for progress on the legal front with regards to the gastro documentary.
>
> I therefore decided this evening to put in a call to the producer and request more time – I asked for three more weeks. I pointed out that we could do this with legal letters sent via ITV but it would be easier if we could reach this agreement directly.
>
> He will get back to me asap and I will let you know. He did not sound unwilling to do so (and was almost certainly expecting that request).
>
> In the meantime, [redacted] is pressing ahead with pulling together responses to the points they raise that we can discuss more fully when we meet.
>
> Best wishes
> [redacted]
>
> [redacted]
> Great Ormond Street Hospital Children's Charity
>
> [redacted]

[redacted]

From: [redacted]>
Sent: 16 June 2017 16:29
To: [redacted]; Peter Steer; [redacted] David Hicks
Subject: RE: Gastro Documentary Details

Hi [redacted]

Very helpful intelligence. I will digest this over the weekend and pick up with [redacted] on Monday.

Meanwhile have a great break.

Kind rgds

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 20 July 2017 15:17
To: Elizabeth Jackson
Cc: David Hicks
Subject: Gastro Documentary

Dear Liz

I am currently finalising the first stage of our response to the production company who are making the documentary on our gastroenterology department.

In a meeting with David Hicks earlier he suggested that you had been very close to the review process and might be able to give a well-informed review of the letter we are planning to send.

Would you be able to do this? It would be very much appreciated.

Best

[redacted]

[redacted]
Great Ormond Street Hospital and Children's Charity

[redacted]

[redacted]

From: [redacted]
Sent: 11 September 2017 10:48
To: Peter Steer <Peter.Steer@gosh.nhs.uk>; [redacted]; David Hicks <David.Hicks@gosh.nhs.uk>;

Andrew Long <Andrew.Long@gosh.nhs.uk>; [redacted]

Cc: [redacted]

Subject: Gastro Report

A password protected attachment has been sent to you. Please note that the message could not be scanned for malware/viruses due to the message being password protected.

For your security it is highly recommended to confirm the sender's email address and details before attempting to open and extract the file contents.

This is an informational warning from the NHSmail Team.

Dear All

I am re-circulating the draft report from the RCPCH to make sure that everyone advising on the gastro documentary response has a response, along with all of the executive team.

[redacted] has agreed to collate comments so please send your review comments back to him. As there may be some key decisions made on the back of this, we do need your comments urgently.

Please send your comments to [redacted] by 10 am on Wednesday 13 September (ie this Wednesday)

Do let me know if you have any questions.

Best wishes
[redacted]

If you have received this communication in error please notify us immediately by return email, and delete this email and all attachments immediately. This email is for the exclusive use of the intended recipient and may contain information that is privileged, confidential and exempt from disclosure under applicable law. If you are not the intended recipient please note that any form of disclosure, distribution, copying or use of this communication or the information in it or any attachments is strictly prohibited and may be unlawful. The views or opinions are solely those of the author of this email, and do not represent those of the Great Ormond Street Hospital Children's Charity unless specifically stated.

[redacted]

From: [redacted]
Sent: 16 June 2017 18:28
To: [redacted]; Peter Steer; [redacted] David Hicks
Subject: RE: Gastro Documentary Details

Hi

Thanks [redacted]. I have more information (received this afternoon) which also provides further clarity – specifically the draft serious case review document which adds context to what [redacted] describes.

I will send it to you and we can discuss Monday.

In the meantime have a great weekend.
[redacted]

From: [redacted]]
Sent: 16 June 2017 16:29
To: [redacted]; Peter Steer; [redacted]; David Hicks
Subject: RE: Gastro Documentary Details

Hi [redacted],

Very helpful intelligence. I will digest this over the weekend and pick up with [redacted] on Monday.

Meanwhile have a great break.

Kind rgds

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 04 October 2017 11:26
To: David Hicks
Subject: RE: Amazing
Attachments: refined gastro drugs list - probably at the limit of my knowlege now!; RE: refined gastro drugs list - FINAL REVISION attached; RE: refined gastro drugs list - FINAL REVISION attached; RE: GOSH Gastro Service Plans 23.2.16; FW: GOSH Gastro Service Plans 23.2.16; Welcome back; Gastro - Flash Report for week ending 11th March; FW: Gastro Flash Report for week ending 4th March; Gastro Flash report for w/e 1st April 2016; Final List of immunosuppressant for 2013 -2015

Follow Up Flag: Follow up
Flag Status: Flagged

Hi David, I am attaching some emails that I sent to Vin around the time of 4th March 2016. As you can see, [redacted] in pharmacy generated a master excel spread sheet for us with ALL the drugs dispensed by pharmacy to Gastro patients in the preceding three years (ie prior to March 2016). I/we then took out *'everyone **other** than those who have received these drugs below (having already removed the IBD patients on the Improve Care Now register and a couple of others, and the post BMT patients):'* (for the list of drugs that remained see the email of 04/03/2016 at 19.31), and this left 345 unique patients in the last three years of which 152 were patients in the last calendar year (2015). You will see that the list of drugs that we used for this trawl was fairly wide ranging.
Vin then came back to me at 14.55 on 5th March 2016 suggesting that some more of these drugs were removed, and so I took these drugs out and this reduced the numbers to 329 unique patients in the last three years of which 144 were unique patients in the previous year. See email of 07/03/2016 at 12.22.
Vin then checked whether I had taken out deceased or transitioned patients but I replied that this needed to be done by correlation with PIMS. See email of 07/03/2016 at 14.44.

I attach a couple of email trails between Vin and Peter (Steer) and between Vin and Rob Heuschkel (from Cambridge) in which some of these numbers were mentioned.

I went on two weeks holiday and came back to a Welcome back' email from Vin (attached) dated 29/03/2016 which mentions '[redacted]*is busy booking all 43 patients needing review into defined outpatient slots*' .
I attach two 'flash reports' (4th and 11th March) from [redacted] from this time that again mention the 345 number and plans being put in place to see all these patients over time.
I attach the flash report from 6th April which details a note saying that:
PATIENTS
Patients on immunosuppressant in the last three years *. Data cleaned to include only those patients where gastroenterology started immunosuppressant-* ***Approx. 50 patients were started and remain on immunosuppressant medication from 2013/2014 &2015.*** *Final validation to be completed prior to letters being sent.* So I think this was revised down to the '43' who were the patients who gastro (as opposed to other teams) teams had started on true immunosuppressants and were STILL on them – then therefore being the children that logic would dictate needed reviewing first. And there is also an email from 04/04/2016 from [redacted] explaining the criteria for the final validated list.
Hope this is what you need, let me know if you need anything else.
BW, [redacted]

From: David Hicks
Sent: 04 October 2017 08:23
To: [redacted]
Subject: FW: Amazing

Hi [redacted]
do you have any recall of this please?
Your help is much appreciated,

Best Wishes,
David

From: DIWAKAR, Vinod (NHS ENGLAND) [mailto:vdiwakar@nhs.net]
Sent: 03 October 2017 22:31
To: David Hicks
Cc: [redacted]
Subject: RE: Amazing

Dear David

Thank you for your email.

As we have discussed, it is difficult for me to answer this without access to my old email account at Great Ormond Street.

However, I am happy to confirm that your suggestion matches my recollection. [redacted] was clinical director of the service at the time and I have a feeling that she took the lead in compiling the final list. However, I may not have remembered this accurately.

I hope that helps.

It would be useful if you could let NHS England's communications team know of the date of the transmission.

All the best

Yours sincerely

Vin

Vin Diwakar
Regional Medical Director
NHS England (London Region)| Skipton House | 80 London Road | London SE1 6LH
[redacted]
GMC Number: 3332517

From: David Hicks [mailto:David.Hicks@gosh.nhs.uk]
Sent: 03 October 2017 09:21
To: DIWAKAR, Vinod (NHS ENGLAND) <vdiwakar@nhs.net>
Subject: Amazing

Dear Vin

[redacted]

[redacted]

From: [redacted]
Sent: 04 October 2017 11:26
To: Vinod Diwakar; [redacted]
Cc: [redacted]
Subject: RE: refined gastro drugs list - FINAL REVISION attached
Attachments: Copy of 130101 to 151231 gag issues (3) master list of all drugs dispensed MINUS PATIENTS WITH KNOWN IBD or POST BMT with only core drugs remaining (2).xls

Hi Vin, I have taken out the drugs in red below as requested – so all the drugs in black remain. After doing this I have the second version (2) attached here. The releveant chart is on the tab 'sheet 2'. I am sending you the whole chart as you (or someone) may want to manipulate the data in my absence. Taking out these drugs you requested reduced the number **to 329 unique patients in the last three years** (of which some/many may no longer be on some/all of the drugs), of which **144 are unique patients in the last year**. I have copied and pasted the ones from the last year here (to get us ahead) but of course you can get them from the attached chart (first data sort the whole chart by patient name (A-Z)and date (newest to oldest), then highlight whole chart and remove duplicates by column C, and then sort whole chart by date newest first). Just to reiterate – some of these patients will have IBD but are not in the Improve Care Now programme, and the chart doesn't capture patients who are having drugs prescribed directly by the GP – although some of these will hopefully be caught in our net as the first prescription was probably from here.
BW, [redacted]

31/12/2015	[redacted]	INFLIXIMAB (REMICADE)
31/12/2015		INFLIXIMAB (REMICADE)
14/12/2015		AZATHIOPRINE (CARDIFF)
14/12/2015		AZATHIOPRINE (CARDIFF)
12/12/2015		INFLIXIMAB (REMICADE)
11/12/2015		INFLIXIMAB (REMICADE)
11/12/2015		AZATHIOPRINE (CARDIFF)
08/12/2015		AZATHIOPRINE
08/12/2015		AZATHIOPRINE
07/12/2015		MERCAPTOPURINE
07/12/2015		HYDROCORTISONE (as SODIUM PHOSPHATE) (1r
04/12/2015		INFLIXIMAB (REMICADE)
04/12/2015		AZATHIOPRINE (CARDIFF)
03/12/2015		PREDNISOLONE(SOLUBLE)
03/12/2015		INFLIXIMAB (REMICADE)
01/12/2015		PREDNISOLONE(SOLUBLE)
01/12/2015		ADALIMUMAB(HOMECARE)
30/11/2015		AZATHIOPRINE (CARDIFF)
27/11/2015		ADALIMUMAB
27/11/2015		INFLIXIMAB (REMICADE)
24/11/2015		AZATHIOPRINE
24/11/2015		DEXAMETHASONE
18/11/2015		AZATHIOPRINE (CARDIFF)
17/11/2015		PREDNISOLONE(SOLUBLE)
16/11/2015		INFLIXIMAB (REMICADE)
12/11/2015		PREDNISOLONE(SOLUBLE)
10/11/2015		AZATHIOPRINE
10/11/2015		PREDNISOLONE
03/11/2015		AZATHIOPRINE
30/10/2015		PREDNISOLONE(SOLUBLE)
28/10/2015		AZATHIOPRINE (CARDIFF)
28/10/2015		BUDESONIDE(BUDENOFALK)
28/10/2015		METHOTREXATE

27/10/2015	[redacted]	BUDESONIDE(BUDENOFALK)
19/10/2015		TACROLIMUS
19/10/2015		PREDNISOLONE(SOLUBLE)
19/10/2015		INFLIXIMAB (REMICADE)
19/10/2015		HYDROCORTISONE (as SODIUM PHOSPHATE) (1r
13/10/2015		AZATHIOPRINE (CARDIFF)
07/10/2015		PREDNISOLONE
05/10/2015		AZATHIOPRINE
05/10/2015		AZATHIOPRINE
05/10/2015		PREDNISOLONE
05/10/2015		MERCAPTOPURINE
03/10/2015		DEXAMETHASONE (HAMELN) (2mL)
23/09/2015		PREDNISOLONE
23/09/2015		AZATHIOPRINE (CARDIFF)
22/09/2015		AZATHIOPRINE (CARDIFF)
21/09/2015		AZATHIOPRINE (CARDIFF)
18/09/2015		INFLIXIMAB (REMICADE)
18/09/2015		INFLIXIMAB (REMICADE)
17/09/2015		AZATHIOPRINE (CARDIFF)
17/09/2015		ADALIMUMAB(HOMECARE)
17/09/2015		AZATHIOPRINE
10/09/2015		PREDNISOLONE
08/09/2015		PREDNISOLONE(SOLUBLE)
08/09/2015		PREDNISOLONE(SOLUBLE)
02/09/2015		PREDNISOLONE(SOLUBLE)
27/08/2015		AZATHIOPRINE (CARDIFF)
27/08/2015		AZATHIOPRINE (CARDIFF)
26/08/2015		AZATHIOPRINE (CARDIFF)
24/08/2015		SIROLIMUS
21/08/2015		ADALIMUMAB(HOMECARE)
20/08/2015		AZATHIOPRINE (CARDIFF)
20/08/2015		HYDROCORTISONE
19/08/2015		AZATHIOPRINE (CARDIFF)
17/08/2015		INFLIXIMAB (REMICADE)
12/08/2015		METHYLPREDNISOLONE SODIUM SUCCINATE
04/08/2015		AZATHIOPRINE
03/08/2015		INFLIXIMAB (REMICADE)
29/07/2015		AZATHIOPRINE (CARDIFF)
28/07/2015		ADALIMUMAB(HOMECARE)
28/07/2015		ADALIMUMAB(HOMECARE)
23/07/2015		INFLIXIMAB (REMICADE)
23/07/2015		AZATHIOPRINE
20/07/2015		ADALIMUMAB(HOMECARE)
20/07/2015		ADALIMUMAB(HOMECARE)
15/07/2015		AZATHIOPRINE
15/07/2015		PREDNISOLONE(SOLUBLE)
14/07/2015		INFLIXIMAB (REMICADE)
13/07/2015		PREDNISOLONE(SOLUBLE)
13/07/2015		AZATHIOPRINE
07/07/2015		MERCAPTOPURINE (XALUPRINE)
01/07/2015		PREDNISOLONE(SOLUBLE)
29/06/2015		AZATHIOPRINE (CARDIFF)
26/06/2015		ADALIMUMAB(HOMECARE)
19/06/2015		INFLIXIMAB (REMICADE)
15/06/2015		PREDNISOLONE(SOLUBLE)
11/06/2015		ADALIMUMAB(HOMECARE)
02/06/2015		DEXAMETHASONE
29/05/2015		AZATHIOPRINE (CARDIFF)
28/05/2015		AZATHIOPRINE

20/05/2015	[redacted]	TACROLIMUS (PROGRAF)
15/05/2015		AZATHIOPRINE (CARDIFF)
13/05/2015		INFLIXIMAB (REMICADE)
11/05/2015		AZATHIOPRINE (CARDIFF)
07/05/2015		AZATHIOPRINE
06/05/2015		AZATHIOPRINE
05/05/2015		AZATHIOPRINE (CARDIFF)
27/04/2015		PREDNISOLONE(SOLUBLE)
27/04/2015		PREDNISOLONE(SOLUBLE)
20/04/2015		PREDNISOLONE
16/04/2015		INFLIXIMAB (REMICADE)
15/04/2015		AZATHIOPRINE
13/04/2015		PREDNISOLONE(SOLUBLE)
08/04/2015		METHYLPREDNISOLONE SODIUM SUCCINATE
28/03/2015		INFLIXIMAB (REMICADE)
27/03/2015		DEXAMETHASONE
25/03/2015		AZATHIOPRINE
25/03/2015		ADALIMUMAB(HOMECARE)
24/03/2015		ADALIMUMAB(HOMECARE)
20/03/2015		INFLIXIMAB (REMICADE)
18/03/2015		AZATHIOPRINE
18/03/2015		AZATHIOPRINE
18/03/2015		AZATHIOPRINE
14/03/2015		ANAKINRA
12/03/2015		PREDNISOLONE(SOLUBLE)
05/03/2015		FLUDROCORTISONE
05/03/2015		AZATHIOPRINE
03/03/2015		CICLOSPORIN (1mL)
02/03/2015		INFLIXIMAB (REMICADE)
23/02/2015		INFLIXIMAB (REMICADE)
23/02/2015		AZATHIOPRINE
19/02/2015		TOCILIZUMAB (4mL)
16/02/2015		AZATHIOPRINE (CARDIFF)
16/02/2015		AZATHIOPRINE
13/02/2015		INFLIXIMAB (REMICADE)
11/02/2015		ADALIMUMAB
09/02/2015		AZATHIOPRINE (CARDIFF)
09/02/2015		AZATHIOPRINE (CARDIFF)
07/02/2015		INFLIXIMAB (REMICADE)
05/02/2015		AZATHIOPRINE
04/02/2015		ADALIMUMAB(HOMECARE)
02/02/2015		AZATHIOPRINE
29/01/2015		AZATHIOPRINE (CARDIFF)
26/01/2015		METHYLPREDNISOLONE SODIUM SUCCINATE
23/01/2015		AZATHIOPRINE
23/01/2015		HYDROCORTISONE
22/01/2015		AZATHIOPRINE
14/01/2015		AZATHIOPRINE
06/01/2015		ADALIMUMAB
06/01/2015		PREDNISOLONE(SOLUBLE)
02/01/2015		ADALIMUMAB
01/01/2015		AZATHIOPRINE (CARDIFF)

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 04 October 2017 11:26
To: Vinod Diwakar
Cc: [redacted]
Subject: RE: refined gastro drugs list - FINAL REVISION attached
Attachments: Gastro patients for review by drug list 20150307.xls

No I haven't taken out the deceased patients or the transitioned patients – as this requires correlation with PIMS. Now that you have reminded me perhaps [redacted] could have a joint blitz through first 144 patients so we have a final list to start making appts for. (I think [redacted] was optimistic this could be done in a couple of hours, or we could get [redacted] on to it?).
Many thanks, [redacted]

[redacted]

[redacted]

From: Vinod Diwakar
Sent: 04 October 2017 11:26
To: Heuschkel, Robert
Cc: [redacted]
Subject: RE: GOSH Gastro Service Plans 23.2.16
Attachments: Letter to urgent cohort of patients 18 02 16.pdf; Script for urgent cohort 18 02 16.pdf

Dear Rob

Thank you for agreeing to see gastroenterology patients whose diagnosis and management has raised concern as per your proposal below.

I enclose the letter and subsequent script that will be used to inform patients

This has been highly effective and all the patients reviewed by your expert group have been seen or are about to be seen.

I will ask [redacted], our turnaround programme manager to contact you to set up the relevant clinics and to start booking these patients in

I am copying [redacted] who has been seeing these patients for his experience as to how the second opinions have been going.

As discussed, the rate limiting factor in establishing second opinions for these patients is the number of external gastroenetologists that we can engage to undertake this work.

With very best wishes and thanks for all your support for this area. Please would you pass our thanks on the to rest of your team.

Vin

Vin Diwakar
Executive Medical Director and Consultant Paediatrician: **T:** 0207 405 9200 ext. 5257 | [redacted]
Level 3 Paul O'Gorman Building | **Great Ormond Street Hospital for Children** | **Great Ormond Street** | **London WC1N 3JH**

From: Heuschkel, Robert [mailto:robert.heuschkel@addenbrookes.nhs.uk]
Sent: 24 February 2016 06:35
To: Vinod Diwakar
Subject: Gastro Service Plans 23.2.16

Dear Vin,

[redacted]

[redacted]

From: [redacted]
Sent: 18 October 2017 11:58
To: David Hicks
Subject: FW: Gastro Report
Attachments: image001.jpg; image002.png

Follow Up Flag: Follow up
Flag Status: Flagged

Thank you David

That is a very helpful and comprehensive summary. It is good that the system seems to be working across the Trust . As I mentioned yesterday there remained when we visited a significant group of people whom we spoke to who appeared not to have heard the message, perhaps having experienced close-up their properly raised concerns not being heard or a punitive approach being inferred and a perception that their views are unwelcome. We will instead perhaps recommend a proactive push for those in gastro and general paediatrics to feel confident to use the system without fear and particularly to get feedback / be involved in any investigation. I've been exploring with [redacted] how that is happening with the case reviews and the importance of involving the experienced general paediatric consultants with the development of any systems.

[redacted] It was very helpful to meet Peter and I understand how much he has to deal with running such a complex Trust with so many stakeholders. [redacted] I know that is not your personal approach and you have worked hard to engage the clinicians, but it would be such a positive step for the draft report or its essence to be shared confidentially with the clinical lead and Divisional Director to listen to their comments before it goes externally to the CQC. That would go some way towards building trust and encouraging them towards greater accountability and leadership responsibility. They can then perhaps help with the messaging and development of the action plan when the report is more widely available.

The people who talked to us seemed almost universally to be good decent people really keen to improve things for their patients but seeking encouragement from the top to help them to turn the tanker round now it's stopped. The messages that reach the troops alongside our report are so crucial to making the change happen. But I know you know all that.

I'll get back to Peter [redacted] with the revised exec summary once we have the PO number; sorry, not allowed to do any more till we have it. I'm astonished that the finance systems are so complex!

Best wishes

[redacted]

[redacted] RCPCH
5-11 Theobald's Road London WC1X 8SH
[redacted]
http://www.rcpch.ac.uk/invitedreviews

Leading the Way in Children's Health

From: David Hicks
Sent: 17 October 2017 16:21
To [redacted]
Subject: FW: Gastro Report

Dear [redacted]

This is some information about the freedom of speech ambassadors we spoke about this morning.

Please let me know if the invoice does not transpire soon.

Best Wishes

David

Dr David Hicks Interim Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229

From: [redacted]
Sent: 14 September 2017 09:33
To: [redacted]
Cc: [redacted]; Peter Steer; David Hicks; [redacted]
Subject: Re: Gastro Report

Hi [redacted]

Comments for response below on FTSU Ambassadors and approach to raising concerns within the hospital.

_____

GOSH currently have seven FTSU Ambassadors including a senior consultant, senior nurses, lab-based staff and those who work in administration. It is intimated in the RCPCH report that the Trust erred in some way when it decided to appoint a number of ambassadors, rather than appoint one individual who is at a senior level (the example of Medical Director is given). The decision to appoint a number of Ambassadors was a deliberate strategy to ensure that the GOSH Ambassadors, through representing a diversity of job roles, grades etc. would be approachable and easily accessible to all staff. We can anticipate from the very low number of cases that were previously raised at GOSH, that staff may not wish to use, for whatever reason, the agreed mechanisms for raising concerns – such as approaching their manager or the Non-Executive Board member who is responsible for Raising Concerns. We have found since its inception that the approach has worked; Ambassadors have been contacted about patient safety concerns by a variety of people, including medical staff. We have also found that staff with concerns have been able to speak to Ambassadors as they carry out their day-to-day roles 'on the ground'. We believe that this

has encouraged more people to come forward about issues they are concerned about given that it helps to remove any stigma or fear associated with having to especially seek out a full-time and/or senior level Ambassador / Guardian. We also have some evidence that our approach has been well received by people who have used it; our Ambassador team recognised that it was important for them, and for GOSH, to generate indicators highlighting their effectiveness / success in supporting staff and as a result they have started to ask people who come to them to give feedback about how they found the service and whether they would encourage others to use it. To date all responses received back, which whilst low in number (this is a new approach) have been extremely positive.

The role of the Ambassador at GOSH is extremely clear and a thorough selection process was undertaken to ensure that we arrived at the service we required. The ambassador role was advertised across the Trust using the GOSH specific Ambassador role specification and interested staff invited to attend drop-in sessions to find out more. Those who decided to apply then completed an application form and a formal shortlisting process was undertaken. Shortlisted candidates then underwent a two-stage selection process. This involved panel interviews and an assessed role play exercise. It was clear that those who applied were of high calibre, keen and enthusiastic and eight were appointed (one has subsequently left the role due to personal reasons).

The Ambassador team have received considerable development and support, and contrary to what is written in the report meet monthly to learn from each other and to offer each other support when dealing with issues which are brought to them. We have also seen more experienced (through their substantive role) Ambassadors actively supporting and mentoring more junior team members to ensure they are able to take on cases and provide appropriate advice and support to staff who have concerns. All Ambassadors have received a bespoke and ongoingdevelopment programme in order to ensure they obtain a wide range of skills and knowledge. This includes Safeguarding and HR policy training as well as input around relevant employment legislation from an employment lawyer and attendance at national training events through the National Guardian's office.Ambassadors are also well supported on a day-to-day basis by the HR&OD Directorate.

Ambassadors have a direct line to the CEO, should they need it, and one Ambassador has used this avenue to date.

In terms of raising their profile, Ambassadors have attended and spoken at the Chief Executive Lunchtime Briefing Sessions which open to all staff. All Ambassadors have taken time out of their duties to speak to colleagues and to those in other teams about the importance of speaking up and the service they provide. In the summer the Trust hosted Henrietta Hughes, the National Guardian and one of the Ambassadors spoke at a conference held on the same day which attracted both internal and external attendees. There is no on-going involvement with the National Guardian about the role of Ambassadors at GOSH.

Having been established for nearly a year the service is being reviewed to ensure it continues to meet the needs of the Trust. The review is not currently concluded but there are no plans to re-advertise for more 'volunteer (non-staff) Guardians' as has been suggested.

In more general terms the Trust takes its responsibilities towards creating a safe culture and environment very seriously. It has a Raising Concerns Policy which is available to all staff. It has also launched a route map for staff to make the process of raising concerns easy to follow. All staff are told about the Ambassadors at their corporate induction and are encouraged to raise issuesof concern early, either to them or via another agreed route. In May 2017 we held two listening events to explore issues which surfaced in the staff survey which included making GOSH a great place to work, Harassment, Bullying & Violence and looking after our staff. Ambassadors attended these events to listen to, and learn from, colleagues.

Hope this helps and happy to discuss

Best wishes

[redacted]

[redacted]

On 13 Sep 2017, at 3:34 pm, [redacted]

[redacted]

[redacted]

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[redacted]

From: Andrew Long
Sent: 02 August 2017 09:11
To: [redacted]
Subject: Fwd: Amazing Productions
Attachments: image001.jpg; image002.jpg; image003.jpg; image004.jpg; image005.png; image006.jpg

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

You will remember that, just before you went on your London-Paris ride, I spoke to you about the Gastro documentary and FoI requests that had come in to the trust.

You will see the email string below from Vin, and I have already spoken to [redacted] who has a great deal of information however I know that you were quite heavily involved at the time and wondered whether you might know where the original data was stored?

There seems to be a suggestion that it was stored on the K drive but no one seems to know who might have access to the relevant files. Can you help?

Best wishes

Andrew

Sent from my iPad

[redacted]

From: DIWAKAR, Vinod (NHS ENGLAND) [mailto:vdiwakar@nhs.net]
Sent: 01 August 2017 19:43
To: David Hicks
Cc: [redacted]; [redacted]; [redacted]
Subject: RE: Amazing Productions

Dear David

I did not keep personal records of the work, and so this email is from memory and might not be accurate.

[redacted]

[redacted]

We used the standard harm classifications recommended by the NHSLA.

The classification was based on clinical review of the patient by one of [redacted].

They recorded and fed back their assessment to [redacted] the programme manager, who recorded their assessments in a table which was stored on a shared drive set up to file all papers related to the review of the gastroenterology service. [redacted] had access to the shared file since she led the work on a Freedom of Information request.

In terms of formal organisational governance, I cannot recall whether the assessment of individual patients was presented in committee, discussed, tested or signed off formally. I have a vague recollection that [redacted] also developed a table which triangulated the clinical review by [redacted] with the rapid case note review undertaken by the Drs [redacted]/Heuschel/Croft group and with the detailed case note review undertaken by one of [redacted]

Email discussion on any matter relating to the review was using my vinod.diwakar@gosh.nhs.uk account and I have not had access to those emails since I left GOSH [redacted].

I hope that is helpful. I'm very happy to discuss by telephone.

Yours sincerely

Vin

Vin Diwakar
Regional Medical Director
NHS England (London Region)| Skipton House | 80 London Road | London SE1 6LH
T: 0113 80 70830 | [redacted]
GMC Number: 3332517

From: [redacted]
Sent: 01 August 2017 14:56
To: DIWAKAR, Vinod (NHS ENGLAND) <vdiwakar@nhs.net>
Subject: Amazing Productions

Dear Vin

I was wondering if you could help us make a response to amazing productions by explaining the process which determined the classification of harm for patients reviewed in the gastro process.

Can you tell me who was on this group, where the minutes were kept, what classification was used and who the team reported to please. Did anyone provide admin support since I can approach them or their records.

Your anticipated help is much appreciated

Best Wishes

David

Dr David Hicks Interim Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229

** **From:** DIWAKAR, Vinod (NHS ENGLAND)
Sent: 24 July 2017 06:38
To: [redacted]
Cc: [redacted]
Subject: FW: Questions as discussed

Dear [redacted]

Thank you for your call earlier.

[redacted]

[redacted]

I did not keep records or correspondence or papers relating to gastroenterology when I moved from Great Ormond Street t[redacted]. All records were retained within the trust and access to emails from the vinod.diwakar@gosh.nhs.uk should be available from the trust's IT department. I do not have access to those emails.

In answer to your questions:

1. I cannot recall whether the figures that you have quoted are accurate. A summary of the case note reviews undertaken by the expert panel chaired [redacted] was made. Another summary was kept of patients who were reviewed by either by [redacted]

[redacted]. All the papers relating the reviews were filed on a single shared drive on the GOSH servers.

2. We sought a list of clinicians from several sources and Great Ormond Street approached the potential reviewers directly. You will need to speak to [redacted] at the Royal College to ask whether the College would be happy to use the term "recommended".

3. I cannot answer this accurately without access to the relevant reports. You will need to ask one of the senior clinicians to review the relevant reports on each patient.

I'm sorry that I cannot be more helpful. It's clearly difficult to answer your queries in any degree of detail after so long and without access to the records.

Yours sincerely

Vin

Vin Diwakar
Regional Medical Director
NHS England (London Region)| Skipton House | 80 London Road | London SE1 6LH
T: 0113 80 70830 | [redacted]
GMC Number: 3332517

From: [redacted]
Sent: 21 July 2017 13:50
To: DIWAKAR, Vinod (NHS ENGLAND) <vdiwakar@nhs.net>
Subject: Questions as discussed

Dear Vin

Thank you for your time just now on the phone.

As discussed there are a few points I wish to validate before we send our response to the production company.

1. In the spokesperson briefing that was prepared with you in December 2016 (see attached), it states:

How many patients' drug treatments were questioned?
Of the 1,125 patients in the service, the reviewers found 24 patients who had had unnecessary procedures, exclusion diets or questioned some drug treatments. Of these, the reviewers questioned drug treatments of 10 patients.

To your recollection, are the 24 and 10 figures accurate? I cannot find the original source for these calculations, based on the various patient cohorts that were reviewed.

2. Additionally, I am under the impression that following the RCPCH report, the individual external reviewers were recommended by the RCPCH. It would be helpful for us to state this clearly, as it shows we sought objective assessment of the service.

So in essence I am asking did the RCPCH recommend individuals or did GOSH select themselves:

- The members of the Nov 2015-Jan 2016 panel featuring Rob Heuschkel et al
- And subsequently the experts who did in depth reviews of the 14 ([redacted])

3. Finally, I am finding it difficult to establish a clear view of the findings of the Leeds Histopathology reviews. Did these correspond with the diagnoses made at GOSH or deviate?

Thanks for your help with this as you are across the detail of the entire review process.

It would be great if you could look at this after clinic. I'm on [redacted] if easier to chat on the phone.

Best wishes
[redacted]

[redacted]

[redacted]

[redacted]

From: Andrew Long
Sent: 02 August 2017 09:46
To: [redacted]
Subject: Re: Amazing Productions
Attachments: image001.jpg; image002.jpg; image003.jpg; image004.jpg; image005.png; image006.jpg

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks [redacted]

We will try [redacted]

Andrew

Sent from my iPhone

On 2 Aug 2017, at 09:31, [redacted] wrote:

> Hi Andrew
> Have read the chain and so sorry but cannot help! All these events were way after me but if [redacted] was the programme manager how strange it is not on the drive used locally within her dept? Try [redacted] regarding the drive used as he worked in the old MDTS and may be able to help – also knew a bit about Gastro.
>
> Looked out for you on Sunday – hope you had a good time. I really enjoyed it this year – was fitter than last time!
> [redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 11 September 2017 10:48
To: Peter Steer; [redacted]; David Hicks; Andrew Long [redacted]
Cc: [redacted]
Subject: Gastro Report
Attachments: 170908 GOSH Gastro report draft for client review.doc

Follow Up Flag: Follow up
Flag Status: Flagged

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For your security it is highly recommended to confirm the sender's email address and details before attempting to open and extract the file contents.

This is an informational warning from the NHSmail Team.

Dear All

I am re-circulating the draft report from the RCPCH to make sure that everyone advising on the gastro documentary response has a response, along with all of the executive team.

[redacted] has agreed to collate comments so please send your review comments back to him. As there may be some key decisions made on the back of this, we do need your comments urgently.

Please send your comments to [redacted] by 10 am on Wednesday 13 September (ie this Wednesday)

Do let me know if you have any questions.

Best wishes
[redacted]

[redacted]

From: [redacted]
Sent: 28 June 2017 12:45
To: [redacted]
Cc: Andrew Long; David Hicks
Subject: FW: [redacted] Right of Reply
Attachments: [redacted] Right of Reply 270616 .pdf; [redacted] Right of Reply 280616.pdf

Follow Up Flag: Follow up
Flag Status: Completed

Categories: Orange Category

Now with the correct email address for [redacted].

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 18 September 2017 18:52
To: Andrew Long
Subject: Re: Gastroenterology

Perfect.
[redacted] I think we will aim to implement the shorter working day model earlier than planned.
See you soon.
[redacted]

Sent from my iPhone

> On 18 Sep 2017, at 17:30, Andrew Long <Andrew.Long@gosh.nhs.uk> wrote:
>
> Many thanks [redacted]
>
> I am meeting [redacted] on Wednesday so should be clearer after that.
>
> Andrew
>
> Sent from my iPhone
>
>> On 18 Sep 2017, at 18:27, [redacted] > wrote:
>>
>> Dear Andrew
>>
>> Just to let you know that I have updated [redacted] today. [redacted] We are planning to meet at 1pm on Thursday to discuss our options, hopefully you will be available to join us.
>>
>> Have a safe journey home.
>>
>> [redacted]
>>
>>
>>
>>> On 15 Sep 2017, at 22:37, Andrew Long <Andrew.Long@gosh.nhs.uk> wrote:
>>>
>>> I think it would be politic to mention it on Monday. It may help to explain my absence today and the fact that I shall be around in the office less over the next few weeks. You might also let everyone know that the Gastro documentary is due to air on 28th September which is why there is so much urgency to get our house in order.
>>>
>>> I am afraid that I was on a three line whip [redacted] and there is some more stuff due to be revealed through the College report and other things that will slowly become apparent. Can you tell [redacted] (quietly) that I will take him for a coffee and explain something of what I told you yesterday, but also talk about the approach to Gastro in more detail.
>>>
>>> Thanks for your understanding and support.
>>>
>>> BWs
>>>

>>> Andrew
>>>
>>> Sent from my iPad
>>>
>>>> On 15 Sep 2017, at 20:53, [redacted] > wrote:
>>>>
>>>> Dear Andrew
>>>>
>>>> Many thanks for letting me know as soon as possible, I know that we both appreciate that the short time scale is unfortunate for us, but cannot be helped. Are you sure you want me to mention it before your return? I am happy to do so, and perhaps the additional 48h before you return may help emotions, if they flare, subside a little before you come back on Wednesday. I can discuss it on Monday with whoever is around, but please do confirm that is really what you want me to do. Do have a think about that, as long as you let me know before Monday, I am happy to do so, we don't need to confirm anything before then.
>>>>
>>>> Enjoy Egypt, take care.
>>>>
>>>> [redacted]
>>>>
>>>> Sent from my iPhone
>>>>
>>>>> On 15 Sep 2017, at 19:11, Andrew Long <Andrew.Long@gosh.nhs.uk> wrote:
>>>>>
>>>>> Dear [redacted]
>>>>>
>>>>> As suspected, I had a call from Peter this afternoon telling me that he wanted me to focus all my energies on the gastro service with imminent effect.
>>>>>
>>>>> I am really sorry that I am in Egypt on Monday/Tuesday next week and so will not have the opportunity to discuss it with the team. I also don't want to risk additional antibodies by telling anyone else in the team in isolation. I wondered, therefore, whether you could start the process and I will fill in the details on my return on Wednesday.
>>>>>
>>>>> At the current time, I think you should assume that I am not going to be doing any attending for the foreseeable future. Fortunately I have just completed my two attending weeks so there is a little gap before a crisis however it will need some careful management. As we discussed yesterday I think the timing should be OK provided we ensure that [redacted] fulfils his commitment and [redacted] is happy to pick up the odd shifts as she has said that she is prepared to do.
>>>>>
>>>>> I am really sorry to do this however you will understand that it is none of my making but needs to be done in the best interests of the service.
>>>>>
>>>>> Happy to chat on Weds but it will be expensive in call costs before then.
>>>>>
>>>>> Have a good weekend.
>>>>>
>>>>> Andrew
>>>>>
>>>>> Sent from my iPhone
>>>>>
>>>>>> On 15 Sep 2017, at 14:07, David Hicks <David.Hicks@gosh.nhs.uk> wrote:
>>>>>>
>>>>>> you have my support Andrew and thank you,
>>>>>>
>>>>>>
>>>>>> Best Wishes,
>>>>>> David

>>>>>>
>>>>>>
>>>>>>
>>>>>>
>>>>>> -----Original Message-----
>>>>>> From: Andrew Long
>>>>>> Sent: 15 September 2017 14:06
>>>>>> To: David Hicks; [redacted]
>>>>>> Cc: [redacted] Peter Steer; [redacted]; [redacted]
>>>>>> Subject: Gastroenterology
>>>>>>
>>>>>> Dear David/Andrew
>>>>>>
>>>>>> I recognise that I have agreed to take on a significant commitment to Gastroenterology without agreeing how I can make it work within my current jobplan/work commitments.
>>>>>>
>>>>>> I realise that David and [redacted] are going to be away next week so I probably need to meet with Andrew on Wednesday to sort out how this is going to work without a major hiatus in General Paediatrics. I had taken the initiative of discussing this with [redacted] yesterday prior to the Gastro meeting so she is aware that it is likely that I will need to drop much of my general paediatric workload commitments, at least for the short term however I probably need to discuss this with [redacted] as well.
>>>>>>
>>>>>> Many thanks
>>>>>>
>>>>>> Andrew
>>>>>>
>>>>>> Sent from my iPad

[redacted]

From: DIWAKAR, Vinod (NHS ENGLAND) [mailto:vdiwakar@nhs.net]
Sent: 03 October 2017 22:31
To: David Hicks
Cc: [redacted]
Subject: RE: Amazing

Dear David

Thank you for your email.

As we have discussed, it is difficult for me to answer this without access to my old email account at Great Ormond Street.

However, I am happy to confirm that your suggestion matches my recollection. [redacted] was clinical director of the service at the time and I have a feeling that she took the lead in compiling the final list. However, I may not have remembered this accurately.

I hope that helps.

It would be useful if you could let [redacted] communications team know of the date of the transmission.

All the best

Yours sincerely

Vin

Vin Diwakar
Regional Medical Director
NHS England (London Region)| Skipton House | 80 London Road | London SE1 6LH
T: 0113 80 70830 | [redacted]
GMC Number: 3332517

From: David Hicks [mailto:David.Hicks@gosh.nhs.uk]
Sent: 03 October 2017 09:21
To: DIWAKAR, Vinod (NHS ENGLAND) <vdiwakar@nhs.net>
Subject: Amazing

Dear Vin

I hope you are well. We are still yet to hear a confirmed broadcast date for the gastro documentary, but will keep you posted as we find out more. We expect to receive at least two weeks' notice ahead of transmission.

In the meantime, we have received some further correspondence from the journalists which is pertinent to your involvement in the review process. They are scrutinising the composition of the second cohort of patients to be externally reviewed - the 42 on immunosuppressants without an alternative diagnosis that unquestionably required such treatment (i.e. children without IBD or post bone marrow transplant on immune-modulation).

The journalists have obtained from an unknown source a confidential document authored by you. They believe you shared this document with NHS England in March 2016 (see attached).

The document, dated 04.03.2016, outlines actions initiated in response to the RCPCH Review and the External Clinician Panel Review (of the 18 patients). This document suggests that the second cohort of patients on immunosuppressants initially consisted of 345 patients. I have copied the relevant information from the document below:

> *A higher risk group are 345 patients were started on immunomodulatory drugs in the absence of inflammatory bowel disease or bone marrow transplant of which 152 were started in the last year.*
>
> *The rate limiting factor which determines the speed within which all these patients can be seen is the number of gastroenterologists.*
>
> *Each patient takes 1h to review. The trust has agreed 0.5wte consulant locums ([sec 40 (2)], started in January 2016). [sec 40 (2)], is a [sec 40 (2)], but will not be in place till June 2016 and [sec 40 (2)],, a [sec 40 (2)], will not be in place till April 2016.*
>
> *Assuming that they each see 9 patients per week:*
> *- 152 patients will have been seen by the end of May*
> *- All 345 patients will have been seen by the end of August*
>
> *Patients have been prioritised so that patients on immunosuppression without inflammatory bowel disease or post Bone Marrow Transplant are seen first (before patients who are on diet restriction or patients who have been labelled with eosinophillic colitis but who are not on treatment). Ideally, clinics should be conducted at GOSH…*

The journalists are questioning why the group of 345 patients on immunosuppressants subsequently became a smaller group of 42 patients to be externally reviewed.

We believe this reduction in numbers is a consequence of further analysis of this cohort, identifying and removing any patients with other diagnoses that would necessitate immunomodulation therapy e.g. for those patients with rheumatological conditions and so on – and not just those with IBD and post-bone marrow transplant.

As you led on this stage of the review process, are you able to confirm our understanding is accurate? This 345 number is not something we have seen referred to elsewhere.

Best Wishes,
David

PS your earliest attention to this would be much appreciated.

Thank you in anticipation

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Gastroenterology Service Review

Media Investigation

1. Overview:

Amazing Productions, an independent production company, is developing a documentary for ITV as part of the broadcaster's '*Exposure*' current affairs strand, which broke the Jimmy Savile scandal. Episodes typically air in a post-News at Ten slot and receive less than one million viewers

Amazing is working in partnership with the Bureau of Investigative Journalism (BIJ) who plan to place coverage in a national newspaper on the same day as the documentary airs.

2. Amazing Productions and BIJ's contributors and sources:

Amazing Productions and the BIJ have obtained a number of confidential documents, reports, emails and correspondence from the review process.

These include the original RCPCH report, the case note report and emails between GOSH, reviewers and NHS England. They have also sought additional information under various Freedom of Information (FOI) requests.

Amazing Productions and the BIJ have interviewed multiple clinicians from other hospitals who are highly critical of the gastroenterology service, GOSH's approach to the review (suggestive of a 'cover up') and the Trust's sharing of information with patients. The clinical contributors are individuals who have had former GOSH patients referred to them, and have taken issue with their former care management. The clinical contributors include one of the reviewers who was invited by GOSH to take part in the case note review of patients.

A number of patients and parents have also contributed, some anonymously and some identifiably. None of the patients that have been identified to GOSH by Amazing Productions and BIJ were subject to the review process.

The journalists also have internal sources within the hospital.

3. Amazing Productions and the BIJ's allegations

Amazing Productions and the BIJ have outlined their allegations in the form of Right to Reply letters to the Trust. They allege:

- The GOSH gastroenterology department has routinely over-investigated, over-diagnosed, misdiagnosed and over-treated children suspected of having EGID (eosinophilic gastro-intestinal disease) that treatment was sometimes unnecessary and that sometimes this was harmful to the patients.

- Patients diagnosed with EGID at GOSH have received these inappropriate treatment paths for many years; a practice that has caused deep concern to the wider profession.

- Over-treatment, including use of potent and potentially harmful medication over prolonged periods, with little or no review has led to harm, with psychological and behavioural consequences, poor school attendance, inability to eat normally, and an impact on family life and general development.

- GOSH has not shown full candour to many patients, parents or fellow professionals in relation to the problems in the gastroenterology department and their consequences.

- GOSH's communications with patients and their families about the findings of the review have not fully adhered to its Duty of Candour, as defined in Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

- GOSH's failure to show full candour means many families are unaware that medications taken by their children over a sustained period may have been unnecessary and even have caused harm. It also carries the risk that children not under – or no longer under - the direct care of GOSH may continue to be on unnecessary and harmful treatment paths and that clinicians who trained at GOSH may continue to initiate such treatment paths.

- GOSH's gastroenterology department had lost sight of what is acceptable medical treatment. According to clinical contributors from other hospitals who have been interviewed for the documentary, the department has "gone rogue" and lost medical, scientific, and clinical perspective in relation to its treatment of EGID. One clinical contributor describes the gastro service issues as "one of the biggest scandals in paediatric practice".

- GOSH's international reputation makes it very hard for medical professionals to criticise its diagnosis and treatment.

4. GOSH strategy and response to-date

Amazing and the BIJ have been researching their story since at least late 2016, and did not directly engage with the Trust until June 2017 when they initiated a series of Right to Reply letters. In the case of Amazing, ITV's legal team are involved in this process.

We have provided detailed responses outlining the review process we undertook. We have acknowledged that there have been issues with the gastroenterology service and accepted that we should be held publicly accountable but that they are overstating, exaggerating and distorting the true picture, which risks breaching their obligations under OfCom.

Details of our response include:

- We have acknowledged that issues were identified and that we regret that some parts of the service did not come up to the high standards that we seek to deliver.

- We maintain that these issues were appropriately investigated and due care and attention has been taken to remedy these issues through a very thorough review process and action plan.

- We have duly involved our regulators at NHS England and the CQC every step of the way.

- No evidence of significant / serious harm was recorded by any of the reviewers, as per the national classification criteria.

- We maintain that we have acted transparently in our communications with patients and met our obligations under our legal duty of candour.

- We have challenged their allegations concerning the scale of the issues identified, highlighting that the issues relate to a relatively small and select cohort of patients.

These responses have been supplemented by providing a timeline of the review process, the communications that were sent by letter to patients and other hospitals and - [redacted] an in depth case note review which scrutinised his approach to care management and disputed many of the original, critical findings of a less detailed case note review.

[redacted].

The BIJ has also sent a Right of Reply letter to the CQC and NHSI, suggesting the regulator has not appropriately investigated GOSH and held it to account over the issues identified in the gastro service.

5. Differences of Opinion between GOSH and the Journalists

- Amazing and the BIJ contend that the second stage of the review was commissioned for the purpose of investigating the treatment of EGID (and have obtained documentation which can be interpreted this way). GOSH maintains that the review was not commissioned solely to focus on EGID.

- GOSH has produced details of the numbers of patients reviewed and summarised the findings of 'no serious or long-term harm'. Amazing and the BIJ do not accept that this represents a comprehensive review of patients at risk and query why more cases were not reviewed.

- GOSH maintains that Amazing and BIJ have exaggerated the scale of the problem. In contrast, Amazing and the BIJ accuse GOSH of trying to play down the problem.

  - Amazing and the BIJ are focusing on a document they sourced in the summer of 2017. This is authored by Dr Vinod Diwakar, the former Medical Director at GOSH (now medical director at NHSS London), which they believe categorically states that GOSH has 345 patients receiving immunosuppressants as a result of a diagnosis of EGID.

- GOSH maintains that this has been a comprehensive review process and that action is being taken to respond to the findings. Amazing and the BIJ query why we are not willing to release the paperwork that provides evidence from the third stage of the review as evidence (inferring that this is because the findings were not positive). We maintain that, due to the level of concern raised in the second stage, the third stage became part of a performance management process which renders all documentation confidential unless the identities of all involved can be removed and everyone consents to its release. Amazing and the BIJ believe we should redact and release this paperwork.

- Amazing and the BIJ have requested exact patient numbers of patients diagnosed with EGID over a number of years. We have not provided these numbers because we do not have them on file and they would take too long to produce. The journalists find it shocking that we could have a review with particular emphasis on the diagnosis and treatment of one particular condition and yet to not have accurate numbers on this condition.

- Amazing and the BIJ contend that GOSH has failed in its Duty of Candour due a) to its failure to communicate with former patients diagnosed at GOSH and b) the tone and content of the letters we did send out. GOSH maintains that our communications documents and processes were shared with our regulators who have not expressed any dissatisfaction with our communications processes. Furthermore, we maintain that it is not reasonable to expect us to communicate with every former patient of the service.

NB: EGID is a highly complex condition from a diagnostic perspective; it is not universally recognised as a condition; it is likely to be more prevalent in young children than in adults; and there are no international agreed guidelines on its diagnosis and treatment.

6. Next steps

- We are currently awaiting our next formal Right of Reply letters, which should set out how, or if at all, the programme makers intend to reframe their allegations in light of the information we have provided about the nature and scope of the review.

- We have advised Amazing Productions that until they reframe their allegations, we will not be answering any more questions (having received a further 20+ questions from them two-weeks ago). They have informed us that they are currently working with ITV legal on the next round of questions.

- When they next come back to us, they will give us two weeks to respond. We will then need to decide whether we provide a statement, answer their questions in full or grant an on-camera interview.

- We have been assured that we will receive at least two weeks' notice of the programme's airdate.

- We are liaising with CQC, NHS England and NHS Improvement about future engagement.

- We need to agree a communications strategy for broadcast (various ideas have been mooted) and are currently assessing if we wish to engage ITV directly to share our concerns about the programme and the way Amazing and the BIJ are handling their investigation.

- We are preparing an infoline for families to call following transmission of the programme if they have any concerns. This will be supported by communications on our website and social media channels. A detailed Q&A will also be prepared for any follow up media interest from other press outlets in response to the ITV documentary.

/ends

[redacted]

From: [redacted]
Sent: 20 December 2017 00:34
To: [redacted]; [redacted]; Andrew Long
Subject: Review of Amazing Letter
Attachments: Amazing R2R v3.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Hi [redacted] Andy

Please find attached my initial thoughts on the Amazing letter. We need to think very carefully about how we respond to this, particularly due to the nature of their questions.

I have highlighted some initial thoughts but the challenge is going to be how we respond to their specific questions. Do we have the answers? And if we do, do we want to share them? What are the consequences of if we do / if we don't?

Anyway, I will pick this up again in the new year but it would be helpful if you could add any thoughts you may have on this. The timeline will be tight when we get back.

Enjoy the break!

[redacted]

[redacted]
Great Ormond Street Hospital and Children's Charity

[redacted]

[redacted]

From: Andrew Long
Sent: 28 June 2017 15:54
To: [redacted]
Subject: RE: [redacted] and [redacted] Right of Reply

Importance: High

Follow Up Flag: Follow up
Flag Status: Completed

Dear [redacted]

As you can imagine, this is not currently the highest thing on our agenda for today/tomorrow however I do think that this requires urgent attention.

Have we received the separate Right of Reply request mentioned in the last paragraph?

Has this been discussed with [redacted]?

I will try and meet with [redacted] as soon as possible however I am happy to come and find you if you think that would be helpful?

Best wishes

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
Email: andrew.long@gosh.nhs.uk

[redacted]

[redacted]

From: [redacted]
Sent: 03 January 2018 11:05
To: [redacted]
Cc: [redacted]; Andrew Long
Subject: RE: Gastro Documentary

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

[redacted]

The latest news on the TV documentary is that it is to air sometime in February (whether it will or not remains to be seen) and we will be given two-weeks' notice of broadcast.

I am copying Andrew Long - who has taken over the Medical Director role for the next few months - and [redacted] and hope they will keep you informed about future plans for the programme.

Thank you for all your help in digging into the facts surrounding this investigation. It has been very much appreciated.

Best wishes
[redacted]

-----Original Message-----
From: [redacted]
Sent: 17 November 2017 10:22
To: [redacted]
Cc: [redacted] David Hicks <David.Hicks@gosh.nhs.uk>; [redacted]
Subject: RE: Gastro Documentary

Hi

I am just enquiring to see if you have any further updates on date for the documentary to be aired?

Kind Regards

[redacted]

_____
From: [redacted]
Sent: 25 July 2017 11:49
To: [redacted]

Cc: [redacted]; David Hicks; [redacted]
Subject: RE: Gastro Documentary

Many thanks for getting back to me.

Absolutely understood about managing impact on your current role and we will be sensitive of that in any requests we make.

Best wishes
[redacted]

From: [redacted]
Sent: 25 July 2017 11:44
To: [redacted]
Cc: [redacted]; David Hicks <David.Hicks@gosh.nhs.uk>; [redacted]
Subject: RE: Gastro Documentary

Dear [redacted]

Thank you for keeping me in the loop. Yes I am happy to be contacted, however it will need to be at prearranged times, as I am trying to limit the impact on my current role. Can I also suggest that a trawl of the shared drive will give you all the information regarding the review.

Many thanks

Regards
[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 25 July 2017 11:28
To: [redacted]
Cc: [redacted] David Hicks
Subject: Gastro Documentary

Hi [redacted]

Dropping you a line to update you on the gastro documentary. We still do not have a broadcast date for it – but it is now looking more likely for the autumn.

In the meantime, we continue pulling together our side of what happened.

With that in mind, I was hoping you could help. Given your role in the review, you may be able to fill in some gaps in our knowledge. Can we get in touch with you if we have any questions?

My colleague, [redacted](copied on this email) is leading on the fact-finding. Please let us know if you are happy for him to get in touch with any questions.

In the meantime, I will keep you posted if we hear anything more about broadcast plans.

Best wishes

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 08 February 2018 17:34
To: Andrew Long
Subject: FW: Gastro documentary filming script

Follow Up Flag: Follow up
Flag Status: Flagged

Hi Andrew, This is what we overheard….
Pieces to camera for the documentary

[redacted]**Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health**

40 Bernard Street, London WC1N 1LE | [redacted]

From: [redacted]
Sent: 08 February 2018 16:11
To: [redacted]
Subject: Gastro documentary filming script

FYI

Gastro doc filming script – ITV Exposure, producer/director is [redacted]
These were all separate pieces to camera, so order is unknown.

Tonight on Exposure we're trying to discover what went wrong in one department of Great Ormond Street Hospital. We investigate the series of medical reviews which led to it closing its door to most new referrals.

Tonight on Exposure we try to discover what went wrong and why one department here closed its doors to most new referrals.
Tonight on Exposure we try to discover what went wrong and why one department here had to close its doors to most new referrals.

We've established that some patients in the gastroenterology department have been exposed to the risk of unnecessary investigations and to drugs with potentially serious side effects.

We have spoken on the record to three senior consultants from other hospitals who told us of their serious concerns. And many more have shared their misgivings in private.

We've spoken to dozens of parents, many of them worried about the way their child was treated.

We've gained access to some confidential reports, but the key documents have been withheld.
We've gained access to some reports, but the key documents remain confidential.

We don't have all the answers. But given the hospital's unique reputation, we feel that what we have learned/heard is important enough to be held up to scrutiny.

A series of reviews has found that Great Ormond Street Hospital over-diagnosed and over-treated some patients. We've spent the last year investigating what went wrong.

The GOSH board acted swiftly. The families of the 14 patients the experts were so concerned about were told they should expect specialists from other hospitals to review the care of their child.

Exposure has obtained a copy of the Royal College warning letter sent ahead of the report. It says...

(couldn't get all this, as they were filming the letter which showed the text rather than reading it out)

"The service was not being delivered to the standard which we expected. It may be causing avoidable harm to children. They'd been told that…
"It called for a swift and thorough review of the diagnosis and management of 40 of the children…"

Great Ormond Street Hospital for Children
NHS Foundation Trust

Great Ormond Street
London WC1N 3JH

T: +44 (0)20 7405 9200
www.gosh.nhs.uk

Address

Date

Dear X

At Great Ormond Street Hospital (GOSH) we continually strive to improve the care we offer to patients and their families.

I am writing to you following information I have received from a television network, ITV, that you have concerns about the care that xxx had here.

The experience of our patients is of paramount importance to us at GOSH and I wanted to get in touch personally to see if you would be willing to meet with me to discuss your concerns further, with a view to us learning from them in the future.

If this would be of interest, please contact XXXXX on XXXXXXX and she will arrange a meeting at your convenience,

Yours sincerely,

XXXXX

[redacted]

From: [redacted]
Sent: 05 April 2018 12:23
To: Matthew Shaw; Andrew Long
Cc: Cymbeline Moore; [redacted]
Subject: Letter to ITV families
Attachments: DRAFT LETTER - ITV families.docx; FINAL Letter in response to PALS enquiry.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Dear Mat and Andrew,

Further to our discussion yesterday, I've started a draft letter to the families taking part in the ITV documentary – see attached. I've written it bearing in mind that each of these families will have already had extensive communication, and some have been invited in already, so I think it is best pitched as a personal note from the Med Director, asking to meet them for our learnings, rather than a letter about the review etc.

Its short and sweet but I'm not sure what else we would want to say in writing at this point, but please feel free to amend or add to it as you wish. And then if you want to send it back to me I'd be happy to proof if helpful…

It will also need to be personalised to each of the 4 families, and we'll need to get their addresses (which I assume [redacted] can provide?)

Please note the history of two of the families mentioned:

- [redacted]
- [redacted]– PALS had interaction with mother at the start of the year questioning why she wasn't included in the review, and the attached letter was sent at the start of February. I'm not sure this affects us writing now, especially as this one is coming from the medical director, but you may want to review and adapt accordingly?

I've copied [redacted] who knows most of these families and may be able to answer any further questions you have (I've also briefed him on the TX and the plan to write to them and he agrees it's the right approach).

I think ideally these should go out by the end of the week, or latest very early next week – do you think that's possible?

Please do let me know if I can help any further,

[redacted]

www.gosh.nhs.uk / www.gosh.org

[redacted]

From: Matthew Shaw
Sent: 05 April 2018 12:51
To: [redacted] Andrew Long
Cc: Cymbeline Moore; [redacted]
Subject: RE: Letter to ITV families

Follow Up Flag: Follow up
Flag Status: Flagged

Yes so I think this is fine other than to say if they have met before then a line of 'we know you have previously met xxxxxxxxx but if you would like to discuss further then'
Something like that otherwise it may look that we don't know they have been seen and chatted to which may look bad and it might look as you are suggesting like a generic letter.
I don't see any reason why it couldn't go out as you suggest.
Mat

[redacted]

Great Ormond Street Hospital for Children
NHS Foundation Trust

Great Ormond Street
London WC1N 3JH

T: +44 (0)20 7405 9200
www.gosh.nhs.uk

Address

Date

Dear X

At Great Ormond Street Hospital (GOSH) we continually strive to improve the care we offer to patients and their families. I am sure that you are aware that our Paediatric Gastroenterology services have been the subject of intense review during the past three years and we are delighted that the review process has now been completed.

~~I am writing to you following information I have received from~~We have been aware that Amazing Productions have been making a documentary about the gastroenterology services and GOSH and that a television network, ITV, are intending to broadcast in the near future. We have been informed by ITV that you have concerns about the care that xxx had here.

The experience of our patients and their family is of paramount importance to us at GOSH and I wanted to get in touch personally to see if you would be willing to meet with me to discuss your concerns further, with a view to us learning from them in the future. We also plan to hold regular Listening Events for users of the service which may also be of interest to you.

If either of ~~this~~ these would be of interest, please contact XXXXX on XXXXXXX and she will arrange a meeting at your convenience,

Yours sincerely,

XXXXX

[redacted]

From: Andrew Long
Sent: 05 April 2018 12:53
To: [redacted]; Matthew Shaw
Cc: Cymbeline Moore; [redacted]
Subject: RE: Letter to ITV families
Attachments: DRAFT LETTER - ITV families - [redacted] suggestions.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

I have made some suggested amendments which you may wish to consider. I am just asking myself why wouldn't we be up front about the documentary?

Best wishes

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
Email: andrew.long@gosh.nhs.uk

[redacted]

[redacted]

From: [redacted]
Sent: 05 April 2018 13:41
To: [redacted] Cymbeline Moore; [redacted]; [redacted]; [redacted] Peter Steer; [redacted]; Matthew Shaw; [redacted]; director@ich.ucl.ac.uk (director@ich.ucl.ac.uk); [redacted]; [redacted]
Cc: [redacted]
Subject: Update on Gastro TV Programme [redacted]
Attachments: [redacted]

Follow Up Flag: Follow up
Flag Status: Flagged

Dear Board members

Gastro Documentary – airing on 16 April 2018

Following the update to the Board on the gastroenterology service last month, we can now confirm that a documentary programme looking into the review will air on April 16.

The programme will be broadcast on ITV 1 and we expect it to air at 22:45 and last 60 mins. It is part of ITV's investigative documentary strand of programmes called 'Exposure'.

As you may be aware, we have worked hard through various routes, including legal, to remove unfounded allegations and ensure that the content of the programme is as accurate as possible. This has been fairly successful and many of the initial allegations have fallen away or been substantially caveated.

We have now been told that the programme will centre around the following:

- There are questions as to whether GOSH should have reviewed a larger cohort of patients both present and past that could have been potentially affected by misdiagnosis, over-investigation and overtreatment
- There are concerns as to whether GOSH has shown full candour to patients, parents, other medical professionals or referring hospitals regarding the review. And that by not doing so
  patients' families may be unaware that the treatment of their children may have been unnecessary, and may have exposed them to unnecessary potential harm, and carries the risk that children not under - or no longer under - the direct care of GOSH may continue to be on unnecessary and harmful treatment paths, and that clinicians at other hospitals may continue to initiate such treatment paths.
- A number of patients diagnosed with EGID who were treated at GOSH appear to have responded positively to a less or non-medicalised treatment path at other hospitals. In one case, the hospital that subsequently treated the child has a concern the child's test results and condition were over-interpreted at GOSH.
- The closure of the gastroenterology department to most new referrals has created pressure on other tertiary paediatric gastroenterology units in the South East that have accommodated those referrals.

The programme is due to feature three clinicians from other hospitals - one who took part in the review. It will also feature four patient case studies which we expect will generate emotive content around the effect their treatment has had on their lives. We are contacting all the patients featured and inviting them to engage with us if they wish. We are not aware that any of our clinicians will be mentioned by name.

Our media handling strategy is to provide a concise statement to the programme makers outlining: the complexity of this area of medicine; the thoroughness of the review; and reassuring patients that changes in clinical

management were only necessary in a very small number of patients. We will share this with you prior to broadcast. We will also produce a longer statement for our website. We have debated whether to put forward a spokesperson for the programme but concluded that this carried much greater risk than benefit.

We will also set up a helpline for patients and are briefing our regulators and commissioners. Finally, we will be carrying out extensive internal communications around broadcast and briefing our Members Council.

Should you have any questions at this stage please do not hesitate to ask.

[redacted]

I hope this is helpful.

Kind regards

[redacted]

[redacted]

Great Ormond Street Hospital for Children NHS Foundation Trust
Executive Offices
Paul O'Gorman Building
Great Ormond Street
London
WC1N 3JH
[redacted]

[redacted]

From: [redacted]>
Sent: 05 April 2018 14:25
To: Andrew Long; Matthew Shaw
Cc: Cymbeline Moore; [redacted]
Subject: Re: Letter to ITV families

Follow Up Flag: Follow up
Flag Status: Flagged

Hi

Yes this looks good to me, thanks Andrew.

I guess I was wary that too much mention of the programme may lead to it being interpreted as a way for us to influence them ahead of the programme, but I don't think it reads like that so I'm happy.

Also agree with Mat that each one probably needs a line relevant to their interaction with us, so it's clear we're joined up - this needs to be done in conjunction with their notes which I don't have, is there someone on the department who could look at those 4 cases and review the letters accordingly?

Thanks
[redacted]

Get Outlook for iOS

[redacted]

[redacted]

From: Andrew Long
Sent: 28 June 2017 18:12
To: [redacted]
Cc: [redacted]
Subject: FW: [redacted] and [redacted] Right of Reply
Attachments: [redacted] Right of Reply 270616 .pdf; [redacted] Right of Reply 280616.pdf

Importance: High

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

I understand that you met with [redacted] with Peter and David before he went on holiday yesterday. I believe that you were expecting these letters having received a similar one for GOSH?

I spoke to both [redacted] and [redacted] (and also with [redacted], as requested by [redacted]) this afternoon to assure them of the support that they can expect from our office in writing a response to these letters.

I am aware that the documentary makers have clearly been able to gather a considerable amount of information and it was of concern to the gastroenterologists that the Executive Producer had clearly had a copy of the RCPCH confidential report, when few of us within the organisation have seen it in its entirety. I came looking for you this evening however I am sure that you have had other pressing matters on your mind today!

I would really like to meet with you sometime during the next couple of days to discuss our approach as I feel that I need to be fully informed in David's absence on annual leave.

Best wishes

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
[redacted]
Email: andrew.long@gosh.nhs.uk

[redacted]

[redacted]

From: Matthew Shaw
Sent: 06 April 2018 14:50
To: Peter Steer; [redacted]; Andrew Long; [redacted]
Subject: Fwd: DRAFT EMAIL TO - Dr Emmanuel & Dr Naik

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all so the pilot on my plane had a stroke mid air this morning!!! It was an interesting flight and now in the middle of no-where!
Anyway below is the first draft of a letter to Emmanuel and Naik and I am sending around for comment. There will be another to follow. The balance of these letters are important that we are curious and trying to learn rather than them think we are going to make allegations against them.
Thanks
Mat

From: [redacted]
Sent: 6 April 2018 at 14:09:45
To: Matthew Shaw
Subject: DRAFT EMAIL TO - Dr Emmanuel & Dr Naik

Sandhia.Naik@bartshealth.nhs.uk

Dear Dr Emmanuel & Dr Naik

I am writing to you as the new Medical Director at Great Ormond Street Hospital. We understand that you have recently contributed to the ITV documentary on our gastroenterology service and as the new Medical Director here at GOSH I am trying to learn lessons of what happened with this service over a number of years. From what we understand in the documentary you will be saying that there have been concerns around the service for a number of years and therefore I was wondering if you could provide me with any evidence, emails or conversations you have had with individuals either from GOSH expressing these concerns or from the regulators, CQC, NHSE or NHSI.

The reason I want to ask this is to identify if there were any missed opportunities in identifying this earlier and whether we were listening to the concerns of the clinicians within the speciality outside of the hospital as part of a bigger piece of work we are doing.

Thank you very much for your help and assistance in this matter.

Kind Regards

Mat Shaw

[redacted]

[redacted]

From: [redacted]
Sent: 06 April 2018 16:21
To: Matthew Shaw
Cc: Peter Steer; Andrew Long; [redacted]
Subject: Re: DRAFT EMAIL TO - Dr Emmanuel & Dr Naik

Follow Up Flag: Follow up
Flag Status: Flagged

Hi

Again, I think this looks good.

The only one thing that jumps out is the word “evidence” and I wonder if we replace it with documentation? Ie “provide me with any documentation, emails or conversations....” etc

Just a thought!

Hoping you are ok after your plane incident!!

[redacted]

Sent from my iPhone

[redacted]

CONFIDENTIAL: COMMS PLAN FOR GASTRO DOCUMENTARY AND SURROUNDING MEDIA COVERAGE

The purpose of this document is to outline communications planning ahead of the TX of the Amazing documentary / BIJ publication.

1) Summary of communications to date, following completion of RCPCH review:

- Update letter to patients – sent w/c 12th March
- Update statement on website – posted w/c 12th March
- RCPCH review published in our board papers with a reviewed narrative - w/c 19th March
- HSJ enquiry handled, resulting in piece on Thursday 29th

2) Communications actions for ITV 1 Documentary, 10:45pm (TBC), Wednesday 18th April [redacted]:

- Produce statements for inclusion in the programme - note this should be as short as possible, with potential for a longer version to go on our website
- Produce separate responses to key elements expected in programme, in Q&A form as per usual crisis comms responses. Elements of this can also be used online or in digital channels as needed.
- Clear direction needed for patients or families with questions post TX - Email address or helpline put on website with statement
- Press team to manage queries reactively, with sign off from Peter Steer/Matthew Shaw[redacted]
- External supportive spokespeople to be approached in case of wider media interest – Andrew Long to contact [redacted] to see if they would be open to that and pass on their details to [redacted]

3) Digital actions [redacted]:

- The agreed reactive media statement will be posted on the GOSH website at the time of transmission/publication with a short news story. Proposal to craft some additional top line, informative copy to provide background information without detail. The web page will also signpost concerned patients and families to our helpline number
- Activity on social media will be monitored and the key messaging will be adapted for use on our social media channels, if required, to address queries from the public/patients and families, and signpost to the website statement and helpline.
- Digital team to monitor responses to advance listings and programme publicity.
- Digital team to check other digital activity and speak to relevant teams to change timing and check content.
- Digital team to review families social footprint and clinicians footprint.
- Comprehensive details of the digital strategy are contained in the "Digital – Scenario Planning" document, which will be updated with relevant information by EOP 03/04/2018.

4) Patients and Families ([redacted]/Andrew L/Mat Shaw):

- Ahead of broadcast and publication, the Medical Director will contact patients and families featuring in the documentary and print coverage to invite them to engage with the Trust in resolving their concerns and ensure communications lines are open
- Helpline to be set up in advance of statement being published on website (or in advance of programme – TBC) This will field queries and concerns from patients and families about their treatment. It is anticipated that the Gastroenterology Clinical Nurse Specialist team could field these calls and seek support from communications team, divisional management and PALS service as required to respond. There will be a clear escalation protocol if any cases of concern emerge.

5) Hospital Internal Comms ([redacted]/[redacted]/Mat):

- Gastro team: Mat and Andrew to attend Gastro Consultant meeting on Thursday 5th to update them; plus brief [redacted] with a view to agreeing how to brief wider gastro team asap, then face to face meeting with Medical Director / CEO w/c 9th April, plus email to include reminder of what to do if contacted by journalists directly. Follow up meeting with Medical Director / CEO post broadcast to think about next steps.
- Board: email on Thursday 3th April updating on CQC and Gastro review, including media interest - COMPLETE
- Members Council: update email w/c 9th April
- SMT: heads up at meeting on 5th April with opportunity for questions, plus information shared for SMT to cascade to their teams as appropriate. - COMPLETE
- ODPG: to be briefed on Wednesday 18th April – [redacted] to ensure it is on agenda
- All staff / mass comms: ahead of broadcast and possible publication, all staff email to prepare staff and demonstrate transparency and support for gastro team, care of our patients etc (to send Friday 13th or Monday 16th). Potential need for post broadcast comms depending on what's included in programme and level of follow up press / social media interest. Include note in newsletter on 16 April (broadcast this week).
- PALS: briefing ahead of broadcast / publication, along with lines to be shared on social media.
- Content of all comms will be based on agreed statements, approaches, internal FAQs.

6) External stakeholder Management ([redacted]/Cym/[redacted]):

- Charity – Directors are aware and wider email (plus face to face if required) to do in w/c 9th April
- Letters to referring hospitals and external clinicians to reference TX date- [redacted]/Mat, w/c 3rd April
- All external comms materials to be shared with RCPCH, CQC and NHSE/NHSI before they are sent out. (QUESTION – should we share wider – [redacted] office?)
- Science Media Centre?

7) Other actions to be considered:

- Contact with complaining clinicians - Mat to action

[redacted]

From: [redacted]
Sent: 09 April 2018 20:30
To: Peter Steer; [redacted] Andrew Long; Matthew Shaw; [redacted]
Cc: Cymbeline Moore; [redacted]
Subject: Gastro - draft statement
Attachments: GASTRO COMMS PLANNING - [redacted].docx

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all,

Ahead of our catch up tomorrow, please see below for a first draft of our statement for the TV programme, which Cym and I have crafted.

Its short – as per our discussion - but we'll also have a Q&A with answers for specific questions that may follow the broadcast, and will likely have a longer version for online.

I'd be grateful for your thoughts on the tone, or indeed the content, before we make final tweaks.

I've also attached the DRAFT Comms plan around the programme – this is a working document capturing the main comms actions, but I thought it might be useful FYI. If you have any questions, concerns or thoughts on any of it do let me know.

Many thanks
[redacted]

PROGRAMME STATEMENT

We strive to provide the best possible care to children and young people and are sorry if any child, young person or family is unhappy with the treatment they have received.

In 2015 we commissioned a thorough review of our gastroenterology service, where we invited independent national and international experts to assess the care being given. It focused on incredibly rare and complex conditions where there are no agreed treatment guidelines.

What the review found was that the vast majority of care in the service was good and there was no evidence of long-term consequences for patients as a result of any packages of care.

We would like to reassure viewers that we have done a comprehensive review of all relevant cases and have been in touch with all those families affected.

Now the review process is complete, we are in active discussion with our commissioners about increasing the number of referrals we receive, as part of the nationwide system of care for these patients.

[redacted]
Great Ormond Street Hospital & Charity
[redacted]
www.gosh.nhs.uk / www.gosh.org

[redacted]

From: [redacted]>
Sent: 10 April 2018 22:14
To: Andrew Long
Cc: Cymbeline Moore
Subject: FW: Letter to ITV families
Attachments: DRAFT LETTER - ITV families - [redacted]suggestions.docx

Follow Up Flag: Follow up
Flag Status: Flagged

HI Andrew,

Im just resending the latest version of the letter to families, as promised in the meeting this morning.

Mat's only suggestion was that this letter also include a single personalised line which says something like, ''we know you have previously met xxxxxxxxx but if you would like to discuss further then' so that it doesn't look like we don't know they have been seen and this is the bit that needs someone from the department (or you if you have the notes?) to do for us, using the attached as their template.

The letter will also have to be amended for the BIJ families to reference the print not the broadcast article.

The list of families is:

- [redacted]

Hope this is all ok?

Thanks very much,
[redacted]

[redacted]

Great Ormond Street Hospital for Children
NHS Foundation Trust

Great Ormond Street
London WC1N 3JH

T: +44 (0)20 7405 9200
www.gosh.nhs.uk

[redacted]

Date

Dear [redacted]

At Great Ormond Street Hospital (GOSH) we continually strive to improve the care we offer to patients and their families. I am sure that you are aware that our Paediatric Gastroenterology services have been the subject of intense review during the past three years and we are pleased that the review process has now been completed.

We have been aware that Amazing Productions have been making a documentary about the gastroenterology services and GOSH and that a television network, ITV, are intending to broadcast in the near future. We have been informed by ITV that you have concerns about the care that [redacted] had here between [redacted]

The experience of our patients and their family is of paramount importance to us at GOSH and I wanted to get in touch personally to see if you would be willing to meet with us to discuss your concerns further, with a view to us learning from them in the future. We also plan to hold regular Listening Events for users of the service which may also be of interest to you.

If either of these would be of interest, please contact XXXXX on XXXXXXX and she will arrange a meeting at your convenience,

Yours sincerely,

XXXXX

[redacted]

From: Andrew Long
Sent: 11 April 2018 19:08
To: [redacted]
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: RE: Letter to ITV families
Attachments: [redacted]

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

I have attached draft letters to the patients below (although please note the comments).

Let me know if they meet the requirements – very happy to amend otherwise.

Best wishes

Andrew

Dr Andrew Long
Associate Medical Director and Responsible Officer
Consultant Paediatrician
Great Ormond Street Hospital
Great Ormond Street
London WC1N 3JH

Tel: +44 (0)20 7405 9200 ext 5257
Email: andrew.long@gosh.nhs.uk

From: [redacted]
Sent: 10 April 2018 22:50
To: Andrew Long
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: Re: Letter to ITV families

Thanks Andrew,
[redacted]

Get Outlook for iOS

From: Andrew Long <Andrew.Long@gosh.nhs.uk>
Sent: Tuesday, April 10, 2018 10:37:32 PM
To: [redacted]
Cc: Cymbeline Moore; Matthew Shaw[redacted]
Subject: Re: Letter to ITV families

Thanks Katie

[redacted]

From: Andrew Long
Sent: 12 April 2018 08:04
To: Vin Diwakar
Subject: Fwd: Gastro all staff email

Follow Up Flag: Follow up
Flag Status: Flagged

Dear Vin

I am sure that your team will have alerted you to the intended publication of the BIJ article this weekend and the ITV documentary next Wednesday night at 10.45.

We are just pleased that it will finally be behind us and we can get on with life as usual!

Best wishes

Andrew

-------- Original Message --------
Subject: Gastro all staff email
From: Cymbeline Moore <Cymbeline.Moore@gosh.nhs.uk>
Sent: Wednesday, 11 April 2018 17:33
To: Andrew Long <Andrew.Long@gosh.nhs.uk>, [redacted]
CC: [redacted]

Hi Andrew
Please find below the copy for the all staff email. This has been approved by Peter. Of note, I have included you as someone people can email should they have any questions – this is in the last line.
Firstly do you mind me doing this? I don't anticipate you'll be swamped. Secondly, if you are happy how should we describe you – the lead for the review?
We are planning to send out first thing on Friday morning.
Bw
Cym
Subject: Gastroenterology Service Review
Dear all
As many of you are aware, we have been conducting a review of our gastroenterology service. This started in 2015 and has been comprehensive and thorough, including assessment of cases by independent national and international experts as well by the Royal College of Paediatrics and Child Health (RCPCH). It has now been completed.
Throughout the review process we have shared all the findings with the Care Quality Commission, NHS Improvement and our commissioners, NHS England.

The time taken to conclude the review reflects the incredibly complex nature of some of the conditions we see. This is highlighted by the fact that there are no agreed clinical guidelines for the treatment of these patients.

The review has found that the vast majority of care in the service was good. It also found that there were a small number of patients with very complex conditions who may have had unnecessary procedures or needed modifications to their medication, though there was no evidence of long-term consequences for any patients as a result of their care.

It has also recommended improvements to ways of working within the department – many of which are underway and have already been recognised by the RCPCH team.

While the review was taking place the service was closed to some new referrals and we are now in active discussion with our commissioners about opening up the service as part of a nationwide system of care for these patients.
As we move forward, I would like to acknowledge the impact that the review has had on some members of the team and the commitment the staff within the service have shown to deliver important changes. This is appreciated by us all.
I also wanted to share this further update with you as we are anticipating two pieces of media looking at the review and its findings and I wanted you to be briefed in advance of those pieces running.
One will be a print article running this weekend, and the other a one-off documentary on ITV. This will air next Wednesday at 10.45pm.
We have been working hard over a considerable period of time to ensure that the content of these pieces of media is accurate and does not undermine the confidence of the patients we treat. We have also developed comprehensive plans to respond to any patient queries - including a helpline – and to inform our referring hospitals.
If you would like any more information about the review, the latest report and action plan is included in our March Public Board Papers – add link. Additionally, you can email Andrew Long who led the review work.

Chief Executive
Peter Steer

Cymbeline Moore

Director of Communications
Great Ormond Street Hospital and Charity

40 Bernard Street, London WC1N 1LE | DL: 020 7239 3119 | int: 6519 | mob: [redacted]

[redacted]

From: [redacted]
Sent: 12 April 2018 11:49
To: Andrew Long
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: RE: Letter to ITV families
Attachments: Draft Letter - [redacted]

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks Andrew – these look good to me. I've made one small amend on [redacted](to remove the ref to him in third person in body of the letter) so that one is reattached, but aside from that I think they're just what we need.

I know things are tricky with [redacted]away but is there any way at all that we can get these out today? Is there anyone else in the department that could send them? I cant ask [redacted]as she is charity staff so shouldn't be handling patient correspondence, otherwise I would offer for her to do it. I think these need to get out pretty urgently now.

Also to note that it needs contact details for them to get in touch with added in – Mat, I assume that would be [redacted], given the letter is coming from you? And similarly would it be your signature?

And finally, sorry for the stupid question but when it refers to the parents as being cc'd, does that mean we send a separate letter to them too?

Thanks
[redacted]

From: Andrew Long <Andrew.Long@gosh.nhs.uk>
Sent: 11 April 2018 19:08
To: [redacted]
Cc: Cymbeline Moore <Cymbeline.Moore@gosh.nhs.uk>; Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>; [redacted]
Subject: RE: Letter to ITV families

Dear [redacted]

I have attached draft letters to the patients below (although please note the comments).

Let me know if they meet the requirements – very happy to amend otherwise.

Best wishes

Andrew

Dr Andrew Long
Associate Medical Director and Responsible Officer
Consultant Paediatrician
Great Ormond Street Hospital
Great Ormond Street
London WC1N 3JH

Tel: +44 (0)20 7405 9200 ext 5257
Email: andrew.long@gosh.nhs.uk

From: [redacted]
Sent: 10 April 2018 22:50
To: Andrew Long
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: Re: Letter to ITV families

Thanks Andrew,
[redacted]

Get Outlook for iOS

From: Andrew Long <Andrew.Long@gosh.nhs.uk>
Sent: Tuesday, April 10, 2018 10:37:32 PM
To: [redacted]
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: Re: Letter to ITV families

Thanks [redacted]

I will look through what notes I have on contact with these families and amend the letters accordingly. You will remember that [redacted] is away this week so we need to work out who is going to finish and send these letters.

best wishes

Andrew

Sent from my iPad

[redacted]

[redacted]

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<DRAFT LETTER - ITV families - aml suggestions.docx>

[redacted]

From: Andrew Long
Sent: 12 April 2018 12:45
To: [redacted]
Cc: [redacted] Cymbeline Moore; Matthew Shaw; [redacted]
Subject: Re: Letter to ITV families

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks [redacted]

Andrew

Sent from my iPhone

On 12 Apr 2018, at 12:41, [redacted] wrote:

> Dear [redacted]
> [redacted] is at her desk now and is happy to send out the letters, please would you liaise with her to ensure she has the correct version and details etc
>
> Many thanks
> [redacted]
>
> [redacted]
>
> **From:** [redacted]]
> **Sent:** 12 April 2018 12:32
> **To:** Andrew Long
> **Cc:** Cymbeline Moore; Matthew Shaw; [redacted]
> **Subject:** RE: Letter to ITV families
>
> No problem!!
>
> [redacted] – please do let me know if I can help at all with the final stages of getting these sent out - there is some urgency Im afraid and I know you'll be new to it so happy to explain or check anything if that's helpful?
>
> Thanks
> [redacted]
>
> **From:** Andrew Long <Andrew.Long@gosh.nhs.uk>
> **Sent:** 12 April 2018 12:02

To: [redacted]>
Cc: Cymbeline Moore <Cymbeline.Moore@gosh.nhs.uk>; Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>; [redacted]>
Subject: Re: Letter to ITV families

Dear [redacted]

I think either [redacted] should be able to send these letters. I would suggest that it should be Mat rather than [redacted], although I am quite happy to be the contact. Copy letters should be sent to the parents although I don't think it is unreasonable to send them in the same envelope.

Andrew

PS thanks for the change in the [redacted] letter. You don't know how many times I had to edit and save!

Sent from my iPhone

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 12 April 2018 12:48
To: [redacted]; Andrew Long
Cc: Cymbeline Moore; Matthew Shaw; [redacted]
Subject: RE: Letter to ITV families
Attachments: Draft Letter - [redacted].docx

Follow Up Flag: Follow up
Flag Status: Flagged

Yes of course, thank you so much [redacted]

I'll send you Andrew's email with the letters in now – the first one is attached.

They all need [redacted] details added in where the XXX is, and then they need Mat's electronic signature. Would you be able to do that for all of them, and then send them across to me and I can do a final proof?

Then they need posting, along with a CC letter for their parents for three of them.

Thanks – do call me if you need to, im at Cym's desk!

[redacted]

[redacted]

[redacted]

[redacted]

From: [redacted]>
Sent: 12 April 2018 12:50
To: [redacted]
Cc: Andrew Long
Subject: FW: Letter to ITV families
Attachments: Draft Letter - [redacted]

Follow Up Flag: Follow up
Flag Status: Flagged

[redacted] Here are the other letters. Its 5 to be mailed in total.

Andrew – sorry for the stupid question again, but for the 3 that need their parents cc'd, what does the CC letter look like? Is it literally the same letter again, or do we readdress it to the parents and change it so it is directed to them….? Sorry…..

[redacted]

[redacted]

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****
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Thank you for your co-operation.

****
****

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<DRAFT LETTER - ITV families - aml suggestions.docx>

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[redacted]

From: Andrew Long
Sent: 12 April 2018 20:01
To: [redacted]
Cc: Elizabeth Jackson; [redacted]
Subject: Re: Urgent query for Sunday gastro piece

Follow Up Flag: Follow up
Flag Status: Flagged

I think this is a real opportunity to show the responsibility of our approach. You will note that the byeline of the ITV documentary is that we closed to referrals and if we can show that we have still accepted referrals along clearly defined referral pathways then it will show that our governance systems are effective.

It would be good to have some numerical data as well as the referral units (eg Birmingham, Addenbrooke's, Royal London) showing that we are fulfilling part (if not most) of our quaternary (nationally commissioned) work but making sure that it is clear that every referral goes through a referral MDT which is part of our QA processes.

Andrew

Sent from my iPhone

On 12 Apr 2018, at 19:00, [redacted] wrote:

> Hi both
>
> We have just heard that the Sunday piece will run in the Observer.
>
> [redacted] is not in touch with them directly and the health editor has some questions.
>
> One thing we need your help with is answering 'what exactly does it mean when say GOSH was closed to referrals'. [redacted] has explained that we were not totally shut to all patients and that this was about referral restriction but we need to describe this further.
>
> Can you help us with a short description of the restrictions to referrals that were put in place?
>
> [redacted] needs it tonight!
>
> Thanks
>
> [redacted]
>
> [redacted]

[redacted]

From: Matthew Shaw
Sent: 17 April 2018 23:56
To: Peter Steer; [redacted] Cymbeline Moore; [redacted] Andrew Long; [redacted]
Subject: Fwd: Email from Mr Mat Shaw, Medical Director at GOSH

Follow Up Flag: Follow up
Flag Status: Flagged

Second response. Clearly playing down involvement.

From: Emmanuel, Anton [a.emmanuel@ucl.ac.uk]
Sent: 17 April 2018 at 23:49:19
To: Matthew Shaw
Subject: Re: Email from Mr Mat Shaw, Medical Director at GOSH

Thanks for your email.

My involvement in this was limited to a brief single interview. I noted that I had received a small number of referrals and at an early stage I realised that I was not the right person to help these individuals. I met [redacted] in the staircase at RLHIM and explained this. Our practice is to approach patients from a psychological perspective when there is no evident physical cause for symptoms - and this was not an approach that the families were open to. This was the basis of the request.

Best wishes
Anton

From: Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>
Sent: 17 April 2018 14:33:32
To: Emmanuel, Anton
Subject: Email from Mr Mat Shaw, Medical Director at GOSH

Dear Dr Emmanuel

I am writing to you as the new Medical Director at Great Ormond Street Hospital. We understand that you have recently contributed to the ITV documentary on our gastroenterology service and as the new Medical Director here at GOSH I am trying to learn lessons of what happened with this service over a number of years. From what we understand in the documentary you will be saying that there have been concerns around the service for a number of years and therefore I was wondering if you could provide me with any documentation, emails or conversations you have had with individuals from GOSH expressing these concerns.

The reason I want to ask this is to identify if there were any missed opportunities in identifying this earlier and whether we were listening to the concerns of the clinicians within the speciality outside of the hospital as part of a bigger piece of work we are doing.

Thank you very much for your help and assistance in this matter.

Kind Regards

Mat Shaw

Matthew Shaw Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229|

[redacted]

From: [redacted]
Sent: 18 April 2018 08:47
To: Matthew Shaw
Subject: RE: Email from Mr Mat Shaw, Medical Director at GOSH

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks – did you have the first response? I will file.

Thanks

[redacted]

[redacted]
Great Ormond Street Hospital for Children NHS Foundation Trust
Executive Offices
Paul O'Gorman Building
Great Ormond Street
London
WC1N 3JH
[redacted]

[redacted]

[redacted]

[redacted]

From: Naik, Sandhia <Sandhia.Naik@bartshealth.nhs.uk>
Sent: 18 April 2018 11:01
To: Matthew Shaw
Cc: [redacted]
Subject: RE: Email from Mr Mat Shaw, Medical Director at GOSH

Follow Up Flag: Follow up
Flag Status: Flagged

Thank you for getting touch and congratulations on your post
I am cc ing my [redacted] and would be grateful that any replies are also copied to them

You shouldn't really have to look externally to find evidence of the concerns around the GOSH gastro service

If you do however require specific details I would be more than happy to meet and discuss in person with either [redacted]

Best Wishes

Sandhia Naik MBChB PhD FRCPCH
GMC 3318492
Consultant Paediatric Gastroenterologist
Clinical Lead for Paediatric Gastroenterology
Training Programme Director
BSPGHAN Education Chair
Royal London Children's Hospital
Level 8 North Tower
Royal London Hospital
BartsHealth NHS Trust
London E1 1BB
W 02035942473
[redacted]

[redacted]

Thank you very much for your help and assistance in this matter.

Kind Regards

Mat Shaw

Matthew Shaw Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229|

[redacted]

From: Matthew Shaw
Sent: 18 April 2018 17:00
To: Peter Steer; [redacted]; Andrew Long; Cymbeline Moore; [redacted]
Subject: FW: Email from Mr Mat Shaw, Medical Director at GOSH

Follow Up Flag: Follow up
Flag Status: Flagged

This one is a lot more defensive.
Clearly [redacted] want MD support from barts.
Mat

[redacted]

[redacted]

Matthew Shaw Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229|

[redacted]

From: [redacted]
Sent: 18 April 2018 17:35
To: Matthew Shaw; Peter Steer; Andrew Long; Cymbeline Moore; [redacted]
Subject: RE: Email from Mr Mat Shaw, Medical Director at GOSH

Follow Up Flag: Follow up
Flag Status: Flagged

Interesting – and not a bad thing to have chance to discuss in front of the MD at Barts,

[redacted]

From: Matthew Shaw
Sent: 18 April 2018 17:00
To: Peter Steer; [redacted] Andrew Long; Cymbeline Moore; [redacted]
Subject: FW: Email from Mr Mat Shaw, Medical Director at GOSH

This one is a lot more defensive.
Clearly [redacted] want MD support from barts.
Mat

[redacted]

[redacted]

From: Cymbeline Moore
Sent: 18 April 2018 19:49
To: Peter Steer; Matthew Shaw; [redacted] Andrew Long; [redacted]
Subject: ITV London evening bulletin

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all

The gastro documentary trail was the 3rd story in ITV London news bulletin at 6pm. It led with 'GOSH apologises for over treatment of children'. The case study was [redacted] a patient seen by Rob Heuschkel.

The 'whistle blowers' were not from GOSH but Dr Naik and Rob Heushkel.

Bw

Cym

Cymbeline Moore
Director of communications
Great Ormond Street Hospital and Charity

[redacted]

From: [redacted]
Sent: 18 April 2018 21:23
To: Matthew Shaw
Subject: RE: ITV London evening bulletin

Follow Up Flag: Follow up
Flag Status: Flagged

Ridiculous indeed! I think this has probably been pushed out by ITV publicity, given the programme shots they've got…

From: Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>
Sent: 18 April 2018 21:18
To: [redacted]
Subject: Re: ITV London evening bulletin

Not a great start with the mail getting it.
What I love is the standard of the comments! Have a look. Utterly ridiculous.
Mat

From: [redacted]
Sent: 18 April 2018 at 20:36:20
To: Peter Steer, Matthew Shaw, [redacted], Andrew Long, [redacted]
CC: Cymbeline Moore, [redacted]
Subject: RE: ITV London evening bulletin

Hi all,

Just to add that the story is now also on the Mail online, leading on our apology and including a short clip of the programme which features an interview with Dr Naik:

http://www.dailymail.co.uk/femail/article-5631013/GOSH-apologises-giving-children-harmful-drugs.html?ITO=1490&ns_mchannel=rss&ns_campaign=1490

Thanks

[redacted]

> **From:** <Cymbeline.Moore@gosh.nhs.uk>
> **Date:** 18 April 2018 at 19:49:07 BST
> **To:** Peter Steer <Peter.Steer@gosh.nhs.uk>, Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>, [redacted], Andrew Long <Andrew.Long@gosh.nhs.uk>, [redacted]
> **Subject: ITV London evening bulletin**
>
> Dear all
>
> The gastro documentary trail was the 3rd story in ITV London news bulletin at 6pm. It led with 'GOSH apologises for over treatment of children'. The case study was [redacted] a patient seen by

Rob Heuschkel.

The ‘whistle blowers’ were not from GOSH but Dr Naik and Rob Heushkel.

Bw

Cym

Cymbeline Moore
Director of communications
Great Ormond Street Hospital and Charity

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[redacted]

From: Andrew Long
Sent: 18 April 2018 21:43
To: [redacted]
Cc: Peter Steer; Matthew Shaw; N[redacted] Cymbeline Moore; [redacted]
Subject: Re: ITV London evening bulletin

Follow Up Flag: Follow up
Flag Status: Flagged

BIJ have also put their FII story online https://www.thebureauinvestigates.com/stories/2018-04-18/treating-fii-the-gosh-approach

Andrew

Sent from my iPhone

[redacted]

[redacted]

From: [redacted]
Sent: 18 April 2018 21:43
To: Matthew Shaw
Subject: Re: ITV London evening bulletin

Follow Up Flag: Follow up
Flag Status: Flagged

Hi Mat
Thanks for that. It was already forwarded to me...let's go through.
I will see you tomorrow morning and I will leave around 12.30.
We will be fine I'm sure
Thanks
[redacted]

[redacted]
Great Ormond Street Hospital for Sick Children
Great Ormond Street
WC1N 3JH, London UK
[redacted]

On 18 Apr 2018, at 21:19, Matthew Shaw <Matthew.Shaw@gosh.nhs.uk> wrote:

> Please see the link below. Nothing surprising.
> Please feel free to call me.
> I am going to the gastro meet up in theatres tomorrow morning and I presume the consultants are still meeting at 5?
> Mat

[redacted]

[redacted]

From: Cymbeline Moore
Sent: 19 April 2018 13:47
To: [redacted]d; Andrew Long; [redacted]; Peter Steer; Matthew Shaw; [redacted]; [redacted]; [redacted]; [redacted]
Cc:
Subject: RE: Update on GOSH Gastro media

Dear all

As many of you may have seen, the documentary on our gastroenterology service aired last night. It is now available on ITV player.

It was, as per the Observer article, a somewhat contradictory piece. While it was negative in tone, the content did include many of our response to their allegations as balance and our full statement. I think the viewer would be left in no doubt that it was a complex area of medicine and that it was a very extensive review process.

In terms of transparency, it was helpful that they referred to material on the website, the supportive NHSE quote and part of the quote from the CQC which stated they had not found us wanting on duty of candour. The second part of the CQC quote was not helpful as it stated that in our CQC inspection/report we had been found to be defensive when challenged on performance and safety.

So far it has had very little pick up in print or online. The only national media coverage today is on the Mail Online. On social media we have received a handful of direct mentions – some neutral and some negative. The majority of the negative comments occurred on Twitter and were made by known GOSH gastro families and journalists involved in the story.

There have been a handful of calls to the dedicated gastro helpline we have set up.

We have sent an email to all staff this morning acknowledging the programme, signposting them to Alison or Mat should they have any questions and reminding them of their responsibilities to raise any concerns about this or any part of our work should they have them.

Please do not hesitate to contact me should you have any further questions.

Best wishes

Cym

Cymbeline Moore

Director of Communications
Great Ormond Street Hospital and Charity

40 Bernard Street, London WC1N 1LE | DL: 020 7239 3119 | int: 6519 | [redacted]

[redacted]

From: J[redacted]
Sent: 19 April 2018 17:19
To: [redacted]; Peter Steer; [redacted]; Matthew Shaw; [redacted]
Cc: Cymbeline Moore; Andrew Long
Subject: RE: Media update - Gastro documentary

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all,

Further to [redacted] email, just an update to say there has been no further media coverage and not much noise on social media throughout the day.

We will continue to monitoring press coverage this evening and flag if there is any further update.

Best wishes,

[redacted]
Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health
[redacted]
Great Ormond Street Hospital (GOSH) has the UK's widest range of health services for children on one site and is the country's only academic Biomedical Research Centre specialising in paediatrics. For more information please visit www.gosh.nhs.uk

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From: [redacted]
Sent: 19 April 2018 13:45
To: Peter Steer <Peter.Steer@gosh.nhs.uk>; [redacted] Matthew Shaw <Matthew.Shaw@gosh.nhs.uk>; [redacted]
Cc: Cymbeline Moore <Cymbeline.Moore@gosh.nhs.uk>; [redacted]>; Andrew Long <Andrew.Long@gosh.nhs.uk>
Subject: Media update - Gastro documentary

Dear all,

I thought it would be worth sharing a lunchtime update on activity after the documentary last night. We are also doing a briefer summary for the board and will update further if things change later today.

In short, there hasn't been any pick up of the story in the media today and we have not received any enquires since the documentary aired. More info below for those interested in the full detail:

PRESS
The only national media coverage today is in the Mail Online. It leads on our apology and focuses on the alleged 'long term health risks' of some of the drugs prescribed to patients.

In terms of further coverage, we're still awaiting one final piece on the BIJ website (re legal costs) and we will share this when its published.

Finally the full programme can also be found here ITV Player. We also have extensive notes of the content, including the quotes from NHSE and CQC so if this is useful please let us know and we can send across.

SOCIAL

Overall, activity has been at a low level across all GOSH social platforms. We have received a handful of direct mentions – some neutral and some negative. The majority of the negative comments occurred on Twitter and were made by known GOSH gastro families and journalists involved in the story.

Here is a more detailed summary:

- Volume:
  - Wider noise on gastro on social media (including wider related terms such as [redacted], and ITV's Exposure) picked up 263 mentions across yesterday and early this morning. A further 51 mentions since 9:30am.
  - We've also had a handful of very active 'patient family' tweeters, all of whom are known to us and most are within the gastro community.
  - Direct mentions to GOSH channels were minimal – approx.50
  - On Facebook: 3 comments under Facebook ads, and one under an organic Facebook post. All have been hidden.
  - On Instagram: no activity.
- Sentiment:
  - Approx half negative: Themes included: how have so many been misdiagnosed, criticism of treatment options, arrogant consultants, letting families down (with CG reference)
  - Approx quarter positive: Themes included: shame ITV is trying to discredit GOSH, Gastro parents at GOSH who have had good treatment
  - Approx quarter neutral: Themes included: flagging programme is on
- Donations: One tweet mentioning cancelling donation: https://twitter.com/DebbieYates1/status/986723698165125121
- Website:
  - Press statement has had 286 unique page impressions since it went live on 15 April – 128 occurred yesterday and overnight
  - Press statement ranked 30th most viewed page on the hospital website from 15-18 April
  - 2016 gastro statement appears as the 32nd most viewed page from 15-18 April with 273 unique page views: https://www.gosh.nhs.uk/news/latest-press-releases/2016-press-release-archive/review-gastroenterology-services-great-ormond-street-hospital

Finally, just to update that there have been no calls at all to the gastro helpline at all today, and no calls to the charity's supporter care line.

Thanks

[redacted]

[redacted]

Great Ormond Street Hospital & Charity

[redacted]

www.gosh.nhs.uk / www.gosh.org

[redacted]

From: [redacted]
Sent: 20 April 2018 17:13
To: Cymbeline Moore; Peter Steer; Matthew Shaw; Andrew Long; [redacted]
Cc: [redacted]
Subject: Documentary ratings

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all,

Just FYI, I thought you might be interested to know the ratings for the Gastro documentary:

Average rating (ie number of people watching it on average): 0.5 million
Percentage audience share (ie percentage of available viewing audience who chose to watch this show): 6.7% share

I'm not planning on sharing this any wider, as I know these still seem like big numbers, but we should take comfort that they're actually very low.

Even in that late slot the channel would be hoping for at least 1 million for a one off documentary like this. So it wont be a success in TV terms.

To give you some context, our GOSH series for BBC 2 (which as a channel always gets much lower ratings than ITV 1) still got an average of around 1.7 million per episode and Paul O Grady on ITV 1 will be aiming for around the 3 million mark.

In other news, we haven't yet seen the final BIJ piece and haven't had any more calls to either the press office or Pals/complaints. I'm going to the Gastro team meeting at 9am on Monday to get a sense of whether they have had any more calls or need any more help, so I'll report back after that, but otherwise its quiet.

Thanks – have a lovely weekend!

[redacted]
Great Ormond Street Hospital & Charity
[redacted]
www.gosh.nhs.uk / www.gosh.org

GREAT ORMOND STREET HOSPITAL NHS FOUNDATION TRUST

Minutes of Clinical Quality Review Meeting
Friday 20th April, 2018
Chair: [redacted]

Present:

[redacted]

Apologies: [redacted]

1.	**Minutes**	
	[redacted]	

2.	**Action Log**	
	[redacted]	

3.	**Feedback from the publication of the CQC report (Well led)**	

	[redacted]

4.	**Headlines from Provider Board Meeting**	
	[redacted] The Trust is formulating a response to a Royal College of Paediatric and Child Health report regarding the gastroenterology service. An ITV documentary and several newspapers covered this story in April 2018, the Trust have reported that there have not been a significant increase in queries since this entered the public domain.	
5.	**GOSH SI and Red Complaint Update Report**	
	[redacted]	

Meeting note – Employer Liaison Service			
Responsible Officer	Dr Andrew Long		
Organisation(s) Single DB	Great Ormond Street Hospital For Children NHS Trust		
Meeting location	[redacted]		
Date and time	11/05/2018	14:00pm – 15.30pm	Meeting type: In person
Previous meeting date	15/01/2018		
Next meeting date	17/09/2018	14:00pm – 15.30pm	Next Meeting Confirmed

[redacted]

[redacted]

[redacted]

ITV documentary: [redacted] is unhappy about the conduct of the non-GOSH doctors who contributed to the documentary. [redacted] has written to the three Drs in documentary asking for further information.

[redacted]

[redacted]

[redacted]

Item 2a – Responding to concerns locally – previously discussed

Last Name	Given Name	GMC Number	Description	Action for ELA or RO	GMC category	Office use only
			Gastroenterology Team [redacted] Documentary been shown. Guardian picked it up. [redacted]		FtP Monitor	

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 26 July 2018 11:16
To: Andrew Long
Subject: Daily Press Cuttings - Thursday 26 July

Follow Up Flag: Follow up
Flag Status: Flagged

Here are today's top health stories… View in Browser

RCPCH in the news…

Yesterday, the Government released its response to the consultation on its Transforming Children and Young People's Mental Health Green Paper. **Dr Max Davie**'s response has been covered by sources including CYP Now, BMJ and Nursery World. You can read his full response on our website.

In addition to the media coverage on the Government's response, **Dr Max Davie** has written a guest blog for the Huffington Post detailing what he thinks needs to be done. Dr Davie focuses on three key areas that the Government must address: a whole systems approach, the role of the child health workforce, and support for all children. He notes that "by choosing to prioritise the most easily helped over the most needy, the implicit message of the green paper is very much that only certain sorts of mental health problem are to be focused on" and asks that the Government implement policies that "include all young people with mental health difficulties, wherever they are and however they present." He adds that "failure to do so will have catastrophic effect on the current, and future, generations of children living in this country."

[redacted] appeared on TRT World in a roundtable discussion about vaccinations and whether we have all the information we need. The programme discusses the larger impact that refusing vaccinations can have, and touches particularly upon the ongoing measles outbreak and the impact of the anti-vax movement, the discredited research regarding the MMR vaccine and autism in the 1990s, and the concerns that some people have about the HPV vaccination. You can hear Dr Elliman at 00:05:05, 00:11:10, 00:16:50 and 00:24:00.

The **RCPCH's Invited Review** into Great Ormond Street Hospital's (GOSH) gastroenterology services has been referenced in an article in Private Eye. The piece talks about the RCPCH's findings and questions why the Care Quality Commission (CQC) graded the hospital's medical services as 'outstanding' following an inspection at the time. The article also refers to the ITV documentary into the service, subsequent investigations and later goes on to say that in 2018, the CQC rated the leadership at GOSH as 'requires improvement.' For a copy of the article, please contact the Media and External Affairs team.

Statistics from the **Royal College of Paediatrics and Child Health** have been referenced in Training Matters magazine, regarding the number of new mothers in England who start breastfeeding (80%). The article goes on to look at the latest statistics from Public Health England which has found that 44.5% of babies were being totally or partially breastfed at 6-8 weeks of life, a slight increase on previous years.

Professor Neena Modi, former President of the RCPCH, has also been quoted by Training Matters magazine, describing the research about the fortification of flour with folic acid. She described the new research as a "game changer" and added that fortification can be particularly important for women who do not know they are pregnant, are unaware of the importance of folic acid, or forget to take supplements.

In child health news…

Parents' lack of knowledge on UV rays 'concerning' as heatwave sizzles on
Almost three-quarters of parents do not protect their child's eyes from harmful UV rays, a survey has found as the UK heatwave sizzles on. The survey found that 78% of those asked were unconcerned about the effect of the sun on

their eyes, with only half aware that eye damage caused by UV rays can be irreversible. Only 30% of parents said they worry about their children having too much exposure to UV and the long-term damage it could cause, the South Wales Argus reports.

Asthma link to ADHD
Doctors have found a “significant” link between asthma and attention deficit hyperactivity disorder (ADHD) in children, The Times reports. Dr Samuele Cortese, of the University of Southampton, said the results suggested a “possible role of allergic mechanisms in ADHD”. He added it could lead to changes in the management of the two conditions.

Britain bakes as pollution alerts issued
Britain’s heatwave has prompted an air pollution alert, the Daily Telegraph reports. With the country just one stage away from a national emergency being declared, air quality warnings have been issued for London due to a mix of toxic air, extreme highs, emissions from the continent, and a lack of cloud. Young people, the elderly, and those with lung or heart problems are advised to reduce strenuous exercise and physical exertion.

In general health news…

Intervene to keep patients safe in overheated hospitals, Labour urges ministers
Labour has called on ministers to intervene urgently to keep patients safe during the heatwave amid stark warnings over extreme temperatures on the wards, the Independent reports. Nurses have reported that vulnerable patients and relatives are passing out and vomiting in overheated hospitals, where temperatures have soared beyond 30C as the country experiences record-breaking weather.

Major reforms to make it easier to get an NHS dental appointment
Finding an NHS dentist should get easier under plans to scrap a 12-year-old deal which forced many patients to go private, the Daily Mail reports. Major reforms scheduled for 2020 will give dentists new incentives to take on more NHS work. Their current contracts, introduced by Labour in 2006, include funding caps which effectively limit their NHS work to half the patients in their catchment area.

Scottish prescription costs rise by 25% over 10 years
The cost of providing prescriptions in Scotland has gone up by 25% in the last decade, with an ageing population and new drugs part of the reason, BBC News reports. NHS figures show the total bill for 2017-18 was £1.3bn, which is 25.7% more expensive than 10 years ago. Paracetamol and aspirin are among the most commonly-prescribed drugs. The data, from the Information Services Division of NHS Scotland, said the overall cost amounted to £248.79 per person. This was also covered by the Scottish Herald, the Scotsman, and the Courier.

Blood donations drop amid spell of warm weather
Health officials are urgently appealing for blood donations, with the prolonged warm weather leading to a drop in supplies. NHS Blood and Transplant (NHSBT) aims to have six days’ worth of stock of O negative in England at any one time but levels have fallen to just three days, the South Wales Argus reports.

Best wishes,

[redacted]

To ensure you receive the best service from your College, you can customise the communications we send to ensure you are always up-to-date and in-the-loop on the areas that suit your interests. It won’t take long to set your preferences and means you won’t miss out on any developments. Simply visit your RCPCH account and choose the communications that are important to you.

[redacted]

[redacted]

From: Andrew Long
Sent: 10 July 2017 09:22
To: [redacted]
Cc: [redacted]
Subject: Re: Meeting

Follow Up Flag: Follow up
Flag Status: Flagged

Fine with me (although may be late if the Gastro meeting goes on longer). I note that Ellen is off site today, do we need to get [redacted] in to discuss the current status of RC?

BWs

Andrew

Sent from my iPad

> On 10 Jul 2017, at 09:20, [redacted] wrote:
>
> 1?
> [redacted]
>
> [redacted]
> Great Ormond Street Hospital for Children NHS Foundation Trust London
> WC1N 3JH
>
> [redacted]
>
>
> -----Original Message-----
> From: Andrew Long
> Sent: 10 July 2017 09:20
> To: [redacted]
> Subject: Meeting
>
> Dear both
>
> We have some incredibly high risk actions involving staff going on all around us at the current time. Peter has called a meeting to discuss the Gastro documentary at 12.00 however we cannot afford to forget the implications of the other clinicians who are at risk. When can we meet today?
>
> Andrew
>
> Sent from my iPad

Timeline: Review of Gastroenterology Department

Date	Activity
May – June 2015	**STAGE ONE:** Review by RCPCH of GOSH gastroenterology department - Reviewers consult over 80 clinicians and other staff who work in or with the service
July 2015	RCPCH share with GOSH Medical Director: a) Draft Report b) Letter recommending review of diagnosis and management of 40 children currently being treated for eosinophilic colitis, to be completed within three to six months GOSH devises action plan to follow RCPCH's initial recommendations, including: - drawing up Terms of Reference for a subsequent case review - sourcing expert external panel members
September 2015	Final version of RCPCH report shared with GOSH
October 2015	GOSH communicates with referring hospitals that some referrals will be paused for at least three months. Criteria for on-going referrals defined as: - Referrals from a paediatric gastroenterologist at another tertiary trust with suspected IBD in children under the age of 6y - Referrals from other a paediatric gastroenterologist at another tertiary trust for chronic intestinal pseudo-obstruction - Existing patients under GOSH - Autoimmune disease leading to bone marrow transplant - Patients with intestinal failure See attached *Letter to referring hospitals*
Nov 2015 to Jan 2016	**STAGE TWO:** Panel of independent gastroenterologists to meet to review 40 cases identified by RCPCH Panel meets four times and examines 18 cases
Jan 2016	GOSH Medical Director contacts shared care centres (where GOSH consultants hold clinics), advising continued pause on new referrals for at least next three-six months while recommendations of RCPCH review are followed. Criteria for new referrals remain as defined in Oct 2015. See *Letter to shared care centres.doc*

Jan 2016	Letter sent to 14 patient families identified as of potential concern by the panel, informing that their child's care is being reviewed and arranging a phone call to discuss further. See *Letter to 14 patients January 2016*
Feb 2016	The Panel complete their review and their report - Clinician's Report – submitted to GOSH: - 18 patients' case notes examined in total - Recommends further in-depth review of 14 cases identified of potential concern. - 4 patients' care is assessed as in line with standard management at other UK hospitals.
March 2016	**STAGE THREE:** Independent paediatric gastroenterologists commissioned to carry out in-depth case note reviews of 14 patients identified in the Clinician's Report as of potential concern
March 2016	Two independent expert centres commissioned to conduct histopathology reviews of 14 patients identified by Clinician Report.
March 2016	External consultant gastroenterologists invited to conduct clinical reviews of: - 42 patients on either immunosuppressants or steroid therapy - 20 per cent of all patients within the service
April 2016	Letters sent to families of 42 patients on either immunosuppressants or steroid therapy, advising that concerns have been identified over the management of complex and difficult to diagnose gastroenterology conditions and that their child will have their care reviewed by a specialist from another hospital. Invited to have a phone call to discuss further. See *Letter to patients Apr 2016*
May 2016	First independent expert centre shares results of histopathology review
August 2016	Second independent expert centre shares results of detailed histopathology review of 14 GOSH patients
August 2016 – October 2016	GOSH shares full set of reports and reviews with regulators: CQC, NHS England and NHS Improvement with details of plans for the next steps. NB: The regulatory bodies had been kept up to date and consulted through each of stage of the entire review process.
Oct 2016 – Dec 2016	Liaison with regulators on next steps and planning further communication to patients and families
Dec 2016	Letters outlining findings of the entire review process, and resulting activity, signed off by NHS England and sent to: a) Cohort of 14 b) Cohort of 42 c) general cohort of 1400 current patients and their families Press release announcing findings uploaded to homepage of website Enquiry phone line set up for patients and families See: *Letter to 14 cohort - Dec 2016, Letter to 42 cohort – Dec 2016 and Letter 1400 Dec 2016*

June 2017	**STAGE FOUR:** RCPCH returns for follow-up invited review to check progress made on recommendations.
July 2017	Listening event held for gastroenterology patients and families to discuss experience of the gastroenterology department.
September 2017 tbc	Publication of RCPCH follow-up review expected

[redacted]

From: [redacted]
Sent: 21 September 2017 17:36
To: [redacted]); David Hicks
Cc: [redacted]
Subject: RE: Fact Check on Gastro

Follow Up Flag: Follow up
Flag Status: Flagged

Thank you so much, [redacted]

They are currently speculating on an early to mid October date but I wouldn't be surprised to see that slip as they are doing a lot of number crunching right now.

I will keep you posted.

Best wishes
[redacted]

From: [redacted]
Sent: 20 September 2017 16:12
To: [redacted]; David Hicks <David.Hicks@gosh.nhs.uk>
Cc: [redacted]
Subject: RE: Fact Check on Gastro

Hi Both

Sorry for the delay in responding.

The detailed timeline below looks accurate from memory. I have made one comment (in red).

Please let me know if you require any further assistance and of course keep me in the loop regarding the broadcast.

Regards
[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 13 September 2017 18:46

To: [redacted] David Hicks
Cc: [redacted]
Subject: Fact Check on Gastro

Dear [redacted]

I am so sorry to bother you as I know you have been constantly followed up on the gastro review because of the media investigations. But I am writing a key document where I am challenging some of their narrative by presenting central facts and I have been advised that no one knows better than you what the actual case is.

I would be very grateful if you could confirm if the below sequence of events is correct.

- The Clinicians' Report identified 14 cases warranting further investigation – out of the 18 it reviewed. These patients were a mix of cases of Eosinophilic Colitis and of "other diagnosis" – as laid out in the Panel's Terms of Reference.
- External experts were commissioned to conduct detailed case note reviews to a medico-legal standard for each of these 14 patients. Each patient also had a review in-person with a clinical appointment led by an external gastroenterologist. [redacted]
- GOSH also identified all gastroenterology patients on immunosuppressant medication and/or steroid therapy without a clear and definitive underlying diagnosis (e.g. post bone marrow transplant). This amounted to 42 patients – not exclusively with a diagnosis of EGID.
- These 42 patients had their care reviewed in clinic by external gastroenterologists.
- A random sample of 20% of all gastroenterology patients (regardless of diagnosis) in the department's active case load were also reviewed in clinic by external gastroenterologists.
- (not sure if we should mention histologies sent to Leeds and Cincinnati in this list of actions. – I think this should be mentioned, it was a very important part of the process.
- Issues were identified in the course of the review but we must emphasise that we have taken significant steps to address these.

I am confident that this is a correct sequence of events but would be so grateful if you could double check. We still do not have a broadcast date but I will let you know when we do.

Best wishes
[redacted]

[redacted]
Great Ormond Street Hospital and Children's Charity

[redacted]

****

[redacted]

From: [redacted]
Sent: 21 September 2017 17:41
To: [redacted]; David Hicks
Cc: [redacted]
Subject: RE: Fact Check on Gastro

Follow Up Flag: Follow up
Flag Status: Flagged

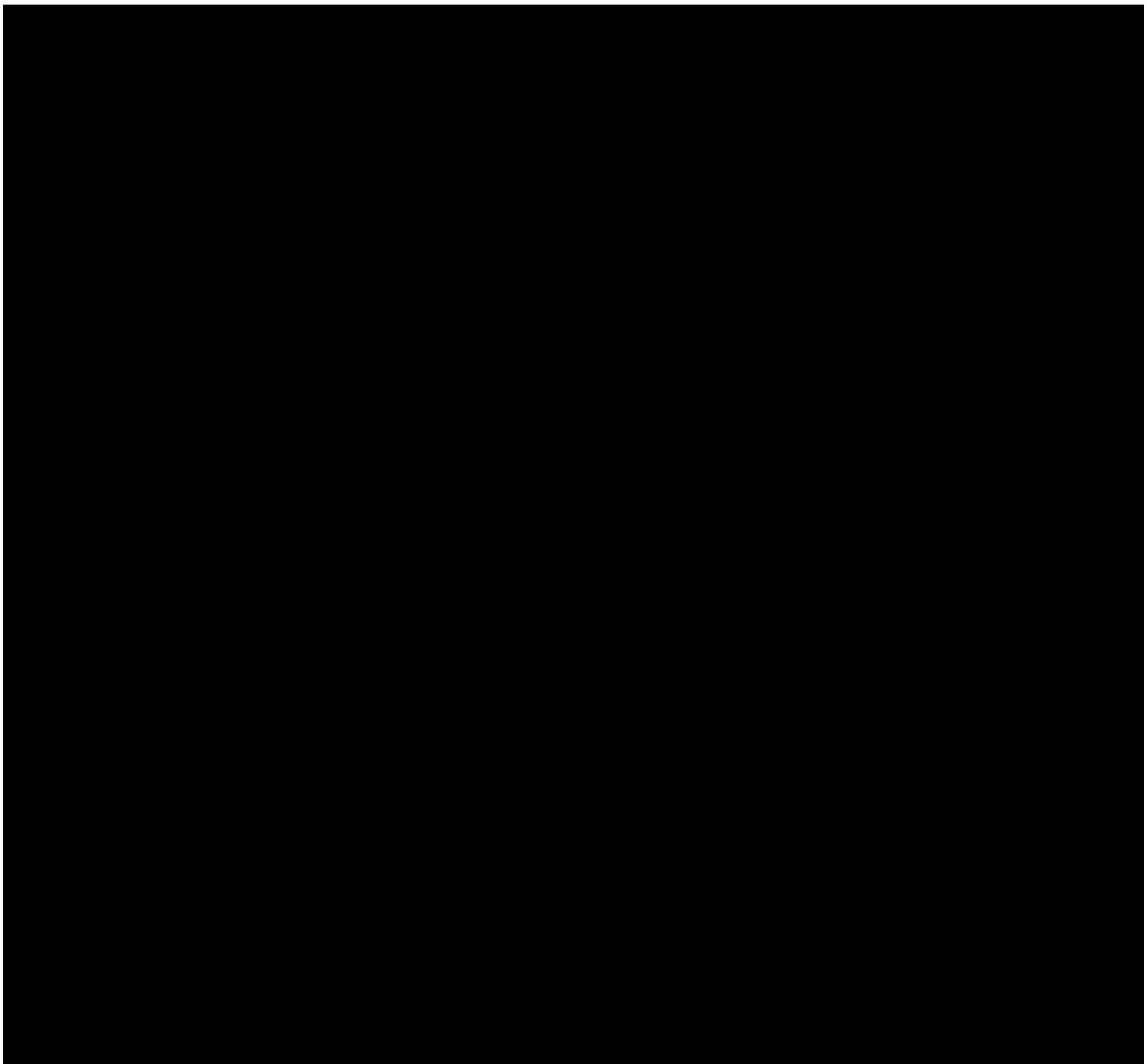
Thank you

Regards

[redacted]

NHS Solihull Clinical Commissioning Group Friars Gate. 1011 Stratford Road. Shirley Solihull B90 4BN
www.solihullccg.nhs.uk

[redacted]



[redacted]

-----Original Message-----
From: [redacted]
Sent: 01 September 2017 14:12
To: [redacted]
Cc: [redacted]; Chesser, Alistair (Chief Medical Officer); [redacted]
Subject: Gastroenterology Service
Importance: High

Dear Dr Naik,

Thank you for your letter of 30 August 2017 which was sent by email.

Your approach is most timely since we have now concluded our review visit from the Royal College of Paediatrician and Child Health; and their report is now imminent.

When I have the assurance as to the quality of our Gastroenterology service at Great Ormond Street Hospital, I can then start to consider accepting referrals along the lines that you describe in your letter.

[redacted] has separately indicated that he requires this assurance from me before our services open up.

If you could provide me with details of the patients who are being rejected; it would be much appreciated and I will look into these.

In relation to your last remark about this matter being separate from the issues around a media programme, then I am in complete agreement.

Subsequent to the RCPCH's report being received and disguised, I'll be in contact to affect the meeting you request.

Best wishes
David

-----Original Message-----
From: [redacted]
Sent: 30 August 2017 14:51
To: David Hicks
Cc: [redacted] Chesser, Alistair (Chief Medical Officer); [redacted]
Subject: FW:

Please find attached letter from Dr Sandhia Naik - hard copy in the post.

[redacted]

[redacted]

****

****

From: NM Croft
Sent: 31 August 2017 12:56
To: [redacted]; david.hicks@GOSH.NHS.UK
Subject: RE: Tertiary paediatric gastroenterology services

Dear [redacted] and David

I have not cc'd all as these are my personal comments and has not been discussed with any others (including Sandhia). If you are able to identify some clear plans I can feed these back to the others. I would be very happy to discuss.

To remind you all our concerns are about the current situation for new patients with tertiary gastroenterology needs (as defined in the Specialised Services Definitions) currently being referred to GOSH, it is not about previous care and the reviews at GOSH.

[redacted]Thank you for your offer of a meeting I would be grateful if that could be set up as this may help the medium to long term plans in London and the SE.

However I (and others) do not think this will improve the immediate problem which is of patients being outright rejected from GOSH with no agreed direct pathway to a new provider and then having to be referred to other providers who do not have extra capacity to accommodate them. It is the patients who are being caught in the middle here and are suffering delays in being seen.

At [redacted] we have a roughly 25% increase in referrals requiring multiple ASI lists and we are unable to make any clear plans to make this sustainable largely due to the lack of information. Unlike Cambridge we do not believe formally closing our doors to 'outside referrals' is in the patients best interests and so have accepted referrals to the best of our ability, it may well be as one of the 2 closest Trusts we are more affected than others.

Without going over the past ground what would help us all plan for providing for the patients is for a clear statement to the tertiary providers addressing the following pieces of information, would you be able to provide this ? I think with this information all the centres (including the referring hospitals) could then start to consider how best to ensure patients are able to access the right care at the right time.

1. Exactly which elements of a tertiary gastroenterology GOSH are not able or willing to provide now (which thus need to be provided elsewhere) – please could these be clearly listed. If you have any idea how this may change in the future that would also help planning.

2. Roughly how many patients this is affecting and from which hospital/regions (ie numbers that will be referred elsewhere).

3. How much longer this is likely to be for (shortest and longest estimate) and (if not known) when decision can/will be made, I appreciate GOSH are awaiting RCPCH feedback for some decisions.

I do think being open and clear about all these issues will make it more feasible to make plans to provide the best care for patients and look forward to hearing back, it will also help show all are doing the best under difficult circumstances.

Thanks for your help

BW

Nick

[redacted]

Ps If the restriction of referrals is likely to persist beyond 2-3 months could I suggest that GOSH take the lead on setting up a shorter pathways for referrals, ie when they reject a patient (or group of patients) they help set up a system where the original referrals is passed on directly to another provider (rather than just rejected and requiring a second referral). Of course that will need some clear discussions and agreements about which patients can/will be accepted. It may be better for the referring hospital to plan for new connections for all tertiary gastroenterology services.

From: NM Croft
Sent: 17 July 2017 13:06
To: '[redacted]
Cc: david.hicks@GOSH.NHS.UK; Heuschkel, Robert <robert.heuschkel@addenbrookes.nhs.uk>; Naik, Sandhia <Sandhia.Naik@bartshealth.nhs.uk>; [redacted]
Subject: RE: Tertiary paediatric gastroenterology services

Dear [redacted]

Thanks very much for your rapid reply. I wonder if some form of initial TC or meeting with a smaller group ie those in this email list would be helpful as a first step, as you saw our letter is about patients affected now so a rapid (even if short term) solution for them is what we hope to find.

At present we do not know exactly what patients are not being accepted by GOSH, how many there are (and where from) and whether these referrals may be taken again in the future. If that information is available it would be most important to have it more widely available.

For the medium-longer term I would assume the meeting below may need to include some of the referring hospitals who may well have thoughts as to what would work best, I would hope this could help firm up the networking arrangements across all of London to fit the Quality Standards.

By chance I will be at Skipton house tomorrow for another meeting (2-4) and would be very happy to meet briefly if you are willing and available.

BW

Nick
[redacted]

From: [redacted]
Sent: 17 July 2017 09:21
To: NM Croft <n.m.croft@qmul.ac.uk>
Cc: david.hicks@GOSH.NHS.UK; Heuschkel, Robert <robert.heuschkel@addenbrookes.nhs.uk>; Naik, Sandhia <Sandhia.Naik@bartshealth.nhs.uk>; [redacted]
Subject: RE: Tertiary paediatric gastroenterology services

Dear Nick,

Thank you for your letter regarding concerns in relation to provision of paediatric gastroenterology services at Great Ormond Street Hospital (GOSH) and arrangements that were put in place as a result of actions taken by the Trust when concerns about quality of care were raised by the clinical community. As you are aware a series on reviews and investigations have taken place since the concerns were formally raised.

My understanding is that the RCPCH are yet to complete their re-review of the service and I am not aware that all actions relating to internal investigations by the Trust are completed.

I am not aware of all the discussions that you refer to where providers, with the exception of Cambridge, have sought clarity with NHSE and the Trust to future plans. Until I have received positive assurance from the GOSH medical director regarding the service I would not support reopening of services to some referrals.

I would welcome the opportunity to meet with all of you as a group along with the GOSH leadership team and clinicians to discuss the issues and potential solutions. It may also be useful to include my colleagues from the South Region and Midlands and East to cover the Southampton, Oxford and Cambridge services. If as a group you are agreeable to this suggestion I will arrange an meeting here in Skipton House and send invites to all the signatures as well as the GOSH team and relevant NHSE staff.

Regards

[redacted]

[redacted]

From: Naik, Sandhia <Sandhia.Naik@bartshealth.nhs.uk>
Sent: 25 September 2017 11:11
To: Chesser, Alistair (Chief Medical Officer)

Info part 2

Am doing in chronology as possible

Sandhia Naik MBChb FRCPH PhD
Consultant Paediatric Gastroenterologist Training Programme Director Level 8 North Tower Royal London Hospital
Barts Health NHS Trust
E1 1BB

Gmc 3318492
Tel No 02035942473
Fax 02035943267
[redacted]

From: NM Croft [mailto:n.m.croft@qmul.ac.uk]
Sent: 05 May 2016 14:30
To: Vinod Diwakar
Cc: [redacted]; Naik, Sandhia
Subject: RE: GOSH Gastro service

Dear Vin

Hope all is well.

We have been discussing the referrals patterns and the full effect of the GOSH closure to new referrals and would be grateful if we could set up a meeting.

We are concerned about the negative impact on patients and the patient pathway, we are probably now more or less seeing the full effect.

1. Our new patient slots are now full for 3 months and so getting patients into clinics in a timely manner is becoming a major issue. This is not in keeping with our patients pathway.

2. Patients are being told that GOSH is too busy and they go back to get a referral to another institution, this inevitably leads to even more delay in them being seen as the referral is not being passed on directly. The patients perceive that our institution is in part responsible for the delays and I understand are calling in some desperation for an appointment.

3. We do not yet have a major problem with endoscopy (or i in patient services) but are concerned this may well come over the next few months.

I think it is clear this situation is not best for patients in our area and think we need to meet to discuss how to deal with it at a local level, if you think we need to involve others please advise, I know you are in contact with the commissioners, NHS England etc.

The key issue will be knowing how much longer you are likely to remain closed to referrals, if it is just a few more weeks then that is a different scenario to 6 months or more.

I have sent this in part as we met previously but copied in are Sandhia Naik (Clinical lead for Gastro), [redacted] is the Clinical Directors for Children's Service and [redacted] is the Children Services manager.

BW

Nick

[redacted]

[redacted]

From: Andrew Long
Sent: 25 September [redacted]
[redacted]
Cc: David Hicks; [redacted]
Subject: RE: Clinical Review of Patients of Concern Cohort 1 2 17082016 (4)
Sensitivity: Confidential

Dear [redacted]

You will probably be aware that I have been asked to take a lead role in gastroenterology to try and pull together some of the loose strands from the previous reviews and the new data that has been unearthed following the review/survey undertaken recently.

I think it would probably be sensible if you and I met sometime this week to discuss where I could be of most use. I will also need to get access to the K drive data for the previous gastro review work.

Let me know when suits you best.

Best wishes

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital

Great Ormond Street Hospital for Children NHS Foundation Trust

QUALITY AND SAFETY ASSURANCE COMMITTEE

Great Ormond Street Hospital for Children NHS Foundation Trust

GREAT ORMOND STREET LONDON WC1N 3JH

A G E N D A

Tuesday 17th October 2017

Great Ormond Street Hospital for Children NHS Foundation Trust

QUALITY AND SAFETY ASSURANCE COMMITTEE
Tuesday 17th July 2017 at 2:00pm – 5:00pm in The Theatre, October Gallery, 24 Old Gloucester Street, Bloomsbury, WC1N 3AL.
AGENDA

[redacted]

5.	**Update on Gastroenterology**	Interim Medical Director	**David Hicks**	**2:25pm**

[redacted]

	[redacted].
26	**Update on Gastroenterology**
26.1	Dr David Hicks, Interim Medical Director said that the Royal College of Paediatrics and Child Health (RCPCH) had returned to begin their follow up review of the gastroenterology service. This would include interviews with staff and other stakeholders such as referrers, a questionnaire, a listening event for patients and analysis of a substantial amount of information provided by the Trust. The actions that GOSH had taken following the previous visit would also be considered.
26.2	Dr Hicks said that the service had only received one complaint in seven months as opposed to 15 complaints in six months in the previous year.
26.3	It was reported that there was media interest through a television production company in the service and additional information had now been received about what the organisation considered should be reported in the public interest. The Trust was writing a detailed response which included a rebuttal in many areas.
26.4	Dr Peter Steer, Chief Executive said that the production company had not been clear about the Trust's openness with the CQC and NHS England and highlighted the information that had been provided on the GOSH website for the purpose of transparency.
27	**Quarterly Safeguarding Report (April - June 2017)**
27.1	[redacted]
27.2	[redacted]
27.3	[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 06 October 2017 15:46
To: [redacted]
Cc: David Hicks; [redacted]
Subject: RE: Gastro review

Follow Up Flag: Follow up
Flag Status: Flagged

Thank you [redacted]

David, just to confirm our conversation, the draft report was sent to you on 6th September and the contract was sent on 22nd May, with the specific request for purchase order number on 25th August (below). Until we have the purchase order number our finance team are unable to raise an invoice. I'm afraid we will not be able to release the report until we have the number and payment .

In the meantime CQC have approached me to ask whether the draft report had been sent to the Trust. Our website carries the guide to reviews which states that the draft report will usually reach the client within around six weeks of the visit. As you and Dr Andrew Long know we are happy to help with any clarification of the report; [redacted] only has Mondays and Thursdays available from November now but I am around to meet in the interim if that would be helpful to move things forward.

With best wishes

[redacted]

Leading the Way in Children's Health
The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299)

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

From: [redacted]
Sent: 06 October 2017 15:25
To: [redacted]
Subject: RE: Gastro review

Dear [redacted]

Please accept our apologies as we organise the payment sorted for you asap

Kind Regards
[redacted]

[redacted]

[redacted] | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
[redacted]

From: [redacted]
Sent: 06 September 2017 11:35
To: [redacted]
Subject: RE: Gastro review

Hi [redacted]

Sorry to bother you but I'm just following up on whether your guys have a purchase order number for us yet?
Our finance director is pressing me but I appreciate that sometimes it can be a long winded process through finance departments

Best wishes

[redacted]

From: [redacted]
Sent: 25 August 2017 15:26
To: 'David Hicks'
Cc: [redacted]
Subject: Last document I hope and fee.....!

Dear David

All on target with our report but still trying to track down the 'End report' from [redacted] hat should answer all my remaining questions. It went to Vin in I think November / December and maybe to the board but [redacted] can't find it . Might you or [redacted] have a copy you could share please?
(passworded by email , Huddle or I can pop over)

On another note I am being pressed to raise the invoice for the work. We would usually send when you receive the draft report but our financial year end is 31st August so if we can raise it before then it's fine not to put it through till the draft is received.

Is that OK ? I've attached the contract for reference as I'll apparently need a purchase order number from your finance team – details are as follows:

Payee: Finance Department RCPCH 5-11 Theobalds Road London WC1x 8SH
Service: Provision of an Invited Review of gastroenterology during June-August 2017

[redacted]

Many thanks, have a lovely weekend when it comes

[redacted]

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: 06 October 2017 16:08
To: David Hicks
Subject: RE: Gastro review

Follow Up Flag: Follow up
Flag Status: Flagged

Thank you, David, I'm obviously being pressed this end ..
[redacted]

From: David Hicks [mailto:David.Hicks@gosh.nhs.uk]
Sent: 06 October 2017 16:04
To: [redacted]
Cc: [redacted]; Andrew Long
Subject: RE: Gastro review

thank you for your patience [redacted]
[redacted] is taking care of the invoice and Peter Steer's PA [redacted] should arrange for you, him, Andrew and myself to meet as soon as is practicable.
Please have a lovely weekend,

Best Wishes,
David

[redacted]

From: Andrew Long
Sent: 09 October 2017 12:37
To: [redacted]
Cc: David Hicks
Subject: FW: Meeting Peter re Gastro review

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

This is [redacted] email from last Tuesday giving some suggested dates.

Does that answer the question in your earlier email?

Many thanks

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
Email: andrew.long@gosh.nhs.uk

From: [redacted]
Sent: 03 October 2017 16:20
To: [redacted]
Cc: Andrew Long
Subject: Meeting Peter re Gastro review

Hi [redacted]
Just to confirm my call just now - nice to talk to you!
It would be good to meet Peter soonish to discuss the report – I can do early/ late too – here are some suggestions

Friday 6th from 7.30am anytime except 10-11 through to 7pm
Monday 7th from 7.30am to 10.30
Wednesday 11th 7.30-9.30
Thursday 12th 7.30-8.30, 11.30-7pm
Friday 13th 7.30-7pm anytime

Hope that helps!

[redacted]

From: [redacted]
Sent: 26 September 2017 19:20
To: [redacted]
Subject: RE: RCPCH report meeting

Dear [redacted]
Oh that is a pity l The problem with busy people! David's got a pretty full clinical programme so I think we are looking at Mondays and Thursdays in November after that
[redacted] is up here this Thursday but his time is all spoken for, unfortunately
Let me know if you get any movement on 16th otherwise we can look later on.

If it would be helpful for me to pop over in the meantime I'd be happy to do that and can provide some background and context to the review team's thinking which might help to move things forward a little?

[redacted]

From: [redacted]
Sent: 21 September 2017 16:15

To: [redacted]
Cc: Andrew Long
Subject: RE: RCPCH report meeting

Dear [redacted]

Unfortunately Peter is scheduled to be out of the Trust on both of those days. The 16th October has yet to be confirmed but I am unable to remove the provisional booking until next week at earliest.

Would you have any further potential dates?

Best wishes
[redacted]

From: [redacted]
Sent: 20 September 2017 18:51
To: [redacted]
Cc: Andrew Long
Subject: RCPCH report meeting

Dear [redacted]
I had a chat today with Dr Andrew Long who has suggested that Dr Steer meet with the RCPCH review team to discuss the draft report. We'd be delighted to meet but [redacted] is unfortunately clinically or otherwise committed until Thursday 19th October.
He would be happy to visit then, ideally in the morning and if that suits Peter then I could see If others in the team are available.
A second choice would be Monday 16th October, also morning preferred, but that would require a little juggling!.

How are those looking please?
Many thanks
[redacted]

[redacted]

From: Andrew Long [mailto:Andrew.Long@gosh.nhs.uk]
Sent: 20 September 2017 17:36
To: [redacted]
Subject: Re: today

I have just spoken to Peter who would be very happy to meet up with the Review Team. Can you set it up from your end and liaise with [redacted]

Many thanks

Andrew

From: [redacted]
Sent: 09 October 2017 12:38
To: Andrew Long
Cc: David Hicks
Subject: RE: Meeting Peter re Gastro review

Follow Up Flag: Follow up
Flag Status: Flagged

Ok brilliant – yes thank you that answers question

From: Andrew Long
Sent: 09 October 2017 12:37
To: [redacted]
Cc: David Hicks
Subject: FW: Meeting Peter re Gastro review

Dear [redacted]

This is [redacted] email from last Tuesday giving some suggested dates.

Does that answer the question in your earlier email?

Many thanks

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
Email: andrew.long@gosh.nhs.uk

[redacted]

From: Andrew Long
Sent: 19 October 2017 15:16
To: [redacted]
Cc: David Hicks
Subject: Re: Gastro review

Follow Up Flag: Follow up
Flag Status: Flagged

Dear [redacted]

I would be very happy to meet when I am back from my study leave trip w/c November 6th.

Best wishes

Andrew

Sent from my iPad

On 19 Oct 2017, at 14:53, [redacted]

> David - We agreed that it might be useful to chat in light of the recent review and my role as Gastro MDT chair. Andrew, I understand that you have taken on Gastro as well.
>
> [redacted] comes to most Gastro MDT's so will have a view re medical management. You might wish to include her.
>
> I am happy to come along and share views if it would be useful.
>
> Best Wishes
>
> [redacted]
>
> [redacted]
> Great Ormond St Hospital
> [redacted]

RCPCH Invited Reviews Programme

Executive Summary

Great Ormond Street Hospital NHS Foundation Trust
Gastroenterology Service

September 2017

RCPCH Invited Reviews Programme
September 2017

Published by:
Royal College of Paediatrics and Child Health
5-11 Theobalds Road
London WC1X 8SH
Tel: 0207 092 6000
Email: enquiries@rcpch.ac.uk
Web: www.rcpch.ac.uk

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Executive Summary

This review report examines progress against the recommendations of the RCPCH Invited Review of gastroenterology service at Great Ormond Street Hospital in 2015. It provides a fresh view of the current service with recommendations that encourage sustainable, achievable and integrated service provision for children and young people with gastroenterological conditions

The review team recognises that the gastroenterology service had faced a difficult period following the 2015 review. The service had significantly reduced activity whilst investigations were carried out including a detailed programme of case review and a thorough overhaul of administration and governance systems.

By the end of 2016 the service was considered by the Trust to be in a positive position and the RCPCH was approached in spring 2017 to carry out a follow up review. The review team comprised two experienced paediatricians and a lay reviewer supported by an RCPCH manager. Terms of reference were agreed and the team interviewed almost 100 people and examined a similar number of documents to the 2015 review

The review team found very good senior clinical and operational leadership which needs to be sustained and embedded. There have been significant improvements in administration of patient communications and clinic organisation and a suite of new governance meetings and reporting pathways which ensure that any new referrals are appropriately investigated and diagnosed in conjunction with their local referring paediatrician. The consultants were working better as a team and engaging more with multidisciplinary colleagues, particularly the more recently appointed and locum consultants.

Many of the consultants and other staff were embracing the new ways of working. There had been significant investment in nursing, and improved involvement of multidisciplinary colleagues including psychology and dietetics. Strong nursing leadership on the wards and investigations units was embedding the governance and quality programme with improved morale and a clear career structure for staff.

However the new approach has not been universally accepted by all consultants and some remained sceptical about the need for change. Many staff expressed concern that the Trust and team had not fully learned from the consequences of the 2015 review and further detailed case review work was required urgently to ensure all children were on appropriate care plans. Whilst the original report had been shared with regulators and commissioners, who had monitored the action planning and progress of the Trust against the recommendations, many staff working in the service had not seen it and tld the review team that they were not yet confident that the climate had changed and that their concerns could be raised and responded to in a climate of openness.

Further encouragement is needed for the gastroenterologists to fully embrace external peer review. Some consultants see their service as only 'quaternary' or highly specialised and are selective about accepting their fair share of specialist ('tertiary') referrals in the London catchment. This is causing friction with other providers and it is important that specialist services work more closely together with clarity about expertise and referral pathways across London and the South East.

The service is currently working at around half of its previous activity and needs to step back up to manage a similar workload to peer units. This may require some investment in staffing and robust job planning to ensure that the gains made in governance and safety are embedded and continue with the changeover of the Medical Director. We would recommend involvement in a networked Quality Improvement programme and/or appointment of an externally-facing senior clinical leader – equivalent to a Chair or professorship appointed by the NHS with an interest in translational research-- to support the development of a strong gastroenterology network in London.

The full report sets out the findings which are wide ranging but reflect the impact of the 2015 report and the extent of turnaround that has been achieved. There has been good progress in dealing with the immediate issues of concern and implementing practical systems but the next stage is ensuring there is an embedded culture that focusses specifically on the best interests of the child.

Although the safeguarding systems have improved with the recent appointment of the Named Doctor, there remains more to do around process and attitudes, strengthening links with the referring communities and ensuring candour and openness when staff raise concerns. The Trust is now aware of these issues and steady progress is being made which must continue to be prioritised.

Involvement of families and management of transition are areas which still require considerable improvement but again the Trust is aware of this and striving to bring the gastroenterology service to the standards of other teams in the Trust and other gastroenterology centres. There is a wide selection of material and support readily available for these schemes and no reason not to move forward more swiftly with this to build healthy trusting relationships with families and other units.

In summary the Trust is making good progress on the significant transformation identified as necessary in the 2015 report but now needs to broaden its activity to play a full part in the regional network. There are some areas of very good practice, but there is still more to do to complete the assurance process, embed the change of culture and restore the confidence of peers and families that the service has truly turned around.

Note: Our review has not looked specifically at clinical outcomes or individual case management. Our recommendations and the plans for network and governance development should facilitate systemic improvements in these areas.

Appendix 1 The Review team

Dr David Shortland MD FRCP FRCPCH DCH has been a paediatrician for 25-years in Poole, Dorset, including ten years as neonatal lead and twelve as clinical director. David was the lead clinician for the rebuild of the paediatric department in 2005 and currently leads on Clinical Quality for the paediatric department.

Following five years as member, then Chair, of the Clinical Directors Special Interest Group, in 2006 David was elected as the National Workforce Officer for the RCPCH leading the 2007 national workforce census and designing a cohort study of trainees to provide a clearer understanding of the current and future workforce, helping to define how the role of paediatricians can evolve to provide consultant delivered care and hence safe and sustainable services. David was elected Vice President (Health Services) in 2009 and played a central role in developing strategy for Child Health Services in the United Kingdom supporting paediatricians through the challenges of radical reform to the health service, working time legislation and service re-design. During David's five years in post he developed a national template for the resident paediatrician and was lead author for "Facing the Future". This document defined 10 quality standards for acute paediatric services and is widely quoted as a template for good practice. David led a national audit of these standards in 2013 and currently chairs a steering group extending the standards approach to care outside hospitals. Since 2014 David has been clinical adviser to the RCPCH Invited Reviews programme and has led a number of high profile reconfiguration, individual and service reviews.

Dr Nadeem Ahmad Afzal MBBS, MRCP, MRCPCH, MD is an Expert Adviser for the NICE Centre for Guidelines and has recently served as Honorary Secretary of the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN). Dr Afzal is a Consultant in Paediatric Gastroenterology, Hepatology and Nutrition at University Hospital Southampton. As Honorary Senior Clinical Lecturer at Southampton University he runs an active research programme. Dr Afzal has established paediatric hepatology services at University Hospital Southampton, is the paediatric endoscopy lead and helps to run the Wessex Paediatric Gastroenterology Network. Dr Afzal is an Invited lecturer to the MSc in paediatric gastroenterology at Barts, London and MSc in Allergy in Southampton University. Dr Afzal has served as Editor in Chief for World Journal of Gastrointestinal Endoscopy and has contributed to the gastroenterology section of the RCPCH Paediatric Care Online.

[redacted]

[redacted].

Sue Eardley joined RCPCH as Head of Health Policy in January 2011 and established the Invited Reviews programme for the College, conducting over 70 reviews in five years. An engineer by training, Sue spent 13 years as a non-executive and then Chairman of an acute trust in London, alongside a range of voluntary activities including national and local involvement in maternity services and the NHS Confederation. Sue led groups contributing to the Maternity NSF and chaired her local MSLC for four years. Before joining the RCPCH Sue spent six years full time leading the maternity and children strategy team at the Healthcare Commission and then Care Quality Commission, overseeing strategy, design and delivery of all inspections and reviews in England of maternity, child health and safeguarding.

From: [redacted]
Sent: 23 October 2017 18:28
To: David Hicks
Subject: report
Attachments: 171023 GOSH Gastro report executive summary and recomendations.doc; 171023 GOSH Gastro report executive summary final.doc

Hi David
the scouts are busy cooking - so here you go - you have one exec summary and one with the recs as well -your call which to use.
if there are any amends let me know - its passworded for editing.
Cheers
[redacted]

From: David Hicks [mailto:David.Hicks@gosh.nhs.uk]
Sent: 23 October 2017 17:08
To: [redacted]
Subject: RE:

you're a star [redacted]
Enjoy,

Best Wishes,
David

From: [redacted]
Sent: 23 October 2017 17:07
To: David Hicks
Subject: RE:

Ok. No probs. Will fix this eve once the scouts are in bed (I'm on Dartmoor!)
[redacted]

[redacted]

From: David Hicks
Sent: 23 October 2017 13:50
To: [redacted]
Subject:

Hi [redacted]
whilst we get back to you with our more detailed reviews of the draft Report, would it be possible for you to release the (slightly amended) Exec Summary please?
This is following a request from CQC to us asking for the draft,

Best Wishes,
David

RCPCH Invited Reviews Programme

Summary and recommendations

Great Ormond Street Hospital NHS Foundation Trust
Gastroenterology Service

August 2017

RCPCH Invited Reviews Programme
September 2017

Published by:
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Although the safeguarding systems have improved with the recent appointment of the Named Doctor, there remains more to do around process and attitudes, strengthening links with the referring communities and ensuring candour and openness when staff raise concerns. The Trust is now aware of these issues and steady progress is being made which must continue to be prioritised.

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In summary the Trust is making good progress on the significant transformation identified as necessary in the 2015 report but now needs to broaden its activity to play a full part in the regional network. There are some areas of very good practice, but there is still more to do to complete the assurance process, embed the change of culture and restore the confidence of peers and families that the service has truly turned around.

Recommendations

We recommend sharing this report with the GI team who have contributed to the review process and the full report or a summary should be shared more widely amongst contributors to demonstrate transparency.

Leadership, Strategy and external focus

Appoint a respected NHS based external clinical leader to the post of senior clinical lead - equivalent to a chair - in gastroenterology to develop the service, working together with other units on London-wide GI network collaboration

GOSH should become part of this London network to equally contribute to the care of the regional population alongside other GI units. In addition GOSH may wish to also agree on their unique focus and to ensure appropriate communications between GOSH and all hospitals in this network

As a commitment to the populations of London working alongside other paediatric gastroenterology units, GOSH should agree and publish a defined specialist geographically based catchment area. This would encourage development of stronger relationships, better networking with provision of services close to patients' homes.

Review the acceptance criteria, pre-and post clinic MDT and job plans carefully to enable greater throughput of patients without compromising governance or increasing risk

There should be a further clinical review of the service and approach to cases 12 months after the lifting of referral restrictions

Management and Governance

Clinical Management should satisfy the Board that an investigation of historical gastroenterology cases has been completed in full, specifically the care of all children on long term interventions without a clear validated diagnosis.

There should be a demonstrated climate of openness in addressing concerns raised by staff to provide assurance that appropriate action and candour has been exercised. This should include the appointment of and demonstrable support for a Freedom to Speak Up Guardian

Take steps to ensure there is stability of clinical and operational management to embed the positive developments

Ensure a UK peer network is involved with development and agreement of guidelines, perhaps through BSPGHAN, not just international partners.

Finalise job plans, including weekend ward presence, appoint to permanent positions and consider additional recruitment to provide cross-cover and manage activity

Increase medical support for the intestinal failure team

Prioritise improvement of the ward environment as a matter of urgency and involve ward staff in discussions about relocation

Consider appointment of a nursing practice educator

Strengthen links with and feedback from the pharmacy team within the overall governance reporting arrangements

Safeguarding and Patient centred care

Maintain current safeguards, governance and QI programmes and consider rolling out the benefits and principles of PNB and ICN across the service

Involve a named general paediatrician in the referrals meeting and any gastroenterology subspecialty case with a perplexing presentation including current cases where a child has a significant disability after receiving treatment or investigations without a proven cause.

Develop a comprehensive and flexible patient centred transition programme - linked with adult services in London closer to home. Pathways should be patient based rather than be clinician's choice and require better networking. The design of such a programme should involve young people and include a suite of communications materials suitable for patients, parents and families

Invest in building sufficient clinical psychology input to meet identified demand and increase mental health screening /support

Plan realistically to ensure the appropriate number of beds so that children with "perplexing presentations" can be admitted, observed and managed cohesively with general paediatrics local paediatric teams and safeguarding where necessary.

Ensure the effectiveness of complex cases MDT to encourage the lead clinician to discuss cases in a forum with other GI consultants, general paediatrician, safeguarding lead (when appropriate) , nursing staff and clinical psychologists. All staff should be empowered to contribute.

Ensure continued support to the safeguarding programme with all clinical staff safeguarding trained to Level 3

Design a formal programme of engagement with all patients/parents/carers including seeking feedback and providing a report on what has changed as a result of comments/ complaints

Consider developing leaflets and web guides for patients and parents to support and improve their experience of using the service.

Develop a proactive programme of quality Improvement and engagement with management and other specialist teams. The team should aim to develop clear service pathways and build a QI/safety dashboard across the London GI Network

Improve liaison and understanding between the gastroenterology consultants and the social care team.

Appendix 1 The Review team

Dr David Shortland MD FRCP FRCPCH DCH has been a paediatrician for 25-years in Poole, Dorset, including ten years as neonatal lead and twelve as clinical director. David was the lead clinician for the rebuild of the paediatric department in 2005 and currently leads on Clinical Quality for the paediatric department.

Following five years as member, then Chair, of the Clinical Directors Special Interest Group, in 2006 David was elected as the National Workforce Officer for the RCPCH leading the 2007 national workforce census and designing a cohort study of trainees to provide a clearer understanding of the current and future workforce, helping to define how the role of paediatricians can evolve to provide consultant delivered care and hence safe and sustainable services. David was elected Vice President (Health Services) in 2009 and played a central role in developing strategy for Child Health Services in the United Kingdom supporting paediatricians through the challenges of radical reform to the health service, working time legislation and service re-design. During David's five years in post he developed a national template for the resident paediatrician and was lead author for "Facing the Future". This document defined 10 quality standards for acute paediatric services and is widely quoted as a template for good practice. David led a national audit of these standards in 2013 and currently chairs a steering group extending the standards approach to care outside hospitals. Since 2014 David has been clinical adviser to the RCPCH Invited Reviews programme and has led a number of high profile reconfiguration, individual and service reviews.

Dr Nadeem Ahmad Afzal MBBS, MRCP, MRCPCH, MD is an Expert Adviser for the NICE Centre for Guidelines and has recently served as Honorary Secretary of the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN). Dr Afzal is a Consultant in Paediatric Gastroenterology, Hepatology and Nutrition at University Hospital Southampton. As Honorary Senior Clinical Lecturer at Southampton University he runs an active research programme. Dr Afzal has established paediatric hepatology services at University Hospital Southampton, is the paediatric endoscopy lead and helps to run the Wessex Paediatric Gastroenterology Network. Dr Afzal is an Invited lecturer to the MSc in paediatric gastroenterology at Barts, London and MSc in Allergy in Southampton University. Dr Afzal has served as Editor in Chief for World Journal of Gastrointestinal Endoscopy and has contributed to the gastroenterology section of the RCPCH Paediatric Care Online.

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the public, practitioners, and organisations. Before joining NCAS Claire was Head of Fitness to Practise at the Nursing and Midwifery Council.

Sue Eardley joined RCPCH as Head of Health Policy in January 2011 and established the Invited Reviews programme for the College, conducting over 70 reviews in five years. An engineer by training, Sue spent 13 years as a non-executive and then Chairman of an acute trust in London, alongside a range of voluntary activities including national and local involvement in maternity services and the NHS Confederation. Sue led groups contributing to the Maternity NSF and chaired her local MSLC for four years. Before joining the RCPCH Sue spent six years full time leading the maternity and children strategy team at the Healthcare Commission and then Care Quality Commission, overseeing strategy, design and delivery of all inspections and reviews in England of maternity, child health and safeguarding.

From: [redacted]
Sent: 24 October 2017 13:49
To: David Hicks
Cc: [redacted]
Subject: RE: report
Attachments: 171023 GOSH Gastro report executive summary and recomendations - updated.doc

Follow Up Flag: Follow up
Flag Status: Flagged

Dear David

Please see attached for the updated version of the executive summary.

Just let me know if you need anything else.

Best wishes
[redacted]

[redacted]

[redacted]

RCPCH is celebrating 21 years of achievement in paediatrics.
Wish us a happy birthday and read about our planned activities throughout 2017.

From: [redacted]
Sent: 24 October 2017 12:31
To: David Hicks <David.Hicks@gosh.nhs.uk>
Cc: [redacted]
Subject: RE: report

Thanks David, will see if Jenni can amend.
[redacted]

[redacted]

From: David Hicks
Sent: 24 October 2017 09:44
To: [redacted]
Subject: RE: report

fantastic and thank you [redacted].
Two typo's only - "told" not tld 3rd line from bottom p3 and add "a" after As on line 11 p5.
Hope the weather is good for your outdoor life,

Best Wishes,
David

[redacted]

RCPCH Invited Reviews Programme

Review Proposal

Follow-up Review of gastroenterology service at Great Ormond Street Hospital NHSFT

May 2017

Version control

Issue	Purpose	Date	Changes since last version
0.1	First draft	18/09/16	
0.2	Second draft	25/09/16	
0.3	For client	9/5/17	Updated progress on previous actions

Contents

1 Aim and Purpose

1.1 This document sets out our proposal for following up on the RCPCH Invited Review of the gastroenterology service at Great Ormond Street Hospital; It is a preliminary document setting our understanding of the current situation and suggestions as to how a review might most effectively be conducted. Colleagues at GOSH are invited to refine and amend the proposal towards agreement of the terms of reference, reviewer team and fee.

2 Background

2.1 During the summer of 2015 the RCPCH Invited Review programme undertook a review of the gastroenterology service at GOSH. This was commissioned by the then Co-Medical Director in April 2015 and received formally by the substantive Medical Director Dr Vin Diwaker five months later. The review included a detailed assessment of the gastroenterology medical team, the operation of the service and consideration of the wider organisational support and governance arrangements within which the service was delivered. Over 100 individuals were interviewed or contributed material to the review and the team spoke to staff, within and working with the team, together with clinicians who made referrals from other organisations to the service. The review team was specially selected for the skills and expertise they brought to the review and the report received additional quality-assurance input to ensure that it was fair and accurate and represented the opinion of the RCPCH..

2.2 The review team highlighted to the Medical Director in July 2015 some areas of significant safety-related concern requiring immediate action, and the consequent report made 20 recommendations to the Trust. In accordance with the recommendations, the Medical Director commissioned a series of casenote reviews and put other steps in place to secure the safety of patients including ceasing the acceptance of new tertiary referrals. Further work to address the governance and operational activity of the service has been carried out, using the RCPCH`s recommendations as a framework These actions and the report`s contents were

shared with the Care Quality Commission and the Specialist Commissioners from NHS England who monitored the Trust's activities in a number of areas and have provided written acknowledgement of the progress the Trust has made. The action plan against the RCPCH report was formally closed in early 2017 as it was considered to have achieved its purpose. Whilst the Trust management acknowledges that there remains more to be done to fully embed the new culture and ways of working throughout the gastroenterology medical team, they support the significant progress made by the current clinical lead in encouraging his colleagues to work in new ways and important indicators of service quality, such as numbers of complaints, are, they feel, markedly improved.

2.3 In order to provide assurance of the progress made since the RCPCH review, demonstrate continuing improvement to the commissioners, regulators, Trust Board, patients and families, and to provide encouragement and support to staff and stakeholders within and outside the service the Medical Director and Deputy Chief Executive have requested the RCPCH conduct a follow up review of the service. This will examine progress against the recommendations, but also remark on the development of new processes and pathways, the emerging strategy for the service going forward and provide an opinion on any further action or issues arising.

2.4 The nature and sensitivity of the original review required a focus on the medical team and the structures and processes of the service. The high level of complaints and concerns raised by parents and families was acknowledged but for a number of reasons meaningful engagement with them by the review team was not accomplished. Alongside the changes to the service, and in line with the recommendations of the RCPCH review, GOSH directors are keen to develop the voice of those who use the gastroenterology service and have taken steps to build provide better routes for engagement. The review needs to gather input from patients and families and their representatives, and it is important to demonstrate transparency of approach that the report is drafted with a view to publication.

3 RCPCH's Invited reviews service

3.1 The Royal College of Paediatrics and Child Health`s review service provides Trusts and Commissioners with an objective and independent analysis of a service or individual based upon clear agreed terms of reference. Reviews are tailored to the specific service or issue under scrutiny and review team members are individually selected to bring appropriate expertise and challenge Recommendations are practical and realistic and recognise the current situation and team who will be expected to implement them alongside national policy initiatives and benchmarking evidence in reconfiguration, workforce planning and user engagement

3.2 Each review we conduct is carried out using tested principles including;

- Openness and transparency about the purpose and terms of reference

- A commitment that findings will be shared as far as possible with those involved
- A standards-based approach, monitoring service provision against professional national or locally agreed guidance, benchmarking with other services where appropriate
- An independent, experienced review team appropriate to the service under review
- Involvement of additional expertise and data sources where relevant
- Follow-up and advice around the implementation phase

4 Proposal

4.1 The RCPCH is pleased to be invited back to follow up on progress with the recommendations. We are aware informally of some of the progress that has been made and appreciate the significant challenges that faced the Trust as a result of our initial review report. This has included some personnel issues and a restructuring of the service alongside changes to the referral thresholds, cessation of some services and a focus on reviewing the care plan for existing patients. The assistance of paediatric gastroenterologists based in other tertiary units has been invaluable in addressing some of the problems identified in the service.

4.2 The follow up review would comprise a number of elements:

- Examine the progress made against the 20 recommendations through a documentation review and a series of interviews with those working within and with the service. This will include clinicians in other centres who have supported GOSH`s gastroenterology team with clinical review work and those who currently refer patients to the team, many of whom contributed to the original review.

- Provide a qualitative `peer review` opinion on the current service arrangements including a comment on the quality of protocols, pathways and guidelines, some of which have been developed with international expert input. The RCPCH has a number of expert contacts to enable this and support the expert reviewer but the extent of this broader collaboration may need some clarification in terms of breadth and formality of comment.

- Work with the gastroenterology team to support and encourage the development of a clinical strategy for the service that recognises the changes in the service and embeds the new ways of working, network approach and clarifies the role and future business model for GOSH as a ‘quaternary’ centre of excellence nationally and in some areas internationally.

4.4 The previous Review lead recognised in 2015 that it was important to gain an understanding of the views and aspirations of the consultant gastroenterologists and meet them individually prior to the formal review visit. This enabled the review team to contextualise the subsequent findings, recognise the immense impact of the review on

each consultant and carefully assess the risks and benefits of the report on the service and individuals. We recognise that the last two years have been difficult for the team and our approach this time would similarly provide an opportunity for the consultants to discuss the review, their reflections, on progress and aspirations for the future ahead of the formal visit.

4.5 It is important that this follow up review includes contact with those who contributed previously to the initial review. Many individuals demonstrated courage in trusting the review team with their experiences and views in confidence, and it is important for 'closure' that when we return we are able to offer them a chance to tell us in confidence what, if any, changes they have experienced since our visit. It may not be possible or appropriate to speak to all 97 previous contributors but we will endeavour to make contact and offer written input if they wish to provide it.

4.6 The 2015 review did not include any conversations with those who used the service or their representatives despite the best efforts of the review team to organise a survey, and there was little evidence of the voice of patients and carers influencing the design or operation of the service. This is an important part of our review approach and will comprise two elements.

- Assessment of the effectiveness of the department's own engagement systems with children, young people and parents/carers, and in particular how well the corporate approach to Voice is working in gastroenterology.

- Direct engagement with those currently using the service and their representatives specifically to inform the review. This is important to ensure transparency and respond to concerns being raised about the content of the initial review. We can seek this input in a number of ways which we have used for other reviews including
    - Involvement at an engagement event,
    - Survey of patients and families specifically for the review
    - Meeting representatives of larger groups of parents/carers

4.7 It is not usually ab effective use of the review team's time to meet individual patients/ parents who do not carry a representative role, and we cannot investigate complaints, but we will always respond to written enquiries and the web-based survey (with paper completion option) provides those using the service with a means of contributing that we have found in the past to be helpful and inclusive.

4.8 The overall review will be focused around a series of one-day visits, supplemented by telephone interviews or written communications to gather the evidence and opinions needed for full coverage of the terms of reference. Further meetings may be required to set up the review, involve those who use the service and provide feedback once the review is complete.

4.9 The review would follow the approach and governance set out in RCPCH's Guide to Invited Reviews dated April 2016[1], modified where appropriate to fit the terms of reference. We would need to receive relevant documents ahead of the visit in order to prepare and make best use of the time on site, and would need an administrator to set up the programme for the two visit days so that all relevant individuals are able to contribute. Assuming all the information we need is available in time or very soon after the visit, we would endeavour to provide the draft report within six weeks. .

5 Draft Terms of Reference

The terms of reference are crucial to ensuing that the review is successful and all involved are able to contribute fully. They must be agreed by the consultants and managers prior to the review taking place A suggested set is as follows:

The RCPCH will conduct a follow up review of the paediatric gastroenterology service at GOSH focusing specifically on:

a) What progress has been made against the recommendations from 2015 in terms of
- Leadership and management
- Concerns arising from MDT work
- Strategic positioning and external referral pathways
- Safeguarding
- Communications and administrative support
- Clinical activity and job planning
- Governance, guidelines and audit
- Training and supervision
- Patient and family Involvement?

b) Are the current protocols, pathways and guidelines fit for purpose and working effectively?

c) Are there any areas of notable practice or achievement?

d) The priorities and strategy for development of the service.

6 Estimated costs and timescale

6.1 The cost of the review, to include reviewer fees, expenses, administrative fee, QA and production of the report, as set out above will be in the region of £35,000 plus VAT at the current rate. Additional engagement work or extra visits may incur a supplement.

[1] www.rcpch.ac.uk/invitedreviews

6.2 We have secured the review team`s availability to conduct the main visit during June and July including a set up meeting including individual discussions with the consultants and any other key staff planned ahead of this. Documentation and reference material should be provided at least three weeks ahead, and is it suggested that the dates of the visit are notified to all potential contributors as soon as possible so that diary space is reserved to meet the team.

7 Next Steps

7.1 Colleagues from GOSH are invited to consider the proposal, advise any suggested amendments and/or confirm acceptance to proceed to sue.eardley@rcpch.ac.uk or by phone to Sue Eardley Head of Invited reviews on 020 7092 6091 A contract letter will be drawn up together with form of indemnity, and the review preparation will begin.

7.2 It would be helpful for smooth running of the review for an administrative point of contact to be identified within the Trust who can co-ordinate arranging the various onsite meetings and obtaining and documents or information that the review team might request.

Appendix 1 – the Review team

Dr David Shortland MD FRCP FRCPCH DCH has been a paediatrician for 25-years in Poole, Dorset, including ten years as neonatal lead and twelve as clinical director. David was the lead clinician for the rebuild of the paediatric department in 2005 and currently leads on Clinical Quality for the paediatric department.

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Lay reviewer

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Management support

Sue Eardley joined RCPCH as Head of Health Policy in January 2011 and now leads the Invited Reviews programme for the College. An engineer by training, Sue spent 13 years as a non-executive and then Chairman of an acute trust in London, alongside a range of voluntary activities including national and local involvement in maternity services and the NHS Confederation. Sue led groups contributing to the Maternity NSF and chaired her local MSLC for four years. Before joining the RCPCH Sue spent six years full time leading the maternity and children strategy team at the Healthcare Commission and then Care Quality Commission, overseeing strategy, design and delivery of all inspections and reviews in England of maternity, child health and safeguarding.

From: [redacted]
Sent: 24 October 2017 15:43
To: David Hicks
Subject: FW: Gastro review
Attachments: 170508 RCPCH Proposal GOSH follow up.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Hi David

Please see the attached doc which has the TOR embedded within it.

Please can you review and confirm if this is the final version that needs to be sent to [redacted]

Thanks [redacted]

[redacted]

[redacted] | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
[redacted]

From: [redacted]
Sent: 11 May 2017 18:19
To: [redacted] 'David.hicks@GOSH.nhs.uk'
Subject: RE: Meeting today

Dear [redacted] and David

Many thanks for your time on Monday , it felt like a very helpful meeting
I have checked with the reviewers and as always diaries are tight!

We are struggling to get two days together for the visit before August so I'm checking whether a series of individual days might be possible instead. The reviewers are all in relatively easy reach of London and it provides a bit more flexibility and enables us to start sooner.

I'm awaiting confirmation for the following provisional dates and just wanted to check this arrangement might work for you

Monday 19th June – meet gastro consultants and key stakeholders
Thursday 22nd June – various telecons with DGH representatives etc
Monday 10th July – main visit day 1
Monday 17th July – Main visit day 2

Thursday 20th July – final mop-up visit – or Thursday 27th July

Other telecons could be arranged on other dates as for the previous review.

We would use the first date to talk to the gastroenterologists individually - reflecting on the last review and progress since then, and discuss their vision and strategy. We would also organise telecons with the DGH representatives whom we spoke to previously and gauge their perception of whether things have changed / update them.

Having a more spread out series of visits does provide an opportunity for reflection and a little more time to seek and engage with any parents' issues.

You mentioned a specific engagement event with parents / carers – do you have a date for this please yet and what input would you envisage? We have included for someone from the review team attending that, and could offer additional focus groups using our &Us engagement team if that would be helpful .

If that is looking OK, once I hear back from the reviewers I'll refresh the proposal document to reflect pull together the contract

Best wishes

[redacted]

[redacted]
http://www.rcpch.ac.uk/invitedreviews

Leading the Way in Children's Health
The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299)

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

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From: [redacted]
Sent: 08 May 2017 09:04
To: [redacted] 'David.hicks@GOSH.nhs.uk'
Cc: [redacted]
Subject: Meeting today

Dear [redacted] and David

[redacted]d and I are looking forward to our meeting at 3-4pm today to discuss following up on the gastroenterology review
We are both out at various meetings this morning and lunchtime but should be with you in plenty of time

With best wishes

[redacted]

From: [redacted]
Sent: 24 October 2017 16:56
To: Harris, David
Cc: [redacted]; Peter Steer; [redacted] David Hicks
Subject: RCPCH gastro report
Attachments: 171023 GOSH Gastro report executive summary and recomendations - updated....doc

Follow Up Flag: Follow up
Flag Status: Flagged

Hi David,

Please see attached the draft executive summary and recommendations on the GOSH gastro service from RCPCH which was received last night. We are pleased to note the acknowledgement of the enormous amount of work and progress made.

Please note that this is still in draft format awaiting factual accuracy check and further editing by the Trust and the College.

For example, three current inaccuracies that exist in this draft are;

- The report suggests a further urgent review of all patients is required; this was in progress at the time the review was conducted and is now complete and these patients are safe
- The report references the need to relocate the inpatient service to improved accommodation and infers there had been no staff consultation/plan for this – there is a new clinical building opening in November at GOSH and there are detailed service moves across our entire estate as a consequence including a well consulted and communicated move for the gastro service
- The report references the need for Freedom to Speak ambassadors – these have been in place for a considerable period of time.

In addition, it is also important to note that the document contains a series of actions which impact far beyond just the GOSH service (e.g. establishing a London network/ appoint a senior clinical chair) and it is important that I highlight that these recommendations have not yet been shared with or agreed by the other Trusts, commissioners or academics – clearly this discussion will form part of the next phase of our service improvements.

As always, any questions, please do not hesitate to ask.

[redacted]

From: Harris, David [mailto:David.Harris@cqc.org.uk]
Sent: 23 October 2017 18:40
To: [redacted]
Cc: [redacted]
Subject: RE: GOSH - News Story

Hi [redacted]

Thank you for the response. For the avoidance of doubt it is the draft report that you already have that we need by close of business tomorrow.

Regards

David Harris
Hospital Inspection Manager London
Care Quality Commission
Telephone number: [redacted]
Email: david.harris@cqc.org.uk
By post to:
CQC London
Citygate
Gallowgate
Newcastle Upon Tyne
NE1 4PA

On the second point we just wanted an initial document setting out the issues as you see them. I would assume you have prepared something internally which would be very similar.

Can I also ask if we can expect the draft Gastro RCPCH report today?

Regards

David Harris
Hospital Inspection Manager London
Care Quality Commission
Telephone number: [redacted]
Email: david.harris@cqc.org.uk
By post to:
CQC London
Citygate
Gallowgate
Newcastle Upon Tyne
NE1 4PA

[redacted]

From: [redacted]
Sent: 24 October 2017 19:13
To: David Hicks
Subject: Re: RCPCH gastro report

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks David!

Sent from my iPhone

On 24 Oct 2017, at 18:57, David Hicks <David.Hicks@gosh.nhs.uk> wrote:

> just what was needed [redacted]
> Thank you,
>
> Best Wishes,
> David

From: [redacted]
Sent: 24 October 2017 16:56
To: Harris, David
Cc: [redacted]; Peter Steer; [redacted]t; David Hicks
Subject: RCPCH gastro report

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[redacted]

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Sent: 23 October 2017 18:40
To: [redacted]
Cc: [redacted]
Subject: RE: GOSH - News Story

Hi [redacted]

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Regards

David Harris
Hospital Inspection Manager London
Care Quality Commission
Telephone number: 07789876070
Email: david.harris@cqc.org.uk
By post to:
CQC London
Citygate
Gallowgate
Newcastle Upon Tyne
NE1 4PA

From: [redacted]
Sent: 23 October 2017 16:17
To: Harris, David
Cc: [redacted]
Subject: RE: GOSH - News Story

Hiya

I think that it was my office on the meeting invite – so you could use the space – but not me personally! The additional half hour was requested, as I understand it to discuss the upcoming visit which really needed [redacted] to be present and so the team thought it best to wait – we thought she would be back this week but sadly she will be away a little longer and so we will probably need to find you a replacement contact to cover her absence. I will confirm back to you on this asap.

In terms of gastro report, the team here are chasing RCPCH now for the executive summary in advance of the full report,

[redacted]

From: Harris, David [mailto:David.Harris@cqc.org.uk]
Sent: 23 October 2017 16:09
To: [redacted]
Cc: [redacted]
Subject: RE: GOSH - News Story

Hi [redacted]

Sorry if there has been some confusion. You were on the meeting invite for Fridays NRLS meeting set up by [redacted] so I assumed you would be there. I think we had also agreed that half an hour would be added to the meeting 1pm-1.30pm so we could discuss wider trust issues.

I will get back to you tomorrow about the Gastro panel details but in the meantime I look forward to receiving a copy of the draft report.

Regards

David Harris
Hospital Inspection Manager London
Care Quality Commission
Telephone number: [redacted]
Email: david.harris@cqc.org.uk
By post to:
CQC London
Citygate
Gallowgate
Newcastle Upon Tyne
NE1 4PA

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Thank you for your co-operation.

****

****

From: [redacted]
Sent: 27 October 2017 14:43
To: David Hicks
Subject: RE: Couple of things

Follow Up Flag: Follow up
Flag Status: Flagged

Hi

I have spoken to [redacted] and she has said that any concerns raised by external parties would not be part of the Trusts complaint process and therefore not be recorded by them. Only complaints raised by patients at the trust would be recorded and investigated.

Complaints from other Trust would be sent to the Medical Director and /or Divisional Director

Kind Regards
[redacted]

[redacted]

[redacted] | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
[redacted]

Great Ormond Street Hospital for Children NHS

From: David Hicks
Sent: 27 October 2017 09:10
To: [redacted]
Subject: Fwd: Couple of things

Hi [redacted]
can you check with Complaints please and let me know?

Best Wishes,
David

Sent from my iPad

Begin forwarded message:

> **From:** Peter Steer <Peter.Steer@gosh.nhs.uk>
> **Date:** 27 October 2017 at 06:37:18 BST
> **To:** David Hicks <David.Hicks@gosh.nhs.uk>
> **Subject: Couple of things**
>
> HI
> Know we have spoken about this many times -
> But as you know, despite numerous complaints prior to the gastro review - we had no actual patient or care complaints (as bizarre as that may seem) is my recollection true
>
> Did we ever get any individual patient complaints / referrals or case names from the difficult external clinicians?
>
> Thanks
> Peter

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Page/ Para No.	Relevant sentence from report	Comment
P.4 *Executive Summary*	However the new approach has not been universally accepted by all consultants and some remained sceptical about the need for change. Many staff expressed continuing concern that the Trust and team had not fully learned from the consequences of the 2015 review and further detailed case review work was required urgently to ensure all children were on appropriate care plans. The report had not been shared and some staff still did not feel confident that their concerns could be raised and responded to in a climate of openness.	The evidence base for this comment is unclear, and seems contradictory given the extensive upheaval acknowledged by the reviewers in the earlier part of the executive summary.
pp.4-5 *Executive Summary*	Some consultants see their service as only 'quaternary' or highly specialised and are selective about accepting their fair share of specialist ('tertiary') referrals in the London catchment. This is causing friction with other providers and it is important that specialist services work more closely together with clarity about expertise and referral pathways across London and the South East.	Important to note the responsibility of the commissioners/NHS England in defining the overall referral pathways for London and the South East.
p.5 *Executive Summary*	The service is currently working at around half of its previous activity and needs to step back up to manage a similar workload to peer units. This may require some investment in staffing and robust job planning to ensure that the gains made in governance and safety are embedded and continue with the changeover of the Medical Director.	This point on appropriate resourcing is not supported with evidence in the report, and in fact inefficiencies are highlighted later on the report.
p.5 *Executive summary*	Although the safeguarding systems have improved with the recent appointment of the Named Doctor, there remains more to do around process and attitudes, strengthening links with the referring communities and ensuring candour and openness when staff raise concerns. The Trust is now aware of these issues and steady progress is being made which must continue to be prioritised.	This far-reaching conclusion is not substantiated with evidence later on in the report.
p.7 *3.2*	There are seven permanent consultants, and three locum appointments pending a decision on the future configuration of the service. There are ten 'middle grade' doctors working as clinical fellows or registrars. Two matrons, eleven clinical nurse specialists (an increase since 2015) and two ward sisters complete the senior clinical team.	The nursing workforce figures are not correct. There is only 1 Ward Sister (not 2), only 9.5 CNS posts (not 11), 2 Matron posts have responsibilities for part of the Gastro services, however, they carry much broader workloads (see below) and it is misleading to suggest that 2 Matron post holders are dedicated to the Gastro service. In detail:

		• Rainforest Ward – 8 beds has 1 x band 7 Ward Sister, 6 x band 6, 10 x band , 4 x band 3 & a ward clerk • GIU Service – 1 x band 7 Nurse Practitioner for which training is a key element), 7 x band 6, 1 x band 4 & 3 x band 3 HCAs. • CNS Team a total of 9.5 WTE posts (including an ANP & a NP) led by 1 x 8a Advanced Nurse Practitioner, • IBD 2 x band 7, 1 x band 6 • PN Service 1 x Band 7 & 1 x Band 6 • Dysmotility 1 x band 7 Nurse Practitioner & 1 x band 7 (CIPO) • General Gastro 1 x band 7 • Complex Gastro 0.5 x band 7 • There are 2 Matron postholders who each have an element of responsibility for part of the above services alongside other non-gastro responsibilities. It presents a false level of resource by suggesting 2 Matrons • Matron A – Rainforest Gastro ward, CNS covering gastro (plus SNAPS Squirrel ward, CAMHS & Mildred Creak Unit, CNS teams for surgery, stoma, gastrostomy, FEDS & eating disorders) • Matron B – Kingfisher & Gastro Investigation Unit (Eagle acute, Eagle Haemodialysis, Squirrel Urology, CNS renal / transplant & urology) • Kingfisher Ward has a nursing establishment to align with its workload with 3 beds identified for gastro children.
p.7 *3.3*	Inpatients staying for longer are accommodated in the 8-bedded Rainforest ward which is not fit for purpose although there remains no firm plan for its relocation.	Firm plans are in place for the relocation of the gastroenterology inpatient ward. These plans are outlined in detail in the comments below, in response to paragraph *5.3.18*
p. 8 *3.5*	The letter recommended that "*a swift but thorough review is undertaken of the diagnosis and management of 40 of the children currently being treated for eosinophilic colitis to determine whether the overall best interests of the child are being met, and if not devise a strategy for resolution. This review should be completed within three to six months and depending upon the findings of the first 40, more cases may need to be examined*". The suggestion of 40 cases was based on information received by the review team that there were around 400 children in this cohort (subsequently revised to 463), so a 10% sample was feasible.	Where do the 400 and subsequent 463 figures come from? We do not recognise these numbers.
p.8 *3.6*	The Medical Director responded swiftly to this notification and advised the RCPCH on 24th July that from Monday 27th July all new referrals to the service were to be reviewed by an intake multidisciplinary team (MDT), all procedures were to be agreed	The Trust responded swiftly, rather than specifically the Medical Director

	in advance against written justification, the cohort of 40 cases for review was being established and consensus –based diagnostic criteria and guidelines for investigation and treatment were to be developed.	
p.8 *3.8*	During autumn 2015 the Medical Director established the expert panel to conduct the external casenote review, comprising four consultant paediatric gastroenterologists and a consultant immunologist. Initial attempts to convene international experts delayed establishment of the panel and the original suggestion of an independent lay chair was not implemented. A list of 42 cases was drawn up for review selected from those diagnosed with Eosinophilic Gastrointestinal Disease (EGID) or suspected or diagnosed food allergy over the last 3 years with coded diagnosis meeting the criteria above. Once established with terms of reference in November 2015 the panel carried out a rapid casenote review and agreed that fourteen of the first 18 cases gave the panel significant cause for concern over the diagnosis and treatment regime. This was formally reported to the Medical Director in December 2015, recommending a more detailed expert review of these same cases including histology, plus a wider clinical review of patients across the service. The panel's report and recommendations were presented in January 2016.	The 40 cases identified by November 2015 for the panel to review appears to have been confused here with the cohort of 42 patients reviewed from March 2016 onwards. There is some overlap between the two groups: A) A list of 40 cases was drawn up for the panel to review. Patients for consideration of review needed to have specifically received any of the following interventions: ○ 1. Exclusion or elimination diet; 2. Presence of gastrostomy or use of NG/J tube; 3. Steroids; 4. Other immunosuppressants (eg MMF, azathioprine) or monoclonal antibody treatments. The panel reviewed 18 cases and had concerns in 14 cases. These 14 were then subsequently reviewed in depth. B) In March 2016, 42 patients in total were identified within the gastroenterology service on immunosuppression and/or steroid therapy without a diagnosis that unquestionably required such treatment (i.e. children without IBD or post bone marrow transplant on immune-modulation). They were reviewed in clinic by external gastroenterologists.
pp.8-9 *3.9*	From January 2016 major restrictions were put on referrals into the service, including significant reduction in endoscopy work, and other specialist centres were asked to increase their activity 'on a temporary basis' to accommodate these referrals and also conduct follow up reviews of some of the existing GOSH patients.	Important to note that these changes were agreed with NHS England
p.9 *3.9*	[redacted].	The use of the word "but" here implies it was not appropriate for these individuals to return to practice; more neutral language may be more appropriate given they had been subject to an in depth process aligned with national standards.
p.9 *3.10*	The review team was told that the GOSH Trust board was kept fully appraised of the findings and recommendations of the review and the progress being made to address them.	It is factually accurate to say "The Trust Board was kept fully appraised…"
p.9 *3.11*	In parallel with these changes, the panel's cases were re-examined by national and international experts and the remaining 24 cases in the initial sample were reviewed and where appropriate the patient was seen and changes to treatment regime discussed. In line with the panel's recommendations, independent assessment of treatment plans in clinic were undertaken for a sample 20% of gastroenterology	Important to note the reviews were conducted by independent paediatric gastroenterologists, and where appropriate the patient was seen and changes to treatment regime discussed. Also important to note in addition to the 20% sample, there were independent

	patients and two consultant gastroenterologists were seconded into the Trust for three days a week during 2016 to assist with assessing these patients in clinic. Their care was discussed with the GOSH gastroenterologist and where appropriate their treatment regime was amended and and/or they were discharged them to the care of their local service. This was completed by June 2016. For each patient a summary was completed detailing two questions using the NPSA harm definition and the Trust Risk Matrix: "Has harm been done?" and "What is the risk of harm?"	clinical reviews of 42 patients identified on immunosuppressants/steroid therapy (children without IBD or post bone marrow transplant on immune-modulation).
p.9 *3.12*	During 2016 the CQC held fortnightly meetings with the Trust but these reduced as the Trust demonstrated more secure governance systems. There was joint oversight with NHS England and NHS Improvement but this moved to operational oversight by the end of 2016. A closeout report for the completion of this process was prepared but this has not been shared with the review team.	We are unclear what report is being referred to here, is there specific documentation you are requesting to see?
pp.9-10 *3.14*	By December 2016 the Trust considered it had made significant progress in addressing the clinical concerns raised by the RCPCH and wrote to a number of stakeholders, including specialist centres who had taken its referrals, commissioners, RCPCH and the CQC summarising the concerns and action taken. A summary statement was posted on the Trust website which set out the steps that had been taken, and included the commitment to invite the RCPCH to conduct a follow up review.	All reports that have been commissioned as part of the review were shared with CQC.
p.10 *3.15*	Both the detailed and the summary statements from the Trust contained the phrase : "the review did not find evidence of long term consequences of over investigation or overtreatment". This, the review team were told, was justified by the Trust from consideration of the cases examined in detail and review of the statements made by the visiting consultants in response to the two questions set out in 3.11, There was recognition that moderate harm had occurred for some; lost school days, side effects and disruption, but no serious significant harm.	The language in 3.15 implies this was an interpretation or judgement applied by the Trust rather than a conclusion that was reached independently; this phrase was a consequence of independent reviewers using NPSA Harm Definition Categorisation and Risk Matrix.
p.10 *3.16*	Some staff in the Trust, and some clinicians in other specialist centres who had not been fully apprised about the process, inferred that this statement had arisen from the RCPCH review, since most staff had not seen the 2015 report. It may not have taken into account other patients still undergoing similar treatment for many years whose care had not been reviewed, nor the psychosocial impact on patients who had been on treatments for many years.	The wording of 3.16 is unclear and may be misinterpreted as casting doubt on the findings of the review.
p.10 *3.17*	Formal communication with the families whose children's care was being reviewed by the team at GOSH was carefully planned. Following the initial casenote review, families were told the conclusions drawn about their child's care. The letters	Important to note that all communication was also agreed to and "signed off" by NHSE.

	explained that the child's care was being reviewed as part of ongoing quality approach and that as a result in some cases changes needed to be made to the treatment regime. The wording used aligned with that on the Trust website and was sent to stakeholders and referring units. In December 2016 the Divisional Director wrote to all children and young people whose care had been reviewed and their parent/carer explaining that the review was complete and that further actions were being addressed including the request for external review.	
p.12 *5.1.3*	Although improved processes and systems are now in place there were still some concerns expressed that more work is needed to tackle deep-seated cultural attitudes amongst some of the consultants.	Could a recommendation be made here about what form this "work" may take
p.12 *5.1.3*	Corporately some staff are not yet convinced that there is a truly open reporting culture and others remain concerned about a perceived failure to extrapolate the findings from the case reviews across the whole cohort of current patients. See 5.2.2.	Unclear on what "corporately" means in this context Work has been undertaken to ensure the findings of the review across the whole cohort of current patients: comprehensive MDTs are in place and agreed signed off care paths and guidelines for conditions. Is there evidence or numbers to substantiate this concern?
p.12 *5.1.4*	A consistent theme amongst almost all staff interviewed, was frustration at the absence of clear communication from senior management about the 2015 RCPCH review report and how and why the changes during 2016 were implemented. Whilst the Board, CQC, commissioners and external reviewers had seen the report it was not shared with the consultants, even in summary form and there was much unhelpful speculation and at times misplaced anger at the report's content and the reason for the imposition of changes. Staff received a brief announcement just before Christmas 2015 explaining that as a consequence of the RCPCH report, activity would be significantly restricted [redacted], but there was too little information for them to understand and plan for the consequences or advise families what was happening.	[redacted]. This may be an appropriate juncture to outline the communications strategy to staff during the review – please let us know if you require more information on this.
p.13 *5.1.4*	Staff had inferred a lack of trust and a sense of isolation from the Board and senior management, which could have been mitigated through greater visibility, briefings and a programme of organisational development to build and retain trust and recognise the efforts of those working with and within the service.	Can this be quantified - was this all/some/a few staff?

p.13 *5.1.5*	Most interviewees did recognise, with hindsight, that the events of 2016 had been necessary and helpful in the longer term. They appeared to understand that given there were personnel issues to deal with, it had been important to be careful with information, sure-footed in managing potential trigger points, particularly around media interest, and to maintain control to make the service safe as swiftly as possible. They recognised the positive medical and operational leadership of the Trust, division and service and were hopeful that the 2017 RCPCH review would trigger sustainable restoration of an open, fully functioning service.	5.1.5 seems inconsistent with the conclusions of 5.1.4. Staff appear to have acknowledged and understood the reasoning behind the internal communications approach.
p.13 *5.1.5*	The General Manager is well respected but is in an interim post and has been the fifth in the role in two years. The Interim Medical Director is also expected to leave in October which introduces a potential risk to the continued improvement in the service as relationships will need to be rebuilt and trust engendered. However, the Divisional Director is highly respected and has a clear vision of how to manage the consultant team and encourage the best from the service and important that the new Medical Director engages swiftly to maintain the confidence of the team and its stakeholders.	The General Manager's post is permanent, not interim. There have not been five postholders in the role in the last two years. There have in fact been three (including the gastroenterology service improvement manager). The current general manager has been in post for over a year.
p.13 *5.1.6*	This has had some impact although more than one of the consultants apparently considered the review had been 'a waste of time'.	Was the consultant recorded as saying this to the RCPCH team, or is this third hand information? We would be concerned about including hearsay without substantiation.
p.13 *5.1.6*	Many interviewees were concerned that the changes made around multidisciplinary working, consistent protocols and peer review may not be sustained once the service gets busier or 'the spotlight is off'.	Could this be expressed more clearly? This is a potential risk
p.14	Recommendation – Take steps to ensure there is stability of clinical and operational management to embed the positive developments	Could this recommendation be made clearer – perhaps examples of what "steps" may be productive?
p.14	Recommendation – Appoint a respected NHS based external clinical leader to the post of senior clinical lead - equivalent to a chair - in gastroenterology to develop the service, working together with other units on London-wide GI network collaboration (see also section 5.8 about networks)	Is this recommending a shared post with other units?
p.15 *5.2.1*	The chair was removed late in 2016 in what some felt to be a very inappropriate manner but the new chair was reported to be well-respected and the meetings are continuing to work effectively with increasing engagement of most of the consultants.	The chair left due to retirement, so incorrect to say they were "removed" inappropriately.
p.15 *5.2.2*	Despite the improvement and changes to functioning of the complex case MDT, there remain concerns amongst some staff that whilst the process continues to improve it is insufficiently effective or thorough at the moment. Very few children are actually discharged home after complex MDT review.	The point here is a little unclear e.g. is the implication that a certain number of children should be discharged after complex MDT review?

p.15 *5.2.2*	Despite the findings of the casenote and physical reviews in 2016, a wholescale review had not taken place of children who had been on long term and/or aggressive interventions, including those on total parenteral nutrition (TPN), without a clear diagnosis.	Important to note that <u>all</u> patients on immunosuppressants without IBD or other relevant diagnosis (42 patients) & 20% of all patients were reviewed so there is assurance of appropriate treatment across the service. Additionally patients within the service will be exposed to an MDT and evaluated against agreed guidelines and protocols so the issue raised here in 5.2.2 should be mitigated.
p.15 *5.2.2*	These staff still did not feel confident to raise concerns within the clinical environment and explained that in some areas they still perceived a culture that suppressed challenge from colleagues which made them fearful of speaking out.	Are there certain staff groups we should be targeting to address this?
p.15 *5.2.2*	The published phrase stating "no evidence of long term consequences" was misleading and further exacerbated their concerns.	It is unclear whether this judgment of "misleading" is being made by the RCPCH review team or the staff members. Important to note the wording of all communications was agreed with NHS England.
p.15 *5.2.2*	Several indicated that there appeared not to have been any organisational learning or remorse from the situation or focus on actually what happened to those children and families – there were several reports of families being left without any support including from those who responded to the review team's survey.	It is important to note that survey feedback includes families for whom care was necessarily corrected as a result of the review, and who objected to the decrease in medical intervention – and so need to be cautious about what they perceive as a lack of support. Additionally, in terms of organisational learning and engagement with families it is important to note the extensive communications with patients and families including meetings in person, letters, listening event.
p.15 *5.2.4*	Under the 2016-7 NHS Contract all Trusts should by 1st October 2016 have appointed a "Freedom to Speak Up Guardian" to support whistleblowing and reporting of concerns. Many Trusts have appointed more than one individual, often including the Medical Director, to this role but GOSH senior management decided instead to appoint a small number of 'Lead Ambassadors' in Autumn 2016. Although these individuals have met a few times the role has not been clear. With the involvement of the national Guardian the Trust is now about to re-advertise for volunteer (non-staff) Guardians to carry out the role.	GOSH currently has seven FTSU Ambassadors including a senior consultant, senior nurses, lab-based staff and those who work in administration. The decision to appoint a number of Ambassadors through a diversity of job roles (not just a senior leader) was a deliberate strategy to ensure Ambassadors were approachable and easily accessible to all staff. Previously a low number of cases were raised at GOSH indicating that staff may not wish to use, for whatever reason, the agreed mechanisms for raising concerns – such as approaching their manager or the Non-Executive Board member who is responsible for Raising Concerns. We have found since its inception that the FTSU approach has worked; Ambassadors have been contacted about patient safety concerns by a variety of people, including medical staff. We have also found that staff with concerns have been able to speak to Ambassadors as they carry out their day-to-day roles 'on the ground'. We believe that this has encouraged more people to come forward about issues they are concerned about given that it helps to remove any stigma or fear associated with having to especially seek out a full-time and/or senior level Ambassador / Guardian. Contrary to 5.2.4, the Ambassador team meet regularly – on a monthly basis - to

		learn from each other and to offer each other support when dealing with issues which are brought to them. All Ambassadors are engaged in an ongoing development programme, including Safeguarding and attendance at national training events through the National Guardian's office. Ambassadors are also well supported on a day-to-day basis by the HR&OD Directorate. In terms of visibility, the role was advertised across the Trust and Ambassadors have attended and spoken at the Chief Executive Lunchtime Briefing Sessions which are open to all staff. The Trust's Raising Concerns Policy is available to all staff and a route map for staff has been launched to make the process of raising concerns easy to follow. All staff are told about the Ambassadors at their corporate induction and are encouraged to raise issues of concern early, either to them or via another agreed route. All Ambassadors have met with colleagues to talk about the importance of speaking up and the service they provide. In the summer the Trust hosted the National Guardian and one of the Ambassadors spoke at a conference held on the same day which attracted both internal and external attendees. Having been established for nearly a year the service is being reviewed to ensure it continues to meet the needs of the Trust. The review is not currently concluded but there are no plans to re-advertise for more 'volunteer (non-staff) Guardians' as has been suggested in 5.2.4. Additionally, there is no on-going involvement with the National Guardian about the role of Ambassadors at GOSH as is suggested.
p.16	Recommendation - There should be a demonstrated climate of openness in addressing concerns raised by staff to provide assurance that appropriate action and candour has been exercised. This should include the appointment of and demonstrable support for one or more Freedom to Speak Up Guardians.	This recommendation requires clarification, in the context of the comments provided in relation to 5.2.4
p.16	Recommendation - There should be a further clinical review of the service and approach to cases 12 months after the lifting of referral restrictions	Is this recommendation suggesting this review be led by the RCPCH or another external party?
pp.17-18 *5.3.2*	There is a referral MDT every Monday morning which all consultants are expected to attend. The MDT was reported to work well with good agreement but the administrative response to some patients whose referral was refused was reported still to be unclear and confusing, without an embedded culture that acknowledges the experience of families struggling for a diagnosis or support.	Could this point be expanded to provide clarification and evidence. The referral criteria as agreed with NHS England are clear – is this staff at other centres that are confused, GOSH staff, or patients/families?
p.18 *5.3.4*	It presumes 5 patients per clinic (1 new, four follow ups) against 6-8 before the review and reflects that the current workload is unsustainable in the long term.	Does this mean "unsustainable" financially or in terms of ability to manage work load?
p.18	The nutrition service/intestinal failure was reported to be very stretched with two	[redacted] *to advise on accuracy of this statement*

5.3.6	consultants and three nurse specialists with up to 52 inpatients on PN across up to ten wards in the hospital. They struggle to meet the RCPCH/BSPGHAN standards that every child on PN should be seen weekly and have seen reduction in clinical fellow support since 2015, which impinges on the consultant job plans. The issue is on the Risk Register and the team are seeking an additional consultant post to enable cover for leave and sickness. There is only capacity to make 45 tailor-made bags per day and PICU and cardiac ICU are not covered.	
p.19 *5.3.8*	Concerns were also raised to the review team from regional centres about the children with complex feeding tubes. A typical cited example is of children with displaced Jejunal tubes, with no clear pathway with regards to point of referral or contact in GOSH to replace these tubes. Presently these referrals may be accepted by either the surgical or gastroenterological teams, partly depending on which unit may have a bed.	Should a recommendation be made in relation to 5.3.8?
p.20 *5.3.15*	All have undertaken four team-coaching sessions to assist this, but it remains relatively fragile,	What is meant by "it"?
p.20 *5.3.16*	There were still no scheduled weekend ward rounds despite the service accommodating extremely sick children.	Consultant cover is available over the weekend
pp.20-21 *5.3.17*	Whilst most patients are accommodated on Rainforest and Kingfisher wards, the gastroenterology and nutrition team also visits those recovering from surgery or receiving parenteral nutrition but under a different department. There was some confusion as to which doctors have overall responsibility and the role of the gastroenterology team and general paediatricians which needs to be addressed.	Should a recommendation be made in relation to 5.3.17
p.21 *5.3.18*	All interviewees agreed that although nursing leadership and culture had improved, the physical environment on Rainforest Ward remains wholly unfit for purpose. There have been numerous reports and business cases highlighting insufficient cubicles, toilets and space resulting in excessive waits for admission, high numbers of complaints, inappropriate outliers and concern about patient safety. This has also been highlighted by the CQC and despite the construction of new ward space elsewhere in the Trust there was still no definitive plan. This is unacceptable.	It is not correct to say there is no definitive plan to move gastroenterology inpatient space to a better environment. All inpatient clinical areas will be moved out of the dated Southwood building. The Trust has acknowledged the current environment is inadequate and although some improvement work was undertaken on Rainforest ward since the CQC inspection in 2015, the intention has and remains that gastro inpatient services will move into an area that will meet the children, families and staff's needs. In January 2017, service moves across the hospital were agreed. Rainforest ward (covering gastro, endocrinology and metabolic) was initially scheduled to move into Sky ward (currently housing orthopaedics), however, due to various clinical service considerations a number of previously agreed ward moves have since been revised.

		Rainforest Ward will relocate to the current location of Squirrel ward in the Variety Club Building, after surgery and urology services move out of the space in November. The Redevelopment Team have been consulting with the two Matrons (who have elements of gastro / gastro related services within their portfolios) and the Rainforest Ward Sisters (one for gastro, one for endo/met) regarding the ward environment and how it will function, and therefore the scope of any works that require consideration. Further meetings are being scheduled that will include operational managers and consultants to plan the specific changes that we will need to make to Squirrel. Currently there are 8 beds (a 4-bed bay and 4 single bedrooms) on Rainforest Gastro and the same provision on Rainforest Met/Endo. Squirrel provides 23 beds in total, 15 of which are in single bedrooms. Therefore, the provision of single bedrooms is significantly better and the bedrooms also have en-suite shower rooms which is not the case on Rainforest. This will dramatically improve the privacy and dignity arrangements for both children and parents, and is an improvement on the initial plans to move to Sky ward. The gastro element within Squirrel will be: • 8 beds for gastro • 2 beds for home PN training It is anticipated that we will not need to make significant changes to the ward but the scope of works will include redecoration, upgrade of patient bedside entertainment and creation of a much better play/dining and adolescent space. This latter requirement will respond to a theme that emerged from the gastro listening event where the young people articulated very clearly that they wanted better adolescent space.
p.21 *5.3.21*	Neither the ward sister nor Matron appeared to have been consulted over the practical requirements of a new ward. Their involvement at an early stage is important when planning use of space and practical operation, alongside the benefits of proximity of the three clinical services (inpatients, day-case and endoscopy). Recommendation – Prioritise improvement of the ward environment as a matter of urgency and involve ward staff in discussions about relocation	As above.
p.21 Rec.	Recommendation - Plan realistically to ensure the appropriate number of beds so that children with “perplexing presentations” can be admitted, observed and managed, cohesively with general paediatrics, local paediatric teams and safeguarding where	We are unclear on why patients with “perplexing presentations” are singled out here as a cohort for GOSH to concentrate on, as other patients require inpatient observation and management

	necessary.	
p.23 *5.4.2*	However the transformation is not complete, as there continue to be complaints about letters, delays and cancellation of appointments so more work is needed to achieve excellence in patient and family communications.	This point is not substantiated by the present complaint figures for gastroenterology
p.23 *5.4.2*	The review team heard reports that discharge summaries were until recently sometimes sent out with incomplete or incoherent information, without detail of follow up plans with the CNS, or they were not sent to the local paediatrician or GP. The GI team could benefit by effective use of direct electronic communication between GOSH specialists and paediatricians in other hospitals to help bypass some of the problems with inadequate admin staff.	The way this is worded indicates this may be a historical issue – is it still a concern that requires addressing? Were these "reports" internal/external? It would be helpful to have more detail on this so it can be addressed if it is still an issue.
p.23 *5.4.3*	This has been recognised by the operational management and a monthly performance dashboard prepared by the clinical service lead and general manager ensures these areas remain a priority for support. In May the gastroenterology RAG meeting noted a plan to address the issues around discharge summaries, but there remained reports that poor patient/family information is resulting in dietitians and others being contacted about general issues.	Could you provide more detail on these "reports" so this can be appropriately looked into and addressed.
p.23 *5.5.1*	The 2015 review report expressed serious concerns about the isolation of the safeguarding (social work) team from the problems in gastroenterology, and the frequent absence on admission of any local data on the child and family in terms of safeguarding or fabricated or induced illness (FII) issues.	A consistent challenge for GOSH is ensuring we are in receipt of accurate social care information as unlike most children's hospital services we do not have a core Local Authority (LA) who the majority of our children are covered by; instead we have to link in with all LAs from across the whole of the UK. There is no automatic transfer of information pertaining to safeguarding activity or concerns, although the implementation of the Child Protection Information System (CP-IS) across England will be a great asset in this area for emergency admissions – i.e. ability to check and share child protection information securely such that if a child who is Looked After or on a CP Plan attends an unscheduled healthcare service health professionals can check and share CP information for vulnerable children securely. In the absence of any automatic information being provided from referring health or local children's social care teams or self-disclosure by families the hospital does not always hold all of the current social care information. This is not a unique situation to GOSH however the complexity of children being referred from across the entire

		UK makes the situation increasingly more challenging.
p.23 *5.5.1*	Concerns raised by referring clinicians were being overruled and there was no documented or written evidence seen of learning from the 2013 FII criminal case from Croydon.	We have documentation of learning from the Croydon SCR which we can share if requested, including a comprehensive GOSH Action Plan. An action arising from the hospital's Individual Management Review of the case was to commission an independent expert review of the care provided at GOSH to two of the children involved. The outcome of that review culminated in a learning event with the Gastroenterology Consultants which was held on the 28.05.2015. The resulting action plan arising from the independent review and learning event was agreed within the Division and all actions were incorporated into the combined action plan with the RCPCH reports actions.
p.24 *5.5.2*	The review team was told of patients requiring extensive therapy on Mildred Creak (CAMHS) ward who were physically well following many years of invasive treatment thought to have been based on functional or fabricated symptoms. There was no evidence of sustained organisational learning from these cases or proactive case review for others in similar situations. On raising this issue the review team was advised that work to identify such patients is in hand but this must be monitored in a fair manner, perhaps by external regulators, to ensure that it is thorough and complete.	Unclear if this is referring to the findings of the RCPCH 2015 review or RCPCH follow up 2017 visit
P.24 *5.5.3*	Following an internal report prepared by the interim named doctor in 2015-6 (which has not been circulated) a more comprehensive external report was commissioned at the end of 2016 coinciding with the arrival of the new Named Doctor.	The report in 2016 (not 2015) was in response to recommendation 5 from the Lampard Report (Themes & lessons learnt from NHS investigations into matters relating to Jimmy Savile) to review structures, resources and processes. A further expert peer review of GOSH safeguarding cases was undertaken in March – April 2017.
p.24 *5.5.3*	The safeguarding annual report 2016-7 highlights the restructuring of the safeguarding team, development of social work function and increased involvement of staff in child protection conferences as well as plans for updating the safeguarding policy, but much more is needed to ensure that all staff are vigilant to safeguarding concerns.	The Safeguarding Team has not been restructured; it has had additional capacity introduced in the form of additional PAs for the Named Dr, additional nursing posts and a small increase in administrative resource. The additional capacity is in recognition of the consistent growth of internal safeguarding activity and associated requirements e.g. specialist training requirements. To ensure that the Trust is focused on continual development to improve our response to all matters of safeguarding, a robust action plan is in place to address learnings following the two safeguarding reports. Could examples be provided in relation to "much more is needed"

p.24 *5.5.4*	The social work team can provide a range of therapeutic support to families, helping them cope with the challenges of a sick child and also exploring issues that may relate to functional problems or psychological need. However there remains a culture within some of the medical staff in particular that involving social care is a stigma on a family, and they are reluctant or apologist when referring, in a similar manner to referral for psychological assessment. An improved 'script' or training would be helpful for clinicians to help them communicate with families about managing functional illness where there is no physiological reason for a child's symptoms.	Work is in hand to ensure staff understand the value of working with the social care team. All mandatory training programmes are delivered with a focus on multi agency working with level 3 face to face training provided by social workers, nursing and medical experts. The new e-learning programmes, also at level 3, are based entirely on past GOSH cases and learning which demonstrate the value of multi-agency working and the unique contribution that each member of the team plays in delivery of safeguarding. The new safeguarding and perplexing consultation surgery for the wider Trust is being met with encouragement by users, and with the new training programmes will help to further strengthen the understanding and appreciation that the role and contribution social care plays within delivery of a holistic service for all children and young people.
p.24 *5.5.5*	Although there have been improvements, particularly amongst the nursing team, there remains insufficient linkage with local safeguarding / children's service teams and the Named Doctor has a significant challenge in many areas to embed a culture of safeguarding throughout the Trust and particularly in gastroenterology. Compliance with safeguarding training across the Trust also requires improvement – all clinical staff should be trained to level 3 of the intercollegiate guidance. The Named Doctor is steadily building support and gaining confidence and authority within and outside the Trust and should continue to be supported in this role.	The scope of the RCPCH work was not to undertake a Trust-wide assessment of the overarching approaches to safeguarding service delivery (unlike the recent commissioned peer review). The terms of reference instead were to "conduct a follow-up review of the paediatric gastroenterology service at GOSH focusing specifically on what progress has been made against the recommendations from 2015 in terms of …… Safeguarding". The recent external expert peer review report had a whole Trust remit in relation to delivery of recent safeguarding cases and activity; the author noted the following findings below which are at odds with the statements made within the RCPCH report: "The author highlights the very strong commitment to safeguarding children & supporting vulnerable adult carers in the hospital specifically noting that the Hospital from Trust Board to front-line staff & through to the Local Safeguarding Children's Board (LSCB) are on the 'right trajectory for child safeguarding'. Many examples of good to excellent practice are highlighted throughout the report including; Good communications & liaison with external agencies Clinicians identification of the need for a system strategy meeting Adherence to Trust guidelines Examples of good partnership working between the Safeguarding Team & the GOSH Social Workers ……" Then in conclusion "The report following the peer review of recent safeguarding activity at GOSH has identified an organisation with a strong commitment to safeguarding children from Ward to Board with strong links to & with the LSCB, supported by a highly dedicated & motivated Children's Safeguarding Team & Social Work service. Specifically, areas

		of good to excellent practice are noted……..The quarterly reporting to QSAC provides the breadth of information required although research activity is & has not formed part of service delivery in part undoubtedly linked to capacity & priorities. However GOSH is & should be well sited to contribute to the field of perplexing presentations / FII research activity……..” The Trust does not recognise either the sentiments expressed within the RCPCH report of their assessment of whole Trust culture towards safeguarding or their legitimacy in making such linked statements when they were neither asked to or provided with access to all the required intelligence to underpin such an assessment.
p.24 *5.5.5*	Compliance with safeguarding training across the Trust also requires improvement – all clinical staff should be trained to level 3 of the intercollegiate guidance.	The Trust is fully committed to achieving the training requirements outlined within the Intercollegiate Guidance, including that all clinical staff are trained to Level 3. The recent investment in additional safeguarding workforce resources (medical & nursing) underpins the Trust’s commitment to ensuring experts are providing specialist training. The Trust’s approach to delivery of Level 3 training has been completely reviewed with mode and content of delivery reworked. Such that the requirement now is that every clinical staff member has to undertake 2 hours of L3 training every year and within a 3 year cycle at least 2 hours of L3 training must be face:face by an expert. All training materials are based on learning from GOSH specific situations ensuring applicability across all elements of the training.
p.25 *Rec*	Recommendation: Ensure continued support for the safeguarding programme with all clinical staff safeguarding trained to Level 3	This recommendation should relate to gastroenterology clinical staff, rather than all Trust clinical staff, as per the remit of the RCPCH review.
p.25 *5.5.8*	The general paediatricians have worked hard since the 2015 review to identify those children whose diagnosis and treatment may have been inappropriate in order to move them more towards ‘normality’ where possible, reducing interventions and tackling psychosocial issues. They reported that whilst there have bene massive improvements in safety and protecting children from harm there is not yet a transparent escalation process to raise or discuss cases of concern, learn from findings and focus on making the child better. They cited individual cases to the review team about which they had raised concerns without effective resolution or feedback.	All patients where concerns have been expressed have been reviewed and assurance established that they are safe. • All pts with an unconfirmed diagnosis or on restrictive exclusion diet have been audited with all pts being regarded as safe
p.26 *5.6.1*	During 2016 the Medical Director chaired a fortnightly action meeting to address the report’s recommendations but actions appeared to take a long time to be implemented.	Can this point be substantiated
p.26	There were reports that nurses raise issues more readily with doctors and incidents	This is pleasing to hear, but again “reports” sounds like hearsay – this should be

5.6.3	are more formally approached and dealt with in a more open way.	substantiated
p.27 *5.6.5*	<u>IBD service</u> The team is apparently keen to increase its networking with peers in this relatively limited field, and they are planning an open day for DGH paediatricians and the development of shared guidelines with local settings, particularly around diagnosis and management of eosinophilic disease.	The guidelines on eosinophilic disease will be determined through the relevant European Society, not by the GOSH service
p.27 *5.6.9*	The service was proud of the reduction in complaints to zero since January 2017 from 2-3 per month during 2015, which comprised almost half of overall complaints in the Trust.	While gastroenterology received a disproportionate number of complaints in 2015 compared to other GOSH services, this did not amount to almost half of overall complaints in the Trust – it was actually approx. 15%.
p.29 *5.8.2*	Relationships with other specialist providers were mixed; whilst individual consultants worked well with external teams (Luton and Dunstable and UCLH were specifically mentioned) there was continued unease about poor communications from GOSH management and lack of recognition that the 'temporary' redirection of referrals had placed considerable strain on other teams. Seven specialist providers were asked to support GOSH on a short term basis in November 2015 when the service closed to new referrals as investigations were in progress. During 2016 only selective referrals from other specialist centres were accepted. In December 2016 GOSH wrote to all units explaining that their internal investigations were complete and that they were asking the RCPCH to revisit but without providing further information about outcomes or anticipated timescales for completion and resumption of normal services. This resulted in increasing frustration at other units which were facing pressure on waiting lists, frustrated families and additional cost which was not covered by the payable tariff.	It is important to note that the impact on other services, including resource and financial implications, is an issue that needs to be managed by commissioners. The tariff was not coming to GOSH either; the implication here appears to be that GOSH benefitted financially to other centres' detriment.
p.29 *5.8.3*	The review team was told that this whole process had been 'utter chaos' with no details about pathways and protocols, alternative specialist centres being overwhelmed and unable to offer shared care to DGH referrers and the consultants being unable to advise as they were not driving the process.	It is important to note the role of NHS England in overseeing the commissioning of these services, with oversight of referrals
pp.29-30 *5.8.3*	There were concerns about patients who had missed several appointments due to the confusion. Particular concerns were raised about ongoing management of gastro tubes placed by GOSH and unable to be replaced locally should they become dislodged and the review team was unable to secure clarity over how this is managed. However, with the improved governance and administration systems in place there were some signs of improvement in recent months.	This point is not consistent with previous comment on improved administrative and management processes nor the drop off in complaints with respect to these issues. The report is unclear whether this is a historical issue that has now been resolved.
p.30 *5.8.4*	During the course of the review team's visits a joint letter was sent to the London Specialist Commissioner from seven specialist units requesting urgent intervention to rebalance the patient flows and require GOSH accepting more specialist referrals. The	It's not clear what steps GOSH could have taken to plan capacity at other centres; would a recommendation in this area be more appropriately directed at NHS England?

	letter highlighted the implications for patients of the reduced activity at GOSH, which included confusion for families whose referral was rejected, long waiting lists to be seen at other centres and no attempt by GOSH over the 18 months of restrictions to proactively liaise with the specialist centres and plan the capacity required to manage the additional workload. The specialist commissioner had confirmed that he was awaiting confirmation from the MD at GOSH that the service was fit to restore activity.	
p.31 *5.9*	This is an area where there has been limited progress despite the high level of complaints being the main trigger for the 2015 review.	This statement is not substantiated in the report; it is unclear how the review has been able to ascertain the level of engagement of parents and families to be able to present an informed view as it does in this document. It is inaccurate to suggest that there has been limited progress with patient and family involvement since the last review in 2015. PALS Contacts has seen a gradual decrease in the numbers as below: Q4 15 / 16 = 81 Q1 16 / 17 = 97 Q3 16 / 17 = 42 Q4 16 / 17 = 36 Q1 17 / 18 = 29 Reviewing the Annual PALS report 2016/17 identified that overall the themes of: • Poor Communication had seen a decrease in queries • Care advice – there has been a gradual decrease of families approaching PALS needing support. • Failure to re-arrange an appointment has shown an increase in contacts between the years of 2014/15 & 2016/17 of which in 2016/17 43 PALS queries directly related to the Gastro service review The Q1 results for 2017/18 have indicated further reduction in contacts as above & a change for the top 3 themes of Poor communication / Ward environment / Incorrect information in clinic letters. Reviewing formal complaints - the service continues to receive the highest numbers of complaints with a total of 15 complaints received in 2016/17. This relates as 15% of the overall complaint activity in the year which is the same percentage as last year.

		The themes in complaints have changed to previous years and are: • Declined referrals • Differing clinical opinions • Transition of care Following completion of the actions arising from the Gastro service review action plan (circa Autumn 2016) the service has seen the numbers of complaints reduce as follows 2016/17 Q1 = 6 / Q2 = 5 / Q3 = 4 / Q4 = 0
pp.31-31 *5.9.2*	Although there is scope and aspiration amongst some of the clinicians to improve engagement with families several do not see this as a priority and were cautious about the RCPCH team seeking patient input. There was mention of an engagement event some years previously that had gone badly and alongside previously high levels of complaints this appears to have paralyzed the approach of the consultant team to seeking feedback. Although the Friends and Family test is operating in the Trust the review team was not made aware of any bespoke gastroenterology patient reported outcome (PROM) or experience (PREM) measures collected yet.	The hospital runs Friends & Family questionnaires as required across all in patient, day care & outpatient environments. Each ward and service is provided with a breakdown of their monthly activity including numbers of responses, percentage response rates, percentage of rating scores. All of the qualitative comments are provided back to each ward and department with both positive and areas for improvement comments. All areas have a dedicated 'You said & We did' notice board where the actions and responses to the past month's FFT comments are displayed; this is a key aspect of local teams noting their current feedback and owning actions for improvement and sharing successes through reporting to the Trust's Patient & Family Experience & Engagement Committee (PFEEC) and through that to the Trust Board and Members Council. PFEEC has both Trust Members Councillors & parents on the committee & through these representatives, parents who have experienced / are currently experiencing the Gastro service. The views of Gastro service parents and challenges they have / are facing through the review process has been consistently considered at PFEEC & Members Council. The development of PREMS & PROMS is starting to be progressed in the hospital with focus in cardiac and oncology services. However, a key development is that of a Real Time Patient Experience System (RTPES) specifically to meet the needs of the children and young people, their parents & family members.
p.32 *5.9.4*	Feedback received by the review team (Appendix 6) indicated that many parents were not satisfied with the communication from the Trust following the 2015 report, and complaints continue around the lack of family-focus and integration when organising appointments. Many families still don't know what the situation is for their child. The listening event provided a clear message that although things appear to be improving, more must be done to build confidence amongst the families and listen meaningfully to, and act upon their concerns and suggestions.	It is important to recognise that some families whose medication had been appropriately decreased as a result of the review, objected to the decrease in medical intervention and expressed their discontent.

p.32 *5.9.5*	Across the wider Trust the level of engagement of parents and families was reported to vary between teams. There is surprisingly no hospital –wide approach to specifically involving children and young people in their care and service planning and these schemes and tools seem to be developed within individual departments. The 'Patient Knows Best' scheme (see 5.6.6) helping individual IBD patients manage their condition was a good model and its principles could be extended to other divisions	It is not correct to say there is no hospital-wide approach to involving children and young people. The hospital continues to actively develop the Young People's Forum (YPF) with increasing membership and reported activities. The YPF are one of the key vehicles for engagement with representative young people who are currently or have very recently been a patient at GOSH, including gastroenterology patients. The YPF are active in development of the Electronic Patient Record (EPR) work, hospital redevelopment programme, the hospital's new strategy, QI projects such as Transition, catering, food and menu choices, research and actively engaged to respond to national NHS England reviews such as the current review of Critical Care and Specialised Surgery. As the recognised Trust-wide forum for the voice of young people within the hospital, increasingly individual services are engaging with the YPF for a broad view of their development work. In addition there will also always be local service specific young people's engagement groups and the hospital will always support and encourage both approaches.
p.32 *5.9.7*	Responses are summarised in appendix 6 and should be taken on board in a 'you said-we did' format along with the open event conclusions as a start to a formal programme of engagement and involvement.	As above, a programme of engagement is already in place so taking the steps outlined in 5.9.7 will represent a "continuation" rather than the "start" of such a programme.
p.33 *Rec*	Recommendation – Design a formal programme of engagement with all patients/parents/carers including seeking feedback and providing a report on what has changed as a result of comments/ complaints Recommendation - Consider developing leaflets and web guides for patients and parents to support and improve their experience of using the service.	These recommendations are in line with work already underway, and also planned as part of the RTPES project. 'You Said & We Did' displays are present in all areas and services, and not only do these display updates from Friends & Family Tests but also from complaints and PALS, with reports through to the Trust Board and Members Council so to ensure spread and transparency.
p.33 *5.10.4*	Historically here may have been a tendency for difficult or complex patients to be referred to GOSH when a local DGH was capable of managing the case but relationships with the family had broken down. The restrictions on referrals since 2015 closed this route and the 'local' paediatrician remains involved and responsible with a view to repatriation as soon as the child's condition permits care to be managed locally. This will improve school attendance, social relationships and a sense of normality and all guidelines and protocols should be based upon this principle, with commissioner support.	Can this point be clarified? We are not clear on what is being outlined here.
p.34 *5.10.6*	Transition arrangements are patchy with each service managing its own patients to linked consultants in other specialist centres or the adolescent's DGH. There is a good	The hospital is in year 2 of a three-year improvement project focused on reviewing and ensuring age appropriate transition is available, accessible and established

	relationship with University College London Hospitals (UCLH) for IBD patients but the links for PN are less assured, and the transition arrangements appeared to lack flexibility, being based on the medical relationships rather than patient choice. The motility service is relatively new so some patients are only just approaching transition and it was not clear what plans are in place. UCLH will not take new patients under 18 years and GOSH policy is to transition at 16 so this needs to be addressed.	across all clinical services that meet all national and international standards. In addition, the hospital has negotiated a bespoke CQUIN also for a three-year period to further impact on this workstream and Transition is a quality priority in the Quality Account 2017/18 again. The reference to GOSH transitioning all young people at age 16 is inaccurate; the age of transition will be specific to the young person's needs and appropriateness of course seeking to ensure that transition has concluded before the age of 18.
p.34 *5.10.7*	There is a webpage outlining the transition process with a downloadable leaflet (dated 2011) but this was aimed at parents and there was no online information for young people. The easy-read version states transition at 18-19 years old and is not aimed at adolescents.	The hospitals web site is under a full review and all of the information on the Transition web pages is scheduled for removal and replacement with current plans, up-to date information and documents.
p.34 *5.10.7*	The appointment of a Clinical Nurse Specialist for adolescent patients was proposed who could see young people by themselves and explore issues around transition and any psychosocial concerns, as well as practical discussion about sexual health and pregnancy which does not currently take place.	The Trust has had a dedicated expert CNS for Adolescent patients for a number of years, covering such areas
p.35 *5.10.8*	The NICE guidance and quality standard published in January 2017 (NG43/QS140) is clear about the minimum requirements for transition and compliance this should be prioritised. Many DGHs and specialist units in the UK have comprehensive arrangements and communication materials for transition such as the Southampton 'Ready Steady Go' scheme and would probably be willing to help GOSH with developing this aspect of its service.	There is active engagement with young people and the Trust's Young People's Forum to support the QI project; the NICE guidance and quality standard is part of the driving force for improvement work. There has been engagement and networking across the country and GOSH will be taking the principles of best practice to design documentation – recognising the move to the EPR by 2019 with a patient portal – that is relevant and owned by the young person.
p.35 *Rec*	Recommendation- Develop a comprehensive and flexible patient centred transition programme - linked with adult services in London closer to home. Pathways should be patient based rather than be clinician's choice and require better networking. The design of such a programme should involve young people and include a suite of communications materials suitable for patients, parents and families.	There are significant numbers of young people with a number of complex health care needs that require transition and very few situations where adult specialist services are co-located within the same organisation. Developing a complex patient transition pathway is part of the Quality Improvement project, however, the complexities will in some cases mean multiple transition pathways across different adult services. As the patient population for GOSH is nationwide it must be acknowledged some young people will be accessing adult services in parts of the country beyond London
pp.35-36 *5.11*	Are there any areas of notable practice or achievement?	Additional point to add: A comprehensive set of guidelines agreed and monitored
p.50 *survey feedback*	[redacted] was very keen for my help and input when it suited but we've been left high and dry with absolutely no tertiary, secondary or primary care now.	Clinician named in survey feedback – should be anonymised.

From: [redacted]
Sent: 01 November 2017 14:53
To: David Hicks
Subject: Feedback to RCPCH - factual accuracy
Attachments: GOSH Factual Accuracy - RCPCH Review 01112017.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Dear David

Further to our meeting earlier, please see attached the latest iteration of GOSH feedback to the RCPCH review. Are you able to take forward with the RCPCH once you have heard from [redacted]?

Two points requiring further input are highlighted in the attached:

- 5.3.6 - regarding Parenteral Nutrition (PN) – [redacted] to advise
- 5.5.8 – regarding patients where concerns raised – you to select preferred wording of feedback

I hope that's all clear and makes sense, please let me know if you need anything additional from me.

Best wishes
[redacted]

[redacted] **Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health**

[redacted]

RCPCH Invited Reviews Programme

Follow-Up Review

Great Ormond Street Hospital NHS Foundation Trust
Gastroenterology Service

August 2017

RCPCH
Royal College of
Paediatrics and Child Health

RCPCH Invited Reviews Programme
August 2017

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The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales(1057744) and in Scotland (SC038299)

Contents

Executive Summary

This review report examines progress against the recommendations of the RCPCH Invited Review of gastroenterology service at Great Ormond Street Hospital in 2015. It provides a fresh view of the current service with recommendations that encourage sustainable, achievable and integrated service provision for children and young people with gastroenterological conditions

The review team recognises that the gastroenterology service had faced a difficult period following the 2015 review. The service had significantly reduced activity whilst investigations were carried out including a detailed programme of case review and a thorough overhaul of administration and governance systems.

By the end of 2016 the service was considered by the Trust to be in a positive position and the RCPCH was approached in spring 2017 to carry out a follow up review. The review team comprised two experienced paediatricians and a lay reviewer supported by an RCPCH manager. Terms of reference were agreed and the team interviewed almost 100 people and examined a similar number of documents to the 2015 review

The review team found very good senior clinical and operational leadership which needs to be sustained and embedded. There have been significant improvements in administration of patient communications and clinic organisation and a suite of new governance meetings and reporting pathways which ensure that any new referrals are appropriately investigated and diagnosed in conjunction with their local referring paediatrician. The consultants were working better as a team and engaging more with multidisciplinary colleagues, particularly the more recently appointed and locum consultants.

Many of the consultants and other staff were embracing the new ways of working. There had been significant investment in nursing, and improved involvement of multidisciplinary colleagues including psychology and dietetics. Strong nursing leadership on the wards and investigations units was embedding the governance and quality programme with improved morale and a clear career structure for staff.

However the new approach has not been universally accepted by all consultants and some remained sceptical about the need for change. Many staff expressed continuing concern that the Trust and team had not fully learned from the consequences of the 2015 review and further detailed case review work was required urgently to ensure all children were on appropriate care plans. The report had not been shared and some staff still did not feel confident that their concerns could be raised and responded to in a climate of openness.

Further encouragement is needed for the gastroenterologists to fully embrace external peer review. Some consultants see their service as only ‘quaternary’ or highly

specialised and are selective about accepting their fair share of specialist ('tertiary') referrals in the London catchment. This is causing friction with other providers and it is important that specialist services work more closely together with clarity about expertise and referral pathways across London and the South East.

The service is currently working at around half of its previous activity and needs to step back up to manage a similar workload to peer units. This may require some investment in staffing and robust job planning to ensure that the gains made in governance and safety are embedded and continue with the changeover of the Medical Director. We would recommend involvement in a networked Quality Improvement programme and/or appointment of an externally-facing senior clinical leader – equivalent to a Chair or professorship appointed by the NHS with an interest in translational research-- to support the development of a strong gastroenterology network in London.

The full report sets out the findings which are wide ranging but reflect the impact of the 2015 report and the extent of turnaround that has been achieved. There has been good progress in dealing with the immediate issues of concern and implementing practical systems but the next stage is ensuring there is an embedded culture that focusses specifically on the best interests of the child.

Although the safeguarding systems have improved with the recent appointment of the Named Doctor, there remains more to do around process and attitudes, strengthening links with the referring communities and ensuring candour and openness when staff raise concerns. The Trust is now aware of these issues and steady progress is being made which must continue to be prioritised.

Involvement of families and management of transition are areas which still require considerable improvement but again the Trust is aware of this and striving to bring the gastroenterology service to the standards of other teams in the Trust and other gastroenterology centres. There is a wide selection of material and support readily available for these schemes and no reason not to move forward more swiftly with this to build healthy trusting relationships with families and other units.

In summary the Trust is making good progress on the significant transformation identified as necessary in the 2015 report but now needs to broaden its activity to play a full part in the regional network. There are some areas of very good practice, but there is still more to do to complete the assurance process, embed the change of culture and restore the confidence of peers and families that the service has truly turned around.

Note: Our review has not looked specifically at clinical outcomes or individual case management. Our recommendations and the plans for network and governance development should facilitate systemic improvements in these areas.

1 Introduction

1.1 Since the RCPCH's review of GOSH Gastroenterology services in summer 2015 the review team maintained contact with the Medical Director at the Trust, as the detailed recommendations from the review were implemented. The actions taken by the Trust as a result of the review involved significant change to internal team function and staff roles as well as investment in new governance systems and restrictions on referrals until the concerns raised by the review had been dealt with.

1.2 Two years on the Trust formally invited the RCPCH to return and review progress against the recommendations, and provide a fresh steer as to what was needed to embed sustainable change and build a service that was confident and respected as part of a wider gastroenterology network. GOSH has an extremely strong reputation for managing the most complex paediatric conditions and there was ambition that the gastroenterology service could be safely restored to fulfil its role as a specialist level provider with world-class expertise in some aspects of its care.

2 Terms of reference

The terms of reference for the review were agreed by the leadership team at the Trust and the gastroenterology team as follows:

"The RCPCH will conduct a follow up review of the paediatric gastroenterology service at GOSH focusing specifically on:

a) What progress has been made against the recommendations from 2015 in terms of
- Leadership and management
- Concerns arising from MDT work
- Strategic positioning and external referral pathways
- Safeguarding
- Communications and administrative support
- Clinical activity and job planning
- Governance, guidelines and audit
- Training and supervision
- Patient and family Involvement?

b) Are the current protocols, pathways and guidelines fit for purpose and working effectively?

c) Are there any areas of notable practice or achievement?

d) The priorities and strategy for development of the service."

3 Background and Context

The current service

3.1 The gastroenterology service at GOSH is managed as three divisions, each hosting one NHS England Highly Specialised Service as well as managing specialist referrals from other centres and limited referrals from other departments within GOSH. The conditions managed by each unit are

- Neuro-Gastroenterology and Motility Unit ([redacted])

Chronic Intestinal Pseudo-obstruction (CIPO NHS England HSS); Refractory / intractable Constipation; Cyclic Vomiting Syndrome (CVS); Gastro-oesophageal reflux disease, Oesophageal Motility Disorders (Achalasia, Oesophageal atresia etc.); Gastric motility disorders (gastroparesis); Feeding and eating disorders (working closely with feeding team and Mildred Creak Unit and Functional Gastrointestinal Disorders

- GI Mucosal Immunology ([redacted])

Irritable Bowel Disease (IBD) early and late onset, (Crohn's Disease, Ulcerative Colitis, unclassified), Coeliac disease, Eosinophilic Oesophagitis, Immunodeficiency, Autoimmune GI diseases, Epidermolysis Bullosa

- Nutrition and Intestinal Rehabilitation ([redacted])

Congenital Diarrhoea (Tufting Enteropathy, Micro-villous atrophy, etc.), Short gut with intestinal failure, Faltering growth, Intestinal failure assessment, Shwachman-Diamond Syndrome, Acute and chronic pancreatitis

3.2 There are seven permanent consultants, and three locum appointments pending a decision on the future configuration of the service. There are ten 'middle grade' doctors working as clinical fellows or registrars. Two matrons, eleven clinical nurse specialists (an increase since 2015) and two ward sisters complete the senior clinical team.

3.3 Day case attendees and elective/non-elective admissions for less than 5 days are admitted to Kingfisher ward which has 10 inpatient beds (3 assigned to gastroenterology patients) and 6 day case beds and closes at weekends. Inpatients staying for longer are accommodated in the 8-bedded Rainforest ward which is not fit for purpose although there remains no firm plan for its relocation.

Actions since the previous review – see Appendix 7

3.4 Completion of the RCPCH's review in July 2015 coincided with the appointment of a new medical director at the Trust. On 20th July the RCPCH raised immediate concerns about, some aspects of the service which were followed up in a letter dated 22nd July. These concerns related to allegations of

- Over investigation of some children
- Over diagnosis of certain conditions without consistent criteria or thresholds

- Poor flow of safeguarding and contextual information from local clinicians and children's services
- A concern about how patients are selected for research projects.

3.5 The letter recommended that "*a swift but thorough review is undertaken of the diagnosis and management of 40 of the children currently being treated for eosinophilic colitis to determine whether the overall best interests of the child are being met, and if not devise a strategy for resolution. This review should be completed within three to six months and depending upon the findings of the first 40, more cases may need to be examined*". The suggestion of 40 cases was based on information received by the review team that there were around 400 children in this cohort (subsequently revised to 463), so a 10% sample was feasible.

3.6 The Medical Director responded swiftly to this notification and advised the RCPCH on 24th July that from Monday 27th July all new referrals to the service were to be reviewed by an intake multidisciplinary team (MDT), all procedures were to be agreed in advance against written justification, the cohort of 40 cases for review was being established and consensus –based diagnostic criteria and guidelines for investigation and treatment were to be developed.

3.7 The full review report was sent to the Trust in draft on 7th August and. following receipt of factual accuracy comments, in its final form on 4th September 2015. It defined the external review caseload to "*children without IBD on immune-modulation; enteral feeds and elemental diets*" and made 24 further recommendations which are included in Appendix 6.

3.8 During autumn 2015 the Medical Director established the expert panel to conduct the external casenote review, comprising four consultant paediatric gastroenterologists and a consultant immunologist. Initial attempts to convene international experts delayed establishment of the panel and the original suggestion of an independent lay chair was not implemented. A list of 42 cases was drawn up for review selected from those diagnosed with Eosinophilic Gastrointestinal Disease (EGID) or suspected or diagnosed food allergy over the last 3 years with coded diagnosis meeting the criteria above. Once established with terms of reference in November 2015 the panel carried out a rapid casenote review and agreed that fourteen of the first 18 cases gave the panel significant cause for concern over the diagnosis and treatment regime. This was formally reported to the Medical Director in December 2015, recommending a more detailed expert review of these same cases including histology, plus a wider clinical review of patients across the service. The panel's report and recommendations were presented in January 2016.

3.9 From January 2016 major restrictions were put on referrals into the service, including significant reduction in endoscopy work, and other specialist centres were

asked to increase their activity 'on a temporary basis' to accommodate these referrals and also conduct follow up reviews of some of the existing GOSH patients. [redacted] There were changes to the management team and a major overhaul of governance, procedures, administration and safeguarding arrangements in line with the recommendations of the RCPCH report, with fortnightly meetings of a task and finish group chaired by the Medical Director.

3.10 The review team was told that the GOSH Trust board was kept fully appraised of the findings and recommendations of the review and the progress being made to address them.

3.11 In parallel with these changes, the panel's cases were re-examined by national and international experts and the remaining 24 cases in the initial sample were reviewed and where appropriate the patient was seen and changes to treatment regime discussed. In line with the panel's recommendations, independent assessment of treatment plans in clinic were undertaken for a sample 20% of gastroenterology patients and two consultant gastroenterologists were seconded into the Trust for three days a week during 2016 to assist with assessing these patients in clinic. Their care was discussed with the GOSH gastroenterologist and where appropriate their treatment regime was amended and and/or they were discharged them to the care of their local service. This was completed by June 2016. For each patient a summary was completed detailing two questions using the NPSA harm definition and the Trust Risk Matrix: "Has harm been done?" and "What is the risk of harm?"

3.12 The Care Quality Commission (CQC) was involved at an early stage and supported the sampling review of 20% of all gastroenterology patients. In total the Trust estimated that care and treatment of around 300 patients was reviewed. During 2016 the CQC held fortnightly meetings with the Trust but these reduced as the Trust demonstrated more secure governance systems. There was joint oversight with NHS England and NHS Improvement but this moved to operational oversight by the end of 2016. A closeout report for the completion of this process was prepared but this has not been shared with the review team.

3.13 The Specialist commissioning team at NHS London was made aware of the review and agreed to the changes in referrals and other steps being taken by the Trust to address the concerns raised by the RCPCH. NHS Improvement was also updated.

3.14 By December 2016 the Trust considered it had made significant progress in addressing the clinical concerns raised by the RCPCH and wrote to a number of stakeholders, including specialist centres who had taken its referrals, commissioners, RCPCH and the CQC summarising the concerns and action taken. A summary

[1] [redacted]

statement was posted on the Trust website which set out the steps that had been taken, and included the commitment to invite the RCPCH to conduct a follow up review.

3.15 Both the detailed and the summary statements from the Trust contained the phrase : “the review did not find evidence of long term consequences of over investigation or overtreatment”. This, the review team were told, was justified by the Trust from consideration of the cases examined in detail and review of the statements made by the visiting consultants in response to the two questions set out in 3.11, There was recognition that moderate harm had occurred for some; lost school days, side effects and disruption, but no serious significant harm.

3.16 Some staff in the Trust, and some clinicians in other specialist centres who had not been fully apprised about the process, inferred that this statement had arisen from the RCPCH review, since most staff had not seen the 2015 report. It may not have taken into account other patients still undergoing similar treatment for many years whose care had not been reviewed, nor the psychosocial impact on patients who had been on treatments for many years.

3.17 Formal communication with the families whose children’s care was being reviewed by the team at GOSH was carefully planned. Following the initial casenote review, families were told the conclusions drawn about their child’s care. The letters explained that the child’s care was being reviewed as part of ongoing quality approach and that as a result in some cases changes needed to be made to the treatment regime. The wording used aligned with that on the Trust website and was sent to stakeholders and referring units. In December 2016 the Divisional Director wrote to all children and young people whose care had been reviewed and their parent/carer explaining that the review was complete and that further actions were being addressed including the request for external review.

3.18 The Medical Director left the Trust in December 2016 and Dr David Hicks, a respected former medical director who had been appointed earlier in 2016 to assist with the service overhaul, took over in an interim role and formalised the arrangements for the RCPCH to revisit the service.

4 The Review Process

4.1. The review team comprised three of the four members who conducted the previous review and details are included in Appendix 1. The team's gastroenterology expert had retired so was replaced by a BSPGHAN Council member who had contributed to the development of the recent 2017 joint standards.

4.2 Members of the review team attended a helpful pre-visit meeting with Dr David Hicks, Interim Medical Director, Nicola Grinstead, Deputy Chief Executive and other colleagues in May 2017. There was agreement that this review should be as open as possible and involve all those who contributed previously (if still in post) as well as others who are new to working with the service. A range of documentation was provided to the team before and during the review period and information requested was provided, where available, swiftly and without hesitation.

4.3. The review was conducted over five individual days to maximise the availability of the review team. The visit programme was put together by the Trust and alongside this the RCPCH made contact with other stakeholders and arranged for written submissions or telephone or face-to-face interviews with one or more members of the team. In all 94 individuals contributed to the review.

4.4 A survey seeking the views of patients and families was made available through the Trust and relevant social media and a member of the review team attended an engagement morning for patients and families on 15th July 2017. The survey generated just 18 responses which was surprisingly low. The RCPCH uses surveys on its reviews to provide an opportunity for patients and families to contribute their views. However it is more important to assess how a service is itself gathering and acting upon the views of patients and families and this is considered in section 5.9.

4.5 Throughout the review the Interim Medical Director and staff across the service have been helpful, open and accommodating and the review team did not feel there was any restriction on access to information. Those contributing from outside the Trust have been open and honest in their opinions and almost all those who participated had noticed an improvement in the service and were keen to continue to work with the Trust to embed the changes.

5 Findings

The findings from the review have been grouped under the headings of the terms of reference.

5.1 Leadership and management

5.1.1 Most of those interviewed recognised that it had been a very difficult two years for the gastroenterology service; [redacted] but also for nursing and other staff who recognised that treatments they had been administering may have been inappropriate. The impact of the changes to the service had been far-reaching in some teams whilst others had seen little change beyond temporary disruption. Some of the external experts who agreed to support the Trust through casenote reviews and taking referrals had found the team unwelcoming and the process and communications unsatisfactory.

5.1.2 At Trust Board level the arrival of the new Medical Director in July 2015, alongside a new Chief Nurse catalysed the change, enabling the Trust to start to tackle longstanding concerns raised by the RCPCH and others about the service. An interim general manager was appointed for a year in February 2016 who gained respect and ensured the casenote review work was delivered and documented systematically. Actions were completed and clear policies began development. A new Divisional Director and replacement General Manager alongside the appointment of a new clinical lead from within the team has enabled swift and positive change in the governance systems, referral pathways, administration of clinics and communication with patients and families.

5.1.3 Although improved processes and systems are now in place there were still some concerns expressed that more work is needed to tackle deep-seated cultural attitudes amongst some of the consultants. Corporately some staff are not yet convinced that there is a truly open reporting culture and others remain concerned about a perceived failure to extrapolate the findings from the case reviews across the whole cohort of current patients. See 5.2.2.

5.1.4 A consistent theme amongst almost all staff interviewed, was frustration at the absence of clear communication from senior management about the 2015 RCPCH review report and how and why the changes during 2016 were implemented. Whilst the Board, CQC, commissioners and external reviewers had seen the report it was not shared with the consultants, even in summary form and there was much unhelpful speculation and at times misplaced anger at the report's content and the reason for the imposition of changes. Staff received a brief announcement just before Christmas 2015 explaining that as a consequence of the RCPCH report, activity would be significantly restricted [redacted], but there was too little information for them to understand and plan for the consequences or advise families what was

happening. Staff had inferred a lack of trust and a sense of isolation from the Board and senior management, which could have been mitigated through greater visibility, briefings and a programme of organisational development to build and retain trust and recognise the efforts of those working with and within the service.

5.1.5 Most interviewees did recognise, with hindsight, that the events of 2016 had been necessary and helpful in the longer term. They appeared to understand that given there were personnel issues to deal with, it had been important to be careful with information, sure-footed in managing potential trigger points, particularly around media interest, and to maintain control to make the service safe as swiftly as possible. They recognised the positive medical and operational leadership of the Trust, division and service and were hopeful that the 2017 RCPCH review would trigger sustainable restoration of an open, fully functioning service. The General Manager is well respected but is in an interim post and has been the fifth in the role in two years. The Interim Medical Director is also expected to leave in October which introduces a potential risk to the continued improvement in the service as relationships will need to be rebuilt and trust engendered. However, the Divisional Director is highly respected and has a clear vision of how to manage the consultant team and encourage the best from the service and important that the new Medical Director engages swiftly to maintain the confidence of the team and its stakeholders.

5.1.6 Amongst the consultants there is a more positive approach to service delivery and governance systems. [redacted] This has had some impact although more than one of the consultants apparently considered the review had been 'a waste of time'. Many interviewees were concerned that the changes made around multidisciplinary working, consistent protocols and peer review may not be sustained once the service gets busier or 'the spotlight is off'.

5.1.7 Whilst the clinical lead has worked hard to bring the team together, support the governance changes and develop, with colleagues, a shared vision for the service, there is an opportunity to establish the service more formally as a centre of excellence, building momentum and respect externally amongst specialist and research colleagues. By creating an NHS based senior clinical leadership post in gastroenterology, high calibre applicants would be attracted to the opportunity to develop and influence the clinical service. This was a recommendation in the 2015 review. The right appointee would bring gravitas, credentials, excellent networking capability and constructive challenge to lead and develop the GOSH team further in regional, national and international circles. Strategically GOSH being based in London has a responsibility to equitably contribute alongside other paediatric GI units to the care of children in the

[2] Maintaining High Professional Standards – an formal NHS process for managing clinicians about whom concerns have been expressed. More details available from the National Clinical Assessment Service

region. They should encourage greater external collaboration and peer engagement amongst the consultant team to develop and demonstrate excellence alongside providing opportunities for critical challenge and enhanced research capability.

Recommendation – Take steps to ensure there is stability of clinical and operational management to embed the positive developments

Recommendation – Appoint a respected NHS based external clinical leader to the post of senior clinical lead - equivalent to a chair - in gastroenterology to develop the service, working together with other units on London-wide GI network collaboration (see also section 5.8 about networks)

Recommendation - GOSH should become part of this London network to equally contribute to the care of the regional population alongside other GI units. In addition GOSH may wish to also agree on their unique focus and to ensure appropriate communications between GOSH and all hospitals in this network

5.1.8 Other teams in the Trust have risen to the challenge and continued to support families and the gastroenterology team, recognising that they have been undergoing significant difficulties. Surgeons have seen a more systematic approach to pathways but are concerned that the systems may have become 'over bureaucratic' and inefficient, with little cross-department representation at team meetings.

5.1.9 The dietetics team were very enthusiastic about the changes since the 2015 review, with much greater MDT involvement in clinics, development of protocols and pathways and rigorous follow up of children following exclusion diets. However, there is more to do to embed the changes and ensure that children with complex needs receive appropriate observation, management and review.

5.1.10 Nursing leadership within gastroenterology has improved significantly with a new matron and ward sisters/nurse practitioner on the wards and investigations unit. Staff turnover has reduced, morale is good, staff have defined career pathways and speak positively about the service outside the Trust. Stronger links have been forged with mental health staff so ward nurses feel better equipped to manage and support complex families.

5.2 Concerns arising from MDT work

5.2.1 The 2015 RCPCH report recognised the intention of the complex cases MDT to identify and review the care of patients with challenging presentations, where there may be a more functional / psychological / factitious cause to symptoms and treatment may need to be revised. This was chaired by a consultant child psychologist, but the 2015 report commented that it was not being robustly supported to work as swiftly and effectively as it should. Since the review the complex case MDT had increased its activity and attendance, and the review team were told of a database of complex cases

numbering around 180 of which 70% were perplexing presentations. The chair was removed late in 2016 in what some felt to be a very inappropriate manner but the new chair was reported to be well-respected and the meetings are continuing to work effectively with increasing engagement of most of the consultants. The local paediatrician for a child whose case is under review is usually invited to telephone in and provide context to the discussions, and the Named Doctor for safeguarding also attends when her diary permits.

5.2.2 Despite the improvement and changes to functioning of the complex case MDT, there remain concerns amongst some staff that whilst the process continues to improve it is insufficiently effective or thorough at the moment. Very few children are actually discharged home after complex MDT review. Despite the findings of the casenote and physical reviews in 2016, a wholescale review had not taken place of children who had been on long term and/or aggressive interventions, including those on total parenteral nutrition (TPN), without a clear diagnosis. These staff still did not feel confident to raise concerns within the clinical environment and explained that in some areas they still perceived a culture that suppressed challenge from colleagues which made them fearful of speaking out. The published phrase stating "no evidence of long term consequences" was misleading and further exacerbated their concerns. Several indicated that there appeared not to have been any organisational learning or remorse from the situation or focus on actually what happened to those children and families – there were several reports of families being left without any support including from those who responded to the review team's survey.

5.2.3 This needs to be tackled urgently, systematically and transparently by the Trust so that all staff understand the process for raising concerns and feel confident that these will be properly investigated and, most importantly, responded to genuinely and honestly with due care and support for the families involved. The concerns were raised swiftly with the Medical Director by the review team in July and the review team has been advised hat the matter is being addressed.

5.2.4 Under the 2016-7 NHS Contract all Trusts should by 1st October 2016 have appointed a "Freedom to Speak Up Guardian" to support whistleblowing and reporting of concerns. Many Trusts have appointed more than one individual, often including the Medical Director, to this role but GOSH senior management decided instead to appoint a small number of 'Lead Ambassadors' in Autumn 2016. Although these individuals have met a few times the role has not been clear. With the involvement of the national Guardian the Trust is now about to re-advertise for volunteer (non-staff) Guardians to carry out the role.

Recommendation – Clinical management should satisfy the Board that an investigation of historical gastroenterology cases has been completed in full, specifically the care of all children on long term interventions without a clear validated diagnosis.

Recommendation - There should be a demonstrated climate of openness in addressing concerns raised by staff to provide assurance that appropriate action and candour has been exercised. This should include the appointment of and demonstrable support for one or more Freedom to Speak Up Guardians.

Recommendation - There should be a further clinical review of the service and approach to cases 12 months after the lifting of referral restrictions

5.2.4 The review team recognises the challenges faced by clinicians and families in discussing changes of treatment or discharge from the service, particularly when families have become familiar with one consultant and the service at GOSH. The two consultants seconded into the service in 2016, as well as gastroenterologists in other specialist units were expected to skilfully manage an unenviable task in explaining to patients and families why the changes had been made and helping them to adapt to a different care plan.

Recommendation: Ensure the effectiveness of complex cases MDT to encourage the lead clinician to discuss cases in a forum with other GI consultants, general paediatrician[3], safeguarding lead (when appropriate), nursing staff and clinical psychologists. All staff should be empowered to contribute.

5.2.5 Every clinic is now preceded and followed by an MDT which reviews the cases and agrees the clinical management. This shared decision-making improves patient safety, provides a teaching and learning opportunity and reassures patients that there is more than one clinician advising on their care. This assurance and consistency of approach has been welcomed by almost all staff involved. There are some consultants who find it burdensome and others noted the additional clinical and administrative time required for reporting and uploading all discussions to casenotes. The universal MDT approach still needs to be fully embedded but will also need to be risk assessed and streamlined so it is sustainable and remains effective once the service has opened up to a wider range of referrals. As a minimum there must be the consultant on take and the lead consultant for the clinic.

Nuclear Medicine and diagnostics

5.2.6 The 2015 report highlighted poor communications between the gastroenterologists and the diagnostic team, with inadequate information for and about patients, a lack of clarity over the purpose and need for some investigations and concerns that children were being over-investigated. The pre-procedure information about patients available to the diagnostic team was reported to have improved, but the review team was told that sometimes patients are still being referred with insufficient justification or checks, or requests for procedures that are unusual, which generates

[3] Section 5.5 on safeguarding explores the role of the general paediatricians

tension between the teams. Regular meetings between the teams should be facilitated to address these concerns and ensure that all procedures are carefully considered in terms of the best interests of each child with a climate of equality and discussion.

Gastroenterology Investigations Unit (GIU)

5.2.7 Following the review there has been a transformation in the GIU and endoscopy service. Activity had dropped significantly; each referral requires detailed supporting information and is now robustly assessed by an MDT to identify where symptoms may be functional. The GIU suite was relocated to a more spacious area near Kingfisher ward and a bid for replacement of the endoscopy stack was successful with the new equipment coming into use at the time of the visit. This investment in the service has been much welcomed and improved morale in the unit as well as significantly reducing risk; the previous stack was not fully compatible with the trust's information systems. Nurses are receptive to doing more investigations and an in house specialist training course is being established

5.2.8 Children and families are much better prepared for the diagnostic procedures in the GIU than two years ago, when communications and administration was very poor and staff felt unsupported. There is reasonably good information on the Trust website and patient leaflets and a newly appointed staff member will focus on pre-admission arrangements and further improve communication and patient/family experience. The nursing leadership has been strengthened, including the recent appointment of a nurse practitioner which has improved morale and reduced turnover.

5.3 Clinical activity and job planning

5.3.1 Following the restriction on accepting referrals, total activity has dropped significantly (Fig 1) yet the consultant staffing numbers remain unchanged, enabling much more time to be spent on MDTs and governance activity. However even with reduced referrals from July 2015 and further reductions six months later the department only succeeded in meeting the 18 week RTT targets in December 2016. It has since remained compliant.

Activity (Source = Qlikview)	2014/15	2015/16*	2016/17	Commissioned 17/18
Outpatient - New	902	1,237	207	263
Outpatient - Follow-Up	2,395	3,922	2,934	2,646
Total Outpatient	*3,297*	*5,159*	*3,141*	*2,909*
Outpatient (Telephone)	1,762	389	617	594
Day Case	1,319	1,344	881	725
Elective	1,190	961	859	840
Non-Elective	41	50	77	46

Fig 1 Gastroenterology Activity *Whilst additional consultants were seeing extra patients

5.3.2 There is a referral MDT every Monday morning which all consultants are expected to attend. The MDT was reported to work well with good agreement but the

administrative response to some patients whose referral was refused was reported still to be unclear and confusing, without an embedded culture that acknowledges the experience of families struggling for a diagnosis or support.

5.3.3 The criteria for accepting referrals were finalised in May 2017 and include all referrals from other specialist centres, plus selective referrals from secondary care in a district general hospital (DGH), and limited in-Trust referrals. These criteria are too limited; they were imposed in 2015-6 when the service was being reviewed and some staff were not available for a period. Whilst the consultants and other teams appreciate a less demanding workload, now the review is almost over and all are working again it is important that the service 'steps up' to deliver at least as efficiently as peer units contributing effectively to paediatric GI care in the region.

5.3.4 The general manager for gastroenterology has drafted a comprehensive service position statement as a basis for future planning, which included a demand and capacity analysis and assessment of the administrative and clerical workforce restructure. It presumes 5 patients per clinic (1 new, four follow ups) against 6-8 before the review and reflects that the current workload is unsustainable in the long term. This is also the view of the specialist commissioner given the increased pressure on other units which previously referred to GOSH. Of course families who have been waiting a considerable time for their appointment and travelled a long way for it expect plenty of time with the doctor or others at the hospital but this is inefficient use of medical time.

5.3.5 The review team concur that the service should be able to see 6-8 patients per clinic including appropriate MDT review. With nursing backup and efficient administration this should be feasible and is more in line with other specialist services nationally.

Recommendation: Review the acceptance criteria, pre-and post clinic MDT, and job plans carefully to enable greater throughput of patients without compromising governance or increasing risk

Nutrition/intestinal failure

5.3.6 The nutrition service/intestinal failure was reported to be very stretched with two consultants and three nurse specialists with up to 52 inpatients on PN across up to ten wards in the hospital. They struggle to meet the RCPCH/BSPGHAN standards that every child on PN should be seen weekly and have seen reduction in clinical fellow support since 2015, which impinges on the consultant job plans. The issue is on the Risk Register and the team are seeking an additional consultant post to enable cover for leave and sickness. There is only capacity to make 45 tailor-made bags per day and PICU and cardiac ICU are not covered.

5.3.7 It is suggested that a review of patients on PN is conducted to ensure that all are requiring the intervention, and comparison with network and European standards as

conducted in 2015 may again provide useful benchmarks. However the current situation is unsustainable and there is a realistic case for increased senior medical cover.

Recommendation – Increase medical support for the intestinal failure team

5.3.8 Concerns were also raised to the review team from regional centres about the children with complex feeding tubes. A typical cited example is of children with displaced Jejunal tubes, with no clear pathway with regards to point of referral or contact in GOSH to replace these tubes. Presently these referrals may be accepted by either the surgical or gastroenterological teams, partly depending on which unit may have a bed.

Managing patient diets

5.3.9 Given the cohort of families that are referred to the department seeking advice, the oversight and management of exclusion diets needs to be robust. The review team heard reports that children had been kept on strict dietary regimes for over 6 months without review and others had been recommended exclusions even before a first appointment, which may not have been necessary and could have affected self-esteem and quality of life. It was reported to have been in some cases hard to reintroduce foods even following inpatient stays, as compliance at home can be patchy.

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5.3.10 Although there is a fortnightly steering group for allergy, and the dietitians have a higher profile within the MDT, there is no paediatric allergy consultant in the Trust, apart from a joint clinic with an allergy service from Guy's hospital.

5.3.11 Whilst the review team was told there are now better explanations about special diets and improved expectation management, including written diet sheets, just two consultants sign off multiple exclusion diets which can cause delays. Clarity is required about what allergy service should be offered and its governance, and there is scope for the general paediatricians to have greater involvement.

Rotas, ward rounds and team working

5.3.12 There has been considerable progress made in rostering and visibility of the consultants. Job plans have been drafted by the clinical lead and general manager but have not been agreed yet pending the recommendations of this review and any consequent changes to service activity.

5.3.13 Nine of the consultants cover a fortnight on 'take' including availability on-call overnight and at weekends. Although this technically risks breaching the Working Time Regulations[4] in terms of compensatory rest for periods on call in the hospital the workload is not acute or excessive (there is of course no emergency department) and

[4] Statutory requirements adopted in the UK based on the European Working Time Directive limiting the number of hours spent on site at work. https://www.gov.uk/maximum-weekly-working-hours/overview

all consultants are content with the arrangement, in effect working seven weeks a year on-call.

5.3.14 The on-take doctors conduct a ward round at least daily and sometimes twice, and others were reported be more visible on the ward seeing their patients and liaising with the nursing staff on Wednesdays and Fridays. Following the Monday morning referral MDT there is a Grand Round at which each inpatient is presented by their consultant to the consultant on-take for the week. Although there were still reports of the on-take consultant changing the management plan of an inpatient there was a greater tendency to discuss the approach with the child's consultant and the increased profile of the specialist nurses has improved consistency of care and involvement of patients and parents in understanding why changes were being made.

5.3.15 Team working amongst the consultants was reported to have improved and some have risen very well to the challenge of new opportunities since the 2015 review. All have undertaken four team-coaching sessions to assist this, but it remains relatively fragile, and continued vigilance around behaviours and attitudes by the General Manager and Strategy/research lead is likely to be required for some time yet. It was suggested that further teambuilding work would be helpful and as we suggest elsewhere, the appointment of a senior clinical leader to the department could provide that. There is more to do to fully involve other disciplines; although the consultants have begun to engage better with managers, nurses and dieticians through multidisciplinary teams, others such as pharmacists struggle to be heard. (see Section 5.10). The paediatric Gastroenterology team has 3 divisions and it is important for these units to not only communicate and work cohesively together but also to come across as a unified paediatric GI team when working with other specialities and hospitals.

5.3.16 There were still no scheduled weekend ward rounds despite the service accommodating extremely sick children. The consultants were reported to often 'pop in' and see their patients or catch up on paperwork, but the surgeons would not involve them for post-surgery review at a weekend. The review team support the BSPGHAN/ RCPCH standards that specialist advice should be available round-the-clock and children should not be in hospital for any longer than absolutely necessary. Development of an efficient seven-day service, as happens in paediatric services around the country will increase throughput and make best use of limited inpatient beds.

Recommendation – Finalise job plans, including weekend ward presence, appoint to permanent positions and consider additional recruitment to provide cross-cover and manage activity.

Outliers

5.3.17 Whilst most patients are accommodated on Rainforest and Kingfisher wards, the gastroenterology and nutrition team also visits those recovering from surgery or receiving parenteral nutrition but under a different department. There was some

confusion as to which doctors have overall responsibility and the role of the gastroenterology team and general paediatricians which needs to be addressed.

Ward environment

5.3.18 All interviewees agreed that although nursing leadership and culture had improved, the physical environment on Rainforest Ward remains wholly unfit for purpose. There have been numerous reports and business cases highlighting insufficient cubicles, toilets and space resulting in excessive waits for admission, high numbers of complaints, inappropriate outliers and concern about patient safety. This has also been highlighted by the CQC and despite the construction of new ward space elsewhere in the Trust there was still no definitive plan. This is unacceptable.

5.3.19 Relocation has been proposed to Sky ward once the space has been vacated by other specialties which would enable the three locations in which the team works to be closer together, but there are concerns about privacy and dignity for adolescents. Many staff expressed anxiety that the new ward space may need to be shared with metabolic and endocrine teams due to risk of 'patient overflow' and other risks to patients; some expressed concerns that the nursing approach is very different and considerable training and team building would be required in such an arrangement, but the senior nurses did not consider that to be significant or insurmountable.

5.3.20 The plans still offer insufficient beds to manage patients needing stabilisation of long term nutrition needs; they cannot be accommodated on Rainforest, making their care inefficient and potentially delaying discharge. Some patients requiring long term observation or two-week pre-transplant assessment before transferring to King's cannot be accommodated to meet the timescale required for the procedure.

5.3.21 Neither the ward sister nor Matron appeared to have been consulted over the practical requirements of a new ward. Their involvement at an early stage is important when planning use of space and practical operation, alongside the benefits of proximity of the three clinical services (inpatients, day-case and endoscopy).

Recommendation – Prioritise improvement of the ward environment as a matter of urgency and involve ward staff in discussions about relocation

5.3.22 If a move is not approved then the service will need to further restrict those referrals that can be accepted. This is not feasible given the pressure on other services and the continued presence of a full complement of paediatricians so it is essential that a move to an appropriate location is expedited.

Recommendation - Plan realistically to ensure the appropriate number of beds so that children with "perplexing presentations" can be admitted, observed and managed, cohesively with general paediatrics, local paediatric teams and safeguarding where necessary.

Mental health CAMHS and psychological support

5.3.23 There is increased awareness, through the MDT and the clinical lead of the importance of psychological input to the gastroenterology service. In November 2016 a band 8b Clinical Psychologist was appointed on a two year fixed term 0.8 wte contract in order to embed psychology within the gastroenterology service. A clinical fellow from the gastroenterology team has been allocated one session a week to link with the feeding team resulting in swift resolution of queries, and much improved pathways for children moving between the services. There is now a rapid response service for medication review which was reported to have made big changes to children's' quality of life. The clinical fellow and administration team have in recent months built much more effective communication channels with the child's local paediatrician and CAMHS service to smooth referrals between the specialist teams, and discharge to integrated local care.

5.3.24 Whilst there have been significant improvements in the approach to children presenting with complex conditions, including advising parents that a psychologist will be present at the initial MDT, and earlier involvement in review, there remains a culture amongst some of the consultants of conducting medical investigations before considering functional /psychological causes for symptoms. The review team was told of inconsistency and confusion over who is responsible for a child once physical investigations have been completed and no clear diagnosis made. This appeared to be a deep-seated view and requires firm and consistent challenge to recognise 'normality' and a more holistic approach to the child and family. Other clinical specialties at GOSH have moved much further forward with this approach for which psychology is well embedded, delivering improved health outcomes. A psychologist should attend every gastroenterology referral assessment meeting and psychosocial assessment should be completed for every patient for whom surgery is proposed.

5.3.25 A business case has been drafted for provision of universal mental health screening as a CQuIN[5] for all children and young people with long term conditions at their first appointment in four specialties, including gastroenterology. However there remains insufficient capacity in the CAMHS team (0.8WTE, 8b Clinical Psychologist fixed term to November 2018) to support the gastroenterology team properly. A business case for two additional Band 7 roles and permanency for the psychologist is awaiting approval.

Recommendation: Invest in building sufficient clinical psychology input to meet identified demand and increase mental health screening /support

[5] Commissioning for Quality and Innovation – Indicators which enables release of funding.

5.4 Communications and administrative support

5.4.1 Since the 2015 review there has been improved leadership and investment in administration systems and personnel, which has reduced turnover and improved morale. A skill-mix review resulted in some posts being regraded to provide a clearer career progression, and each department having a similar administrative support structure. The medical secretaries have clear processes for managing and responding to contacts from families, arranging call-back on telephone calls and monitoring letter turnaround times. Appointment letters were increasingly being sent on time with better templates for patient letters, discharge notes and other notifications. There is a single departmental number for queries, with a rota for taking enquiries enabling the others to concentrate on other duties.

5.4.2 However the transformation is not complete, as there continue to be complaints about letters, delays and cancellation of appointments so more work is needed to achieve excellence in patient and family communications. The review team heard reports that discharge summaries were until recently sometimes sent out with incomplete or incoherent information, without detail of follow up plans with the CNS, or they were not sent to the local paediatrician or GP. The GI team could benefit by effective use of direct electronic communication between GOSH specialists and paediatricians in other hospitals to help bypass some of the problems with inadequate admin staff.

5.4.3 This has been recognised by the operational management and a monthly performance dashboard prepared by the clinical service lead and general manager ensures these areas remain a priority for support. In May the gastroenterology RAG meeting noted a plan to address the issues around discharge summaries, but there remained reports that poor patient/family information is resulting in dietitians and others being contacted about general issues.

5.4.4 Communication within the gastroenterology team was reported to be better – there is less changing of patient regimes when on take and grand round care plans seem to last the week more frequently.

5.5 Safeguarding

5.5.1 The 2015 review report expressed serious concerns about the isolation of the safeguarding (social work) team from the problems in gastroenterology, and the frequent absence on admission of any local data on the child and family in terms of safeguarding or fabricated or induced illness (FII) issues. Concerns raised by referring clinicians were being overruled and there was no documented or written evidence seen of learning from the 2013 FII criminal case from Croydon.

5.5.2 The review team was told of patients requiring extensive therapy on Mildred Creak (CAMHS) ward who were physically well following many years of invasive treatment thought to have been based on functional or fabricated symptoms. There was no evidence of sustained organisational learning from these cases or proactive case review for others in similar situations. On raising this issue the review team was advised that work to identify such patients is in hand but this must be monitored in a fair manner, perhaps by external regulators, to ensure that it is thorough and complete.

5.5.3 The appointment of an experienced Named Doctor for child protection to the General Paediatric team has been widely welcomed as a positive step to resolving the concerns raised in the 2015 report. Following an internal report prepared by the interim named doctor in 2015-6 (which has not been circulated) a more comprehensive external report was commissioned at the end of 2016 coinciding with the arrival of the new Named Doctor. The safeguarding annual report 2016-7 highlights the restructuring of the safeguarding team, development of social work function and increased involvement of staff in child protection conferences as well as plans for updating the safeguarding policy, but much more is needed to ensure that all staff are vigilant to safeguarding concerns.

Social work team

5.5.4 As a result of the previous reviews the social work team has been strengthened and started to link more closely with local units. The social work team can provide a range of therapeutic support to families, helping them cope with the challenges of a sick child and also exploring issues that may relate to functional problems or psychological need. However there remains a culture within some of the medical staff in particular that involving social care is a stigma on a family, and they are reluctant or apologist when referring, in a similar manner to referral for psychological assessment. An improved 'script' or training would be helpful for clinicians to help them communicate with families about managing functional illness where there is no physiological reason for a child's symptoms.

Recommendation: Improve liaison and understanding between the gastroenterology consultants and the social care team.

5.5.5 Although there have been improvements, particularly amongst the nursing team, there remains insufficient linkage with local safeguarding / children's service teams and the Named Doctor has a significant challenge in many areas to embed a culture of safeguarding throughout the Trust and particularly in gastroenterology. Compliance with safeguarding training across the Trust also requires improvement – all clinical staff should be trained to level 3 of the intercollegiate guidance[6]. The Named Doctor is steadily building support and gaining confidence and authority within and outside the Trust and should continue to be supported in this role.

[6] Safeguarding Children and young people – roles and responsibilities for healthcare staff RCPCH 2015.

Recommendation: Ensure continued support for the safeguarding programme with all clinical staff safeguarding trained to Level 3

General paediatrics

5.5.6 The role of the general paediatricians in supporting the gastroenterology service is undervalued and should have a higher profile. General paediatricians can bring objectivity to complex and perplexing cases, particularly motility patients awaiting surgery where it is important that all possible child protection issues or alternate treatments are considered carefully. They should be fully integrated within the department to advise on 'normality' of cases, liaise effectively with local referring clinicians and provide an experienced opinion around safeguarding concerns.

5.5.7 Currently the general paediatricians cover many specialties, offering continuity of advice and support for families navigating several teams within GOSH including surgery, TPN and gastroenterology. They also have an important role in the international and private patients division, ensuring that the principles of the Trust are upheld for these families and the restrictions on accepted referrals and approaches to treatment are consistent with the NHS work carried out in the Trust. They do not of course have oversight of the approach to patients and families who choose private investigations, diagnosis and treatment in other centres but these services are registered with the CQC.

5.5.8 The general paediatricians have worked hard since the 2015 review to identify those children whose diagnosis and treatment may have been inappropriate in order to move them more towards 'normality' where possible, reducing interventions and tackling psychosocial issues. They reported that whilst there have bene massive improvements in safety and protecting children from harm there is not yet a transparent escalation process to raise or discuss cases of concern, learn from findings and focus on making the child better. They cited individual cases to the review team about which they had raised concerns without effective resolution or feedback.

5.5.9 It is essential that a general paediatrician provides regular input to the referrals meeting and complex MDT, that they take lead responsibility for patients as part of the MDT and that they have access to observation and rehabilitation beds. These could be used for children recovering from major surgery, requiring observation before diagnosis or those with a residual disability.

Recommendation – Involve a named general paediatrician in the referrals meeting and any gastroenterology subspecialty case with a perplexing presentation, including current cases where a child has a significant disability after receiving treatment or investigations, without a proven cause.

5.6 Governance, guidelines and audit

5.6.1 The improvements to governance and administrative processes since the 2015 review have been positive and were remarked upon by several interviewees. During 2016 the Medical Director chaired a fortnightly action meeting to address the report's recommendations but actions appeared to take a long time to be implemented.

5.6.2 Since November 2016, with a new general manager and completion of the MHPS process, these meetings have migrated to a more sustainable structure and the following have been introduced

- Monthly Report showing activity, incidents, risks, feedback, finance, various KPIs
- Monthly Risk Action Group with multi-disciplinary representation
- Fortnightly Quality Improvement Group that include the following work-streams
  - Improving Outpatient Clinics
  - Improving Communications
  - Improving Pathways for procedures in the GIU
- Weekly Consultants Meeting
- Monthly Administration & Clerical Team Meeting
- Weekly PTL and planning meeting to assess capacity for GIU admissions
- Quarterly Guidelines and Protocols Review Meeting (from July 2017)

5.6.3 This is a strong system, with good feedback about how the Risk Action Group, chaired by the Clinical Lead supported by the Divisional Director and General Manager with cross-service medical and nursing attendance is driving improvements such as the GIU Stack replacement. Some concerns were raised that a spike in medication errors was not on the Risk register but the systems have been refined with routine double-checking. There were reports that nurses raise issues more readily with doctors and incidents are more formally approached and dealt with in a more open way.

5.6.4 Some of these new work streams are in their early stages, driven by the general manager and will need continued support, encouragement and review to maintain commitment and demonstrate sustainable impact amongst the consultant team. This is particularly important should there be any changes to the management team, and/or if the activity increases in line with the recommendations of this report.

<u>IBD service</u>

5.6.5 This service operates under an international benchmarking collaborative 'Improve Care Now' or ICN which has had pre and post clinic peer review and outcome measures for many years. The department has continued to accept all new referrals aged under 6 years from specialist centres, although referrals for older children have been restricted since late 2015 and are sent elsewhere. The team was reported to have made good progress with the MDT, virtual IBD clinics, regular ward rounds and improved governance with plans for an improved patient database for specialist clinics and a swifter pathway enabling more patients to be seen. The team is apparently keen to increase its networking with peers in this relatively limited field, and they are planning

an open day for DGH paediatricians and the development of shared guidelines with local settings, particularly around diagnosis and management of eosinophilic disease. The IBD team are also working with colleagues through BSPGHAN and taking into account international perspectives.

5.6.6 The IBD unit also subscribes to Patient Knows Best scheme (PNB), a UK-social enterprise-developed patient-controlled online medical records system and tool to help patients better manage their care. GOSH is one of the first UK hospitals to use the scheme and reported positive benefits.

5.6.7 The review team did not examine these schemes in detail but recognise the importance of quality improvement and benchmarking, the enthusiasm of the IBD team and the Trust's international reputation. It is of note that although the service was reported to be respected, it is very selective about the age range covered and few interviewees outside the IBD team mentioned the schemes or the international status of the service, and evidence of Quality Improvement initiatives outside IBD was slim. Many interviewees reflected that a priority should be establishing a stronger presence and benchmarking within UK gastroenterology peer networks but there is scope to use the learning from these schemes in other divisions and indeed departments in the Trust.

Recommendation - Maintain current safeguards, governance and QI programmes and consider rolling out the benefits and principles of PNB and ICN across the service

Patient experience and quality

5.6.8 There are three Assistant Chief Nurses responsible for workforce, patient experience and quality.

5.6.9 The service was proud of the reduction in complaints to zero since January 2017 from 2-3 per month during 2015, which comprised almost half of overall complaints in the Trust. In the year to April 2016 there were 152 informal comments/concerns, with most of the negative ones being about the Rainforest ward environment. However, it is important to acknowledge that the activity has dropped by around half in the period so a proportionate reduction in complaints is to be expected.

5.6.10 The number of reported incidents fell between June and November 2016 but since then has increased positively then plateaued as they are being reported and dealt with, peaking at 33 per month in April 2017. There were no serious incidents reported to NHSE between June 2016 and May 2017; of the comments analysed resulted in minor or no harm but 91% were patient safety and 9% were health and safety issues. The multidisciplinary Risk Action Group monitors and acts on incidents which is good practice.

5.7 Training and supervision

5.7.1 Within the Trust the last 18 months has seen a strengthened process to allocation and support for trainees, with refreshed College Tutor roles linking with Divisional Educational leads and better join-up between departments. The Trust has begun to run College membership training courses and exams and has a positive feel about future developments of teaching and training.

5.7.2 The gastroenterology department suspended its training posts in November 2015 but has indicated to the Head of School that they would like to accept them from September 2017. One grid trainee and two SHO posts will be established in the context of a department that is now better furnished with juniors to contribute to the overall out of hours rota, but some respondents indicated that the department has a poor reputation and UK recruitment may be difficult as the posts do not rotate and the programme is not seen as innovative. Most of the non-consultants used in the department (and Trust) are clinical fellows including international graduates.

5.7.3 The GMC report and other intelligence indicated that junior doctors previously experienced few opportunities to participate in practical procedures – the Trust now has a simulator facility but this is not utilised and could be better co-ordinated.

5.7.4 Not all the consultants had been enthusiastic teachers which was surprising to hear for a team that considers itself to be offering quaternary care. Consultant attendance at the Wednesday afternoon educational /journal club is poor but the College Tutor plans to improve that. There were however no concerns about the consultants' competence. Trainees reported that much of their learning had been from peers, and they were sometimes asked themselves to teach beyond the scope that they were comfortable with.

5.7.5 It is important if the Tier 1 trainees are returned to the department that they are offered protected time for training. The College Tutor was willing to support the reintegration of trainees if the issues above can be sustainably improved.

5.7.6 For Clinical Fellows there has been considerable improvement since 2015, with more time for teaching and learning with the reduced activity and introduction of the pre- and post-clinic MDTs. Some come from overseas with no gastroenterology experience so can struggle a little initially. The timing of the Grand Round after the complex MDT means some registrars cannot attend the first meeting but they see patients regularly and discuss with colleagues. The teaching afternoons are appreciated and feedback about those consultants who regularly attend was very positive.

5.7.7 Consultant compliance with appraisal is monitored and all appeared to be up to date

5.7.8 There has been considerable improvement in career opportunities for nurses within the gastroenterology service with the increased profile of the clinical nurse specialists, but there is still no nursing practice educator. It is a priority for teaching to include a more structured approach to manage total parenteral nutrition (TPN) and double checking prescriptions so patients can leave hospital sooner.

Recommendation - Consider appointment of a nursing practice educator

5.8 Strategic positioning and external referral pathways

5.8.1 Following the 2015 review a restriction was placed on new referrals which was still in place when the review team revisited. The lead consultant and a colleague had developed a positive and clear strategy for the future of the service which concentrated on development of the highly specialised work and providing opportunities for specialist consultants from other units to conduct joint clinics at GOSH. Whilst it is logical and straightforward, the strategy lacks insight as to the capability of the service. It does not recognise the expertise that has over several years developed in other centres from which the GOSH team may themselves learn. Most of the work commissioned from GOSH is relatively routine specialist work and the three 'highly specialist' elements are very low volume.

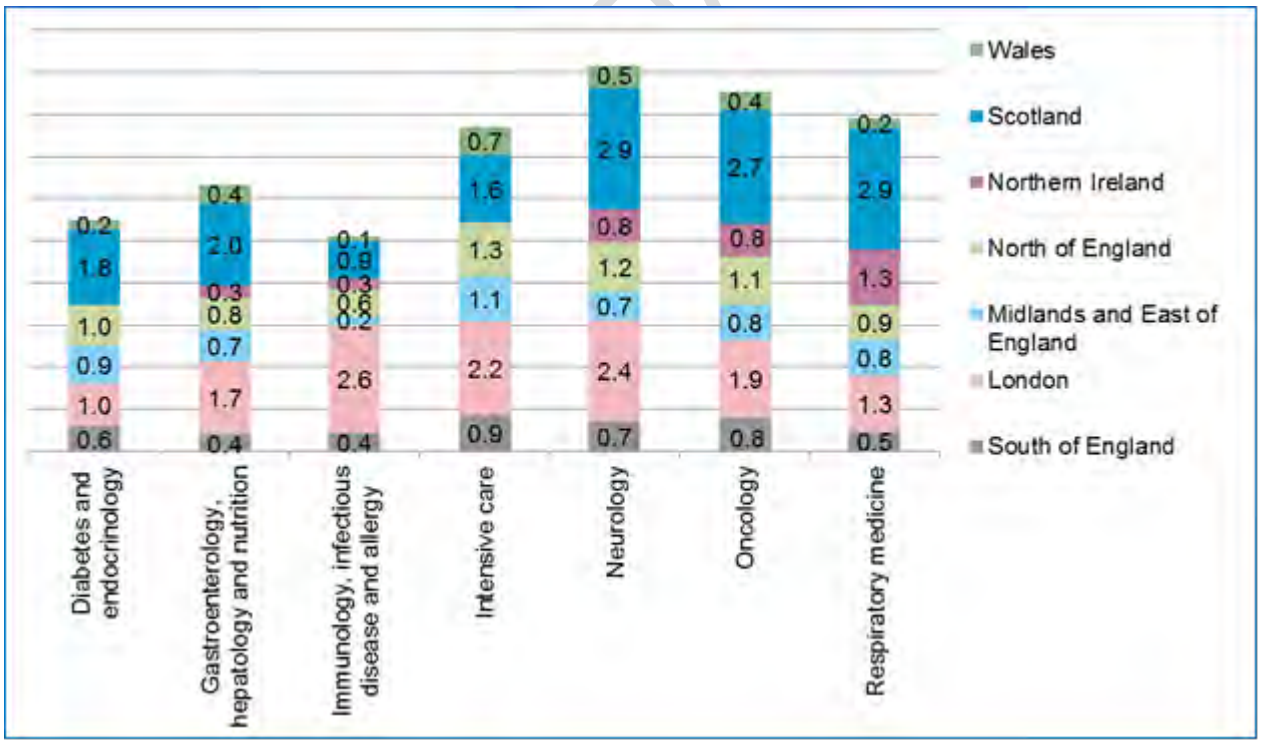
5.8,2 Relationships with other specialist providers were mixed; whilst individual consultants worked well with external teams (Luton and Dunstable and UCLH were specifically mentioned) there was continued unease about poor communications from GOSH management and lack of recognition that the 'temporary' redirection of referrals had placed considerable strain on other teams. Seven specialist providers were asked to support GOSH on a short term basis in November 2015 when the service closed to new referrals as investigations were in progress. During 2016 only selective referrals from other specialist centres were accepted. In December 2016 GOSH wrote to all units explaining that their internal investigations were complete and that they were asking the RCPCH to revisit but without providing further information about outcomes or anticipated timescales for completion and resumption of normal services. This resulted in increasing frustration at other units which were facing pressure on waiting lists, frustrated families and additional cost which was not covered by the payable tariff.

5.8.3 The review team was told that this whole process had been 'utter chaos' with no details about pathways and protocols, alternative specialist centres being overwhelmed and unable to offer shared care to DGH referrers and the consultants being unable to advise as they were not driving the process. There were concerns that children and families were unsupported and confused and that GOSH was practising 'defensive medicine' with the consultants becoming too afraid to practise and being 'micromanaged'. There were concerns about patients who had missed several appointments due to the confusion. Particular concerns were raised about ongoing management of gastro tubes placed by GOSH and unable to be replaced locally should

they become dislodged and the review team was unable to secure clarity over how this is managed. However, with the improved governance and administration systems in place there were some signs of improvement in recent months.

5.8.4 During the course of the review team's visits a joint letter was sent to the London Specialist Commissioner from seven specialist units requesting urgent intervention to rebalance the patient flows and require GOSH accepting more specialist referrals. The letter highlighted the implications for patients of the reduced activity at GOSH, which included confusion for families whose referral was rejected, long waiting lists to be seen at other centres and no attempt by GOSH over the 18 months of restrictions to proactively liaise with the specialist centres and plan the capacity required to manage the additional workload. The specialist commissioner had confirmed that he was awaiting confirmation from the MD at GOSH that the service was fit to restore activity.

5.8.5 Across London there has over recent years been an expansion in provision of specialist gastroenterology with many expert services developing their own preferred catchment areas and building enviable reputations. The RCPCH 2013 census[7] showed a considerably greater proportion of specialists in London (there are 25 paediatric GI consultants for a population of 8-9 million where Department of Health guidance suggests 1 per million.



Ratio of headcount of where specialty consultants are based to 100,000 children aged 0-15 for the largest seven subspecialties (excluding neonatal medicine and community child health) by UK region.

[7] RCPCH 2013 census – specialist services

5.8.6 Although proud of its three small highly specialised elements of its services the GOSH team is not providing leadership to other units and the struggle to appoint to permanent posts stimulates questions about how these services are provided. There is no formal network or opportunity for co-ordinated referral pathways and peer support between specialist units for development of highly specialised expertise and mutual teaching and learning. There appeared to be no formal monitoring of outcomes or quality of the highly specialised (and expensive) services nor whether they offer the NHS value for money as provided.

5.8.7 The Specialist Commissioning team are minded to establish a London network for specialist paediatric gastroenterology services and there is a role for GOSH (or indeed another unit) to take the lead on establishing and administering the network, developing agreed pathways of care and quality indicators. It is important that GOSH plays a full part in that network, managing a specialised service as well as the small elements of highly specialised work, learning from others and restoring relationships following the problems outlined above.

Recommendation – As commitment to the populations of London, working alongside other paediatric gastroenterology units, GOSH should agree and publish a defined specialist geographically based catchment area. This would encourage development of stronger relationships, better networking with provision of services close to patients' homes.

Recommendation: Develop a proactive programme of quality Improvement and engagement with management and other specialist teams. The team should aim to develop clear service pathways and build a QI/safety dashboard across the London GI Network.

5.9 Patient and family Involvement see also 5.6.8

5.9.1 This is an area where there has been limited progress despite the high level of complaints being the main trigger for the 2015 review. This is partially due to the focus having been on ensuring the service is operating safely and dealing with those families who have longstanding concerns, but it was reassuring that the number of complaints has dramatically fallen in recent months in response to improved administration processes and better communication between the clinicians.

5.9.2 Although there is scope and aspiration amongst some of the clinicians to improve engagement with families several do not see this as a priority and were cautious about the RCPCH team seeking patient input. There was mention of an engagement event some years previously that had gone badly and alongside previously high levels of complaints this appears to have paralyzed the approach of the consultant team to seeking feedback. Although the Friends and Family test is operating in the

Trust the review team was not made aware of any bespoke gastroenterology patient reported outcome (PROM) or experience (PREM) measures collected yet.

5.9.3 Families whose child(ren)'s care had been reviewed during 2016 had been invited to talk to the PALS service if they had concerns or questions about the care and treatment of their child. They and their children were invited to an engagement event which was very effectively facilitated by an external agency in July 2017. Disappointingly there were several no-shows but those that attended provided a rich source of material and feedback from which the service can build an engagement strategy for all children and families as well as an action plan to resolve the concerns raised. Given these were generally families with considerable experience of the service it was a good place to start.

5.9.4 Feedback received by the review team (Appendix 6) indicated that many parents were not satisfied with the communication from the Trust following the 2015 report, and complaints continue around the lack of family-focus and integration when organising appointments. Many families still don't know what the situation is for their child. The listening event provided a clear message that although things appear to be improving, more must be done to build confidence amongst the families and listen meaningfully to, and act upon their concerns and suggestions.

5.9.5 Across the wider Trust the level of engagement of parents and families was reported to vary between teams. There is surprisingly no hospital –wide approach to specifically involving children and young people in their care and service planning and these schemes and tools seem to be developed within individual departments. The 'Patient Knows Best' scheme (see 5.6.6) helping individual IBD patients manage their condition was a good model and its principles could be extended to other divisions

5.9.6 In practical terms there were complaints about non-existent parent facilities on Rainforest ward and children on special diets being sent from the catering team foods they were not allowed. Involvement of parent groups in designing information leaflets /webpages and perhaps representation on risk or guidelines groups would begin to demonstrate a genuine desire to listen and respond to the views of patients and families. The RCPCH "&Us" team can provide sources of advice and assistance in establishing such schemes.

5.9.7 The RCPCH was keen to hear from any patients or families who wished to share their views with the review team and a short qualitative online survey was prepared and distributed through the ward (leaflets and posters), via Facebook social media groups and face to face contact at the engagement event. Eighteen responses were received, almost all heard of the survey through social media despite leaflets and posters being provided by the RCPCH to put on the wards. Responses are summarised in appendix 6 and should be taken on board in a 'you said-we did' format along with the open event conclusions as a start to a formal programme of engagement and involvement.

Recommendation – Design a formal programme of engagement with all patients/parents/carers including seeking feedback and providing a report on what has changed as a result of comments/ complaints

Recommendation - Consider developing leaflets and web guides for patients and parents to support and improve their experience of using the service.

5.10 Protocols pathways and guidelines

5.10.1 Since the review a considerable number of internal guidelines and protocols have been redrafted and there was positive feedback from multidisciplinary colleagues that that the approach to care was more consistent and relationships had improved under the new clinical lead. All consultants were now reported to work within the guidelines and the MDT arrangement supports that. Some pathways are still required such as GI Food Allergy, (see 5.10.11) led by dietetics but the guidelines group is in place to oversee that.

5.10.2 International and private patient activity carried out at GOSH was also reported to be compliant with the guidelines used for NHS patients.

5.10.3 Guidelines will be drafted and reviewed in future through the quarterly guidelines and protocols meeting, approved by the trust-wide multidisciplinary Guidelines and Protocols Approvals Committee (GAPAC). The terms of reference for this gastroenterology group mention international links but not liaison with other specialist services within a network; it is important to share learning amongst peers particularly where presentations are rare or complex, and to be sure the protocol enables clinicians to “recognise normal”. Including this element in the approval cycle will enable the service to better serve patients and external peers through clear agreed pathways.

Recommendation – Ensure a UK peer network is involved with development and agreement of guidelines, perhaps through BSPGHAN, not just international partners.

5.10.4 Historically here may have been a tendency for difficult or complex patients to be referred to GOSH when a local DGH was capable of managing the case but relationships with the family had broken down. The restrictions on referrals since 2015 closed this route and the ‘local’ paediatrician remains involved and responsible with a view to repatriation as soon as the child’s condition permits care to be managed locally. This will improve school attendance, social relationships and a sense of normality and all guidelines and protocols should be based upon this principle, with commissioner support. For example, 2-week observations currently based on Rainforest and some diagnostic tests may be possible in local units prior to admission with properly

supported local staff. This is already being explored by the IBD team and benefits the patients and frees ward space at GOSH.

Compliance with national standards

5.10.5 The RCPCH/BSPGHAN standards published in 2017 provide nine criteria which apply to all gastroenterology units, and one of the consultants was on the advisory group. The service is striving to comply with them all but needs additional resource to meet standards

Standard		Compliance
1	Work in a network	Not yet. See recommendation
2	Access to advice/transfer 24/7	Advice possible 9-5, oncall more difficult. No beds for transfers
3	Transition policies and pathways	Patchy. See below
4	Endoscopy facilities and emergencies	Not compliant for emergencies – Business case for an interventional endoscopist
5	Specialist service IBD	Compliant
6	Specialist diets need paediatrician and MDT	All have named consultant but not necessarily a paediatrician – no regular round
7	Inpatient PN are reviewed weekly by consultant led MDT	Risk – not compliant due to insufficient clinical staff. See recommendation
8	Home PN patients have a dedicated team	Compliant
9	The service has links to a hepatology specialist centre	Compliant – linked to King's

Adolescence and Transition

5.10.6 Transition arrangements are patchy with each service managing its own patients to linked consultants in other specialist centres or the adolescent's DGH. There is a good relationship with University College London Hospitals (UCLH) for IBD patients but the links for PN are less assured, and the transition arrangements appeared to lack flexibility, being based on the medical relationships rather than patient choice. The motility service is relatively new so some patients are only just approaching transition and it was not clear what plans are in place. UCLH will not take new patients under 18 years and GOSH policy is to transition at 16 so this needs to be addressed.

5.10.7 There is a webpage outlining the transition process with a downloadable leaflet (dated 2011) but this was aimed at parents and there was no online information for young people. The easy-read version states transition at 18-19 years old and is not aimed at adolescents. The appointment of a Clinical Nurse Specialist for adolescent patients was proposed who could see young people by themselves and explore issues around transition and any psychosocial concerns, as well as practical discussion about sexual health and pregnancy which does not currently take place.

5.10.8 The NICE guidance and quality standard published in January 2017 (NG43/QS140) is clear about the minimum requirements for transition and compliance this should be prioritised. Many DGHs and specialist units in the UK have comprehensive arrangements and communication materials for transition such as the Southampton 'Ready Steady Go' scheme and would probably be willing to help GOSH with developing this aspect of its service.

Recommendation- Develop a comprehensive and flexible patient centred transition programme - linked with adult services in London closer to home. Pathways should be patient based rather than be clinician's choice and require better networking. The design of such a programme should involve young people and include a suite of communications materials suitable for patients, parents and families.

Pharmacy

5.10.9 The relationships between the gastro team and the pharmacy department still had room for improvement. The pharmacists work with a range of teams across the Trust providing advice on new drugs, checking and administering prescriptions and supporting the treatment of patients alongside the medical team. In particular, they support patients on Parenteral Nutrition (PN) who number 45-50 inpatients and around 50 at home which is one of the highest levels in the UK.

5.10.10 The pharmacists are keen to work more closely with the consultants but consider the importance of their service in the MDT is not respected by the consultants– in marked contrast to the engagement of other teams. For example, gastro consultants do not provide input to the development of new protocols, sending a junior doctor who is unable to contribute sufficiently. Consultants refuse to sign prescriptions, citing lack of time, yet other divisions insist on a consultant signature. Although there are regular meetings between the gastro consultants and the pharmacists, agreements made at the meeting were reported not to be followed through. A protocol is needed about joint working with pharmacy and accountability and governance arrangements, perhaps nominating a liaison clinician in each team

Recommendation – Strengthen links with and feedback from the pharmacy team within the overall governance reporting arrangements

5.11 Are there any areas of notable practice or achievement?

5.11.1 A number of positive actions and good practice are covered throughout the sections above but are drawn together in this section to recognise progress since 2015 and encourage further work going forward. For example

- Positive, engaged general management with informed, useful monthly dashboards.
- Improved ward leadership and better links to mental health expertise.

- A systematic governance and reporting structure although this needs to be embedded.
- Better equipped endoscopy suite with reduced turnover and improved morale.
- Administration – managing telephone calls and response times.
- The rapid response service for medication review which was reported to have made big changes to children's' quality of life.
- Positive attitudes in the IBD service– engaging outside the Trust, PNB and ICN
- Development of the Risk Action Group – resulting in tight governance and action.
- Much greater involvement of dietetics.
- Improved clinical nursing leadership and confidence to speak out

5.12 The priorities and strategy for development of the service.

This is covered in the sections above and the recommendations for the service.

6 Recommendations

We recommend sharing this report with the GI team who have contributed to the review process and the full report or a summary should be shared more widely amongst contributors to demonstrate transparency.

Leadership, Strategy and external focus

Appoint a respected NHS based external clinical leader to the post of senior clinical lead - equivalent to a chair - in gastroenterology to develop the service, working together with other units on London-wide GI network collaboration (5.1)

GOSH should become part of this London network to equally contribute to the care of the regional population alongside other GI units. In addition GOSH may wish to also agree on their unique focus and to ensure appropriate communications between GOSH and all hospitals in this network (5.1)

As commitment to the populations of London working alongside other paediatric gastroenterology units, GOSH should agree and publish a defined specialist geographically based catchment area. This would encourage development of stronger relationships, better networking with provision of services close to patients' homes. (5.8)

Review the acceptance criteria, pre-and post clinic MDT and job plans carefully to enable greater throughput of patients without compromising governance or increasing risk (5.3)

There should be a further clinical review of the service and approach to cases 12 months after the lifting of referral restrictions (5.2)

Management and Governance

Clinical Management should satisfy the Board that an investigation of historical gastroenterology cases has been completed in full, specifically the care of all children on long term interventions without a clear validated diagnosis. (5.2)

There should be a demonstrated climate of openness in addressing concerns raised by staff to provide assurance that appropriate action and candour has been exercised. This should include the appointment of and demonstrable support for a Freedom to Speak Up Guardian (5.2)

Take steps to ensure there is stability of clinical and operational management to embed the positive developments (5.1)

Ensure a UK peer network is involved with development and agreement of guidelines, perhaps through BSPGHAN, not just international partners. (5.10)

Finalise job plans, including weekend ward presence, appoint to permanent positions and consider additional recruitment to provide cross-cover and manage activity (5.3)

Increase medical support for the intestinal failure team (5.3)

Prioritise improvement of the ward environment as a matter of urgency and involve ward staff in discussions about relocation (5.3)

Consider appointment of a nursing practice educator (5.7)

Strengthen links with and feedback from the pharmacy team within the overall governance reporting arrangements (5.10)

Safeguarding and Patient centred care

Maintain current safeguards, governance and QI programmes and consider rolling out the benefits and principles of PNB and ICN across the service (5.6)

Involve a named general paediatrician in the referrals meeting and any gastroenterology subspecialty case with a perplexing presentation including current cases where a child has a significant disability after receiving treatment or investigations without a proven cause. (5.5)

Develop a comprehensive and flexible patient centred transition programme - linked with adult services in London closer to home. Pathways should be patient based rather than be clinician's choice and require better networking. The design of such a programme should involve young people and include a suite of communications materials suitable for patients, parents and families (5.10)

Invest in building sufficient clinical psychology input to meet identified demand and increase mental health screening /support (5.3)

Plan realistically to ensure the appropriate number of beds so that children with "perplexing presentations" can be admitted, observed and managed cohesively with general paediatrics local paediatric teams and safeguarding where necessary.(5.3)

Ensure the effectiveness of complex cases MDT to encourage the lead clinician to discuss cases in a forum with other GI consultants, general paediatrician, safeguarding lead (when appropriate) , nursing staff and clinical psychologists. All staff should be empowered to contribute.(5.2)

Ensure continued support to the safeguarding programme with all clinical staff safeguarding trained to Level 3 (5.5)

Design a formal programme of engagement with all patients/parents/carers including seeking feedback and providing a report on what has changed as a result of comments/ complaints (5.9)

Consider developing leaflets and web guides for patients and parents to support and improve their experience of using the service**.** (5.9)

Develop a proactive programme of quality Improvement and engagement with management and other specialist teams. The team should aim to develop clear service pathways and build a QI/safety dashboard across the London GI Network (5.8)

Improve liaison and understanding between the gastroenterology consultants and the social care team. (5.5)

Appendix 1 The Review team

Dr David Shortland MD FRCP FRCPCH DCH has been a paediatrician for 25-years in Poole, Dorset, including ten years as neonatal lead and twelve as clinical director. David was the lead clinician for the rebuild of the paediatric department in 2005 and currently leads on Clinical Quality for the paediatric department.

Following five years as member, then Chair, of the Clinical Directors Special Interest Group, in 2006 David was elected as the National Workforce Officer for the RCPCH leading the 2007 national workforce census and designing a cohort study of trainees to provide a clearer understanding of the current and future workforce, helping to define how the role of paediatricians can evolve to provide consultant delivered care and hence safe and sustainable services. David was elected Vice President (Health Services) in 2009 and played a central role in developing strategy for Child Health Services in the United Kingdom supporting paediatricians through the challenges of radical reform to the health service, working time legislation and service re-design. During David's five years in post he developed a national template for the resident paediatrician and was lead author for "Facing the Future". This document defined 10 quality standards for acute paediatric services and is widely quoted as a template for good practice. David led a national audit of these standards in 2013 and currently chairs a steering group extending the standards approach to care outside hospitals. Since 2014 David has been clinical adviser to the RCPCH Invited Reviews programme and has led a number of high profile reconfiguration, individual and service reviews.

Dr Nadeem Ahmad Afzal MBBS, MRCP, MRCPCH, MD is an Expert Adviser for the NICE Centre for Guidelines and has recently served as Honorary Secretary of the British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN). Dr Afzal is a Consultant in Paediatric Gastroenterology, Hepatology and Nutrition at University Hospital Southampton. As Honorary Senior Clinical Lecturer at Southampton University he runs an active research programme. Dr Afzal has established paediatric hepatology services at University Hospital Southampton, is the paediatric endoscopy lead and helps to run the Wessex Paediatric Gastroenterology Network. Dr Afzal is an Invited lecturer to the MSc in paediatric gastroenterology at Barts, London and MSc in Allergy in Southampton University. Dr Afzal has served as Editor in Chief for World Journal of Gastrointestinal Endoscopy and has contributed to the gastroenterology section of the RCPCH Paediatric Care Online.

Claire McLaughlan is an independent consultant and former Associate Director of the National Clinical Assessment Service with a particular interest in the remediation, reskilling and rehabilitation of healthcare professionals. As a former registered (intensive care) nurse, educationalist and non-practising barrister Claire developed the NCAS Back on Track services for dentists, doctors and pharmacists in difficulty. Over the last 10 years Claire has worked with over three hundred organisations and practitioners to 'make a difference' before irreparable damage was done to patients and

the public, practitioners, and organisations. Before joining NCAS Claire was Head of Fitness to Practise at the Nursing and Midwifery Council.

Sue Eardley joined RCPCH as Head of Health Policy in January 2011 and established the Invited Reviews programme for the College, conducting over 70 reviews in five years. An engineer by training, Sue spent 13 years as a non-executive and then Chairman of an acute trust in London, alongside a range of voluntary activities including national and local involvement in maternity services and the NHS Confederation. Sue led groups contributing to the Maternity NSF and chaired her local MSLC for four years. Before joining the RCPCH Sue spent six years full time leading the maternity and children strategy team at the Healthcare Commission and then Care Quality Commission, overseeing strategy, design and delivery of all inspections and reviews in England of maternity, child health and safeguarding.

Appendix 2 Contributors to the review

The following post holders/staff groups / representatives were interviewed as part of the review

Senior team

Medical Director
Chief Nurse
Deputy Chief Nurse
Divisional Assistant Chief Nurse
General Manger
Deputy Chief Executive#
Head of Communications
Deputy Director of Operations
Divisional Director

Medical staff

Anaesthetics and Surgery
Histopathology
Clinical Psychology
General Paediatrics
Immunology
Gastroenterology consultants
Clinical Fellows,
Junior doctors
Radiology and nuclear medicine
Locum gastroenterologists
Safeguarding
Undergraduate training
Palliative Medicine)

Other staff

PALS, Risk and Complaints
Dietetics
Endoscopy
Feeding
Safeguarding
Management and Administration
Ward Sisters/ Matrons
Pharmacy
Clinical Nurse Specialists:

External representatives from

Southampton University hospital
Southend
Luton and Dunstable Hospital
UCLH
Royal Free Hospital
Alder Hey Children's
Birmingham Children's
Newcastle Hospitals
Cambridge University Hospitals
Barts and the London
Kings College Hospital London
Specialist Commissioning, NHS London
Care Quality Commission

Appendix 3 Standards and reference documents

A1.1 The following standards are referenced in the review

Quality Standards for Paediatric gastroenterology, Hepatology and Nutrition
RCPCH /BSPGHAN January 2017

Transition from Children's to adults'' services for young people
NICE guidance NG43

Transition from children's to adults' services
NICE QS140 to NICE Transition

MHPS – Handling concerns about a practitioner
NCAS June 2012

Appendix 4 Information provided to the review team

Documents were provided by the Trust relating to the following areas and where further documents were requested these were provided swiftly.

- Report from expert panel
- Various update/progress reports from 2016 – flash reports and SMT update
- Template letters sent to parents and patients whose cases were reviewed
- Gastro team strategy for the future
- Business cases for new ward, psychology staff, endoscopy stack,
- Minutes of divisional board meetings
- Correspondence from Addenbrookes outlining pressure on activity
- Improvement group minutes 2016
- Monthly specialty review reports
- Guidelines and protocols committee ToR and list of current guidelines
- Quality Improvement group tor
- Risk register, incident reports, complaints summary and F&F test results
- Safeguarding policy and 2015-6 annual report
- Appraisal and PDR policy and sample forms
- Risk management strategy and ToR and minutes of RAG meeting

Appendix 5 – List of Abbreviations

BSPGHAN – British Society for paediatric gastroenterology, hepatology and Nutrition
CQC – Care Quality Commission
CQuIN – Commissioning for Quality and Innovation
DGH – District General Hospital
GI – Gastro intestinal
GIU – Gastro Intestinal Unit
GOSH – Great Ormond Street Hospital for Children
HEE – Health Education England
IBD – Irritable Bowel Disease
ICN – Improve Care Now scheme
MHPS – Maintaining High Professional Standards
MDT – Multi Disciplinary team
NHSE- HSSS NHS England Highly Specialised Services
NICE – National Institute for Health and Care Excellence
(P)ICU – (Paediatric) Intensive care unit
QI – Quality Improvement
RCPCH – Royal College of Paediatrics and Child Health
TPN /PN - Total parenteral nutrition
UCLH – University College London Hospitals.

Appendix 6 – Summary of survey responses.

A total of 17 parent carers and one patient (aged 14) responded to the online questionnaire. All the children and young people had been under the service for over 18 months, and sixteen for over four years.

Eight had been seen within the last 3 months, and nine had not had contact for over 6 months. Eleven had been under mucosal immunology, five neurogastroenterology and two nutrition and gastrointestinal failure. All who sent their contact details have been acknowledged.

Positive Comments - what was good?

Mucosal Immmunnology (11 responses)

- Good appointment. Shocked to find out that out Dr left the trust and that has been the reason why we have been seen by different doctors. Not really good when one needs continuation of care

- Dr x has been amazing for us and a real expert in his field.(x 2 responses)

- Things have greatly improved within the IBD department. There is follow up before the appointments as well as after. The Dietetics team can be a bit more prompt in their action points after the clinic appointments but otherwise, the Nurses who attend the clinic follow up on everything that is discussed.

- I like my dr and the nurse specialists and the pkb system

- Staff in all areas are superb (x 2 responses)

- Always had a very positive experience with all staff. Patients Know Best service provides an invaluable secure contact point with the department (x 2 responses)

- The doctor my daughter saw was much friendlier than those she has seen in recent visits. She spoke in a manner that meant we felt as though we were believed! My daughter felt at ease and the doctor spoke knowledgeably about what was disgusted xxx

Neurogastroenterology / Nutrition and Intestinal Failure (7 responses)

- Great levels of specialism and medical equipment which have brought me further to a diagnosis

- We now get appointment letters well in advance (however these have been cancelled).

- The last time we were on Kingfisher ward they were helpful and efficient. Mr x is always helpful and speaks directly to my daughter and is happy to explain things and repeat things where needed. We see Dr x at an outreach clinic at our local hospital and appointments are hard to get often waiting over a year.

- Dr x and the kingfisher nurses (x2 responses

Negative – What could be better?

Mucosal Immmunnology

- Sadly nothing [was good] as for the past 2 years their has been no service for our children.

- We recently asked to be dischaged due to the poor care from Dr x whilst Dr x was on leave. He was very rude about my children and said there was nothing wrong with them, when clearly biopsies and test proved otherwise.

- Better admin would be good as it is shockingly bad and better joined up working putting the child first

- Acknowledge and treat Eosinophilic Disorders / Gut allergy using international guidelines. Be honest and open, Carry out your duty of care as a quatinery hospital do not turn the clock back on 15 years of speciality knowledge by playing it safe and discarding your patients. Listen to patients and parents if you support them and believe in them they will be your biggest advocates. Work with patient advocacy groups/ charities, government and scientists etc in a positive manor. It is the only way forward see the USA example www.rarediseasesnetwork.org

- Don't continue to abandon these complex children and their families, doing nothing is "doing harm". Lead the way for the UK, be the best that you can, do what it says on the tin "the child first and always"

- Better contact between appointments, less cancelled and rescheduled appointments, easier contact within the department to reschedule appointments at convenient times.

- A shiny new ward or better administration are pointless without a doctor that can treat your child, acknowledge their symptoms and discuss a condition that had been diagnosed at GOSH.

- Easier contact with the consultant/doctor is required in between appointments

- Listen to children and parents. Better Admin support.

- We were not informed why we were moved to another hospital and another consultant when we contacted GOSH they had limited records of our attendance over the 8 years our son was a patient

- access to test results

- Communication between team members and other professionals outside the in house team. Facilities on gastro ward are poor for patient. As a gastro ward the food sent is of poor standard and is often not labelled correctly and for gastro patients this is important

- If the clinics are in the afternoon and they, invariably, over-run, can the hospital arrange for the blood test departments to be open for longer than 5 pm as it is very inconvenient for parents to bring their sick children to hospital for specific blood tests. Even if there is one person on duty after 5 pm, people would not mind waiting, but it becomes very difficult to come the next day again.

- Better admin support. More openess in changes and consistency

<u>Neurogastroenterology / Nutrition and Intestinal Failure</u>

- Nothing good about Gastro at gosh, impossible to get appointments, no one to call with problems, wards terrible, you get told one thing at appointments but the review letter says completely different information

- Putting patients first. Stop trying to off load the blame for the recent poor review onto parents. Start LISTENING to parents, stop making assumptions, stop putting "diagnoses" on research papers which haven't been given, communicate with local healthcare (God forbid..... GOSH are known as "God's Own Service" here because of their self-inflated opinion) and offer appropriate support to patients they previously claimed to care about instead of rubbishing past diagnoses to get themselves out of a sticky situation. Also - never get clinic letters typed in India again, apart from the time lag a year's

worth of ours went to Australia!

- Also stop the internal private referrals. We were even asked if we wanted to travel to Belgium for oesophageal manometry if we could pay and told how easy it was. Private and NHS gets meshed to together and the children are the biggest losers with parents purely the victims of consultants desire to further their research and/or free up waiting list space.

- Very little! [has improved] Clearly GOSH cannot get rid of EGID patients fast enough. Care has always been haphazard with clinic letter errors, delayed clinic letters, dangerous overdose prescriptions local pharmacy picked up and even merging of one child's notes with another of the same name from the same town who was one day older.... However previously we felt GOSH cared, even though in practical terms it meant keeping your wits about you as errors were common, potentially life changing and continuity of care non-existent. Dr x was fantastic and left the kids in a good place, however Dr x supported local FII referral (happening to a LOT of GOSH EGID patients) and we've now been discharged. Appalling service, no care and the child last or never. I wouldn't recommend GOSH to anyone even if it was a last resort and am so pleased we are out of there. Never ever going back. Children were previously also under Rheumatology, Surgery, Immunology, Dietetics (no input from them, just a name to receive letters, hopeless) and Dentistry. All other departments were excellent. Gastro are in a league of their own!!!

- As a 14 year old, I think communication between the doctors and adolescents needs to improve. Also brighter, cleaner gastro wards with more private rooms for teenagers.

- Better contact and support

- There seems to be a total 'washing of hands' of EGID at GOSH. During our last appointment the focus was solely on motility, even the letter received afterwards stated 'previous eosinophilic infiltration'. My son is on several medications a day to help his EGID and nobody has reviewed them in nearly two years. We need continuation of care of EGID.

- Poor communication, poor decision making, always leaving things to see how they are in x months

- Communication and following up

Other comments

- We were invited to the listening event. I was a founder member (by invitation) of the GOSH Gastro Parent Network which wa rapidly dissolved when the consultants felt it wasn't endorsing their poor practice. Frankly I wouldn't waste the time, travel and childcare cost or effort travelling down to any future event but seized the opportunity to complete this survey. I've run online support forums for gastro parents for years, I'm a parent of 20 years and have been dealing with gastro issues myself all my life. [redacted] was very keen for my help and input when it suited but we've been left high and dry with absolutely no tertiary, secondary or primary care now. Disgusting. We never sought a diagnosis of EGID - indeed we challenged it with respect of two children as there was not evidence, but were reasonably happy with the care - to be dropped as inconvenient is appalling.

Appendix 7 Progress record against recommendations

Leadership and Vision

2015 Recommendation	Progress evidence
a) Create a chair in gastroenterology post Engage a respected gastroenterology leader as a Professor/ Chair with sufficient management time to support and manage the consultant team and lead implementation of the recommendations below.	This has not been addressed although attempts were made in 2015 to identify an individual. We feel the climate has changed and there may be a candidate with the appropriate skills and availability.
b) Address immediate concerns arising from complex gastroenterology MDT work, including initiation of an expert independent UK peer review of children without IBD on immune-modulation; enteral feeds and elemental diets with an action plan for each case completed by end 2015	This has been completed; some further assurance work is suggested in the report.
c) Agree and articulate a clear vision for gastroenterology at GOSH, including • Development of a network with tertiary centre colleagues to support peer review, consider joint clinics and improve dialogue about pathways, diagnosis and management of complex cases.	A strategy has been produced by the clinical lead which is an excellent start. Further work to develop networks and peer working, incorporating some of the suggestions in the report would be helpful and if a Professor/Chair is appointed across the London Network this will further strengthen the plan.
• Exploring the potential to focus on quaternary work delivering highly specialised care to a high standard and diverting routine secondary/tertiary work such as DGH outreach to other tertiary providers to reduce pressure on the service.	This was successful whilst the concerns raised in the 2015 report were dealt with. However it is important to take back the specialist portfolio to enable a sense of 'normality' and reduce waiting times for children and young people within the system
• Considering, in partnership with other tertiary providers, what level of tertiary and investigative work should remain at GOSH to provide second opinion, peer review, parenteral nutrition and training experience to support the quaternary functions.	This conversation needs to be had with specialist providers and commissioners. Unfortunately the corporate communications between units has not been constructive over the last 2 years
Management	
d) Complete the proposed directorate restructuring to align the gastroenterology team managerially with	Directorate restructuring has been completed successfully with new

interdependent medical teams. This includes immunology, metabolic medicine and infectious diseases[8], so the Infection Cancer and Immunity (ICI) team would be the most appropriate fit, alongside dermatology and rheumatology.	General Manager and Divisional Director in place.
e) Conduct an urgent review of safeguarding arrangements in the service and wider Trust to ensure that local information and context about each child/family is securely notified to all who should be aware. Specific issues to address include: • Accurate and diligent completion of ROBOT forms – these must include all pertinent information available about the child with a mechanism for adding further information that becomes available.	We are aware that two such reviews have been undertaken and it is essential that the Trust implements those recommendations and strengthen safeguarding arrangements for the future Not checked but no concerns arose during the review
• Instigate a process of communication with referring clinicians and their organisations to ensure clear 'health dialogue' where there may be any safeguarding concerns	Considerable improvement with local paediatricians involved in complex MDT where possible.
• Examine the culture of safeguarding in the wider trust to provide assurance that staff are skilled in identifying and confident in communicating any concerns about the safety and welfare of children and young people in the care of GOSH.	New Named Doctor is moving this area forward, but still some way to go to be confident that all issues are picked up swiftly
f) Address communications concerns through developing clear and agreed standards of communication and behaviour, with clarity about decision making and dissemination processes. Develop a mechanism to monitor, respond and provide support if standards are not met by individuals or collectively	There is strong governance and administrative process with behaviour issues being dealt with swiftly and effectively and monthly performance reporting. .
g) Strengthen administrative support for the team, reviewing in detail the communications and 'paper trail' of patients with those who administer it. Identify and mitigate any risks or inefficiencies including monitoring and enforcing compliance with elements of the process.	As above, more work is required to fully embed the processes.

[8] See Department of Health Framework of Critical Interdependencies 2008

h) Redesign the external referral pathway – immediately and then in line with (c) above, Review the guidance about referral criteria, template forms and letters to clarify expectations for families and local clinicians, building on comments received on the current approach.	The restrictions on referrals provided an opportunity to consider this. A guideline group has been established to design and document pathways and this needs to involve secondary care paediatricians.
Give advice on which is the most appropriate tertiary gastroenterology team to seek advice from instead.	This should evolve with development of a London Network of gastroenterology units
Monitor discharge arrangements and audit follow-up requests to ensure patients are discharged to local services wherever appropriate	We did not review casenotes but an exercise to this end was conducted in 2016 and the MDT should pick up those who should be seen locally.
Support this with a clear communications plan building on complaint information	We have not seen this.
Clinical activity and Job Planning	
i) Review rotas and clinical attendance to meet current and planned activity and ensure that job plans reflect actual duties (and vice versa). This should include: • Consultant of the Week - scheduled ward rounds, attendance and absence of other clinical work. The care plan for long-stay or 'complex' patients must always be determined by their lead consultant	Job plans have been drafted but not completed. See recommendation Positive action has been taken to reduce instances of the Consultant of the week changing care plans.
• Weekend consultant ward rounds should be instigated	Not yet but consultants respond to clinical calls. recommendation repeated
• Availability of specialist gastroenterology advice out of hours including immediate access to a specialist registrar or consultant. An audit or monitoring of specialist demand out of hours may assist in defining the requirement.	The service is unchanged from the 2015 review but some of the consultants do respond more quickly.
Review of consultants' contracts to reflect the issues raised in this report and require attendance on site for core activities	Included in Job Plans
j) Increase the involvement of clinical psychologists in the pathway where functional disorders are	Some progress but a business case is pending for greater coverage through 2

suspected and audit impact on outcomes. Providing this input to families early in their contact with the Trust can demonstrably improve the quality of experience and speed discharge where either functional problems exist or the long journey to diagnosis has put additional strain on the child or family	x Band 7 support.
k) Review the training and engagement of Clinical Fellows to ensure their training is appropriate and seek feedback from their placements.	Some improvement given the reduce pressure of work but more opportunities could be made.
l) Review and clarify the activity and role of the general paediatricians to provide capacity for them to triage all internal /inpatient referrals and take a lead, co-ordinating medical role for patients with complex, multi-specialty conditions.	Some progress but insufficient capacity to cover more work at the moment
Governance	
m) Establish a regular governance performance work stream and meeting with mandatory clinical attendance and programme of work to include: • agreement of key service indicators (e.g. acceptable and achievable waiting times, standards for communication and responding to enquiries)	There has been a marked improvement in governance arrangements and a monthly report covers these topics.
• A dashboard of performance, including the above, developed by and with clinicians	Done, always could do with review to seek new data
• Strengthened input to management of concerns, complaints and incidents, including trends and 'you said we did' information	Gastroenterology risk assessment group and other structures to bring this data closer to the consultants.
• Development of peer review, service audit and risk management	MDTs before and after clinic provide helpful review
• Action planning as a result of the above	Plans were shared during 2016 and now completed.
n) Ensure ward staff have appropriate training and supervision for managing children and families with mental health needs. This may be a trust-wide issue that affects other teams as well.	Improved cover as Matron also covers the mental health wards and there is good liaison between the teams
o) Initiate a divisional programme of Quality Improvement, perhaps through senior nurses or clinical fellows with clear objectives and	Not yet evidenced

demonstrable outcomes. RCPCH can support this through courses and learning packages. ,	
p) Refresh the protocols and guidelines about which and when interventions are necessary to which all consultants adhere unless there are clear recorded grounds for deviation. More rigorous adherence to such guidelines, with preview and audit of cases could significantly reduce the pressure on the endoscopy service, improve throughput for those patients who do need it and speed up diagnosis care for those who do not.	Guidelines and protocols have bene developed and a formal group established for ongoing refinement and refresh.
Patient Involvement	
q) Ensure all patients are assigned specialist nurses who can provide a 'first point of call' for families.	There has been an increase in CNS availability and involvement and they are consulted more by families and doctors.
r) Establish a user group for children young people and families who can advise on communication issues, support other parents and provide positive input to service development.	Not yet established. A morning workshop session took place on 15th July but this needs to be incorporated into the service.
s) Develop web-based information for children young people and families who use the service which explain what to expect when referred to the service.	Not seen, The website provides plenty of information but is aimed at parents.
Environment	
t) Address longstanding environmental issues and relocate/refurbish Rainforest Ward to provide a more suitable facility - involving families and staff in design,	Little change. Continued recommendation.

From: [redacted]
Sent: 01 November 2017 16:13
To: Harris, David
Cc: [redacted]; Peter Steer; [redacted]; David Hicks
Subject: RE: RCPCH gastro report
Attachments: GOSH Gastro report draft for client review.doc; GOSH Factual Accuracy - RCPCH Review v3.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Hi David

Further to my last email containing the **draft** Executive Summary of the RCPCH report on gastro services at GOSH, please find attached the following documents;

- The **draft** RCPCH report on Gastro services at GOSH
- Our table of factual accuracy recommendations

I know you had previously discussed with [redacted] the idea of a panel review, further to our sharing with you all the documentation we held on our external gastro reviews. Of course we are prepared to speak at any time.

As you know, [redacted] has been unexpectedly away on sick leave which has complicated arrangements being formalised.

To ensure we are prepared to further assure you, as I suggested in my previous note, this process could be assisted with an agenda and clarity on objectives. I note your update below and now seek clarification on the following;

- How many people are attending from CQC? Will this include clinicians?
- What specific gaps have you identified so we can target having the correct people and documents ready for you
- Also, what output is expected from the meeting?

David Hicks, Medical Director is the lead on gastro and will host you here at GOSH. He has indicated that he has availability on the following dates. Please confirm which you prefer;

- Friday 24th November
- Thursday 30th November

Thanks
[redacted]

[redacted]

From: [redacted]
Sent: 01 November 2017 17:21
To: David Hicks; [redacted]; Peter Steer
Cc: [redacted]
Subject: Feedback to share with RCPCH
Attachments: GOSH Factual Accuracy - RCPCH Review 01112017.docx

Follow Up Flag: Follow up
Flag Status: Flagged

Dear David

Please see attached the final table of feedback for you to share with the RCPCH, incorporating the amends we discussed and the further information gathered from the division today and yesterday.

This is the final iteration, following the version [redacted] was planning to share with CQC yesterday (as per email copied below).

Best wishes
[redacted]

[redacted]
Great Ormond Street Hospital
[redacted]

From: [redacted]
Sent: 31 October 2017 16:28
To: [redacted]
Cc: [redacted]
Subject: RCPCH content for CQC

Dear Nicola

Further to our call just now, please see attached:

- The RCPCH draft report, subject to factual accuracy review (watermarked "confidential draft" – password [redacted]")
- The revised executive summary
- Our table of factual corrections

As discussed, there are a few areas of factual accuracy where I am still awaiting clarity from the division. I have removed these in the interim as they are not significant, and we can ensure these are resolved prior to sharing our full factual corrections with the RCPCH.

Best wishes
[redacted]

[redacted] **Great Ormond Street Hospital and UCL Great Ormond Street Institute of Child Health**

[redacted]

From: [redacted]
Sent: 01 November 2017 21:00
To: [redacted]
Cc: David Hicks; Peter Steer; [redacted]
Subject: Re: Feedback to share with RCPCH

Follow Up Flag: Follow up
Flag Status: Flagged

Thanks [redacted]

Just to confirm I sent yesterday's version to CQC.

[redacted]

Sent from my iPhone

On 1 Nov 2017, at 17:20, A[redacted]> wrote:

> Dear David
>
> Please see attached the final table of feedback for you to share with the RCPCH, incorporating the amends we discussed and the further information gathered from the division today and yesterday.
>
> This is the final iteration, following the version [redacted] was planning to share with CQC yesterday (as per email copied below).
>
> Best wishes
> [redacted]
>
> **Communications**
> **Great Ormond Street Hospital**
> [redacted]

[redacted]

From: Andrew Long
Sent: 20 November 2017 09:56
To: David Hicks
Cc: [redacted]
Subject: Re: Gastroenterology report

Follow Up Flag: Follow up
Flag Status: Flagged

Dear David/[redacted]

My responses below

Best wishes

Andrew

Sent from my iPad

On 20 Nov 2017, at 09:44, David Hicks <David.Hicks@gosh.nhs.uk> wrote:

> any comments please?
>
> Best Wishes,
> David

From: [redacted]
Sent: 20 November 2017 07:06
To: David Hicks
Subject: RE: Gastroenterology report

Good morning David
I have the final report ready for you with the reviewer signoff but just wondered whether you wanted to respond on any of the items below.
Andrew popped over last week to provide some encouragement and went off with the list but nothing has yet materialised
I appreciate you have CQC tomorrow so let me know and I can send the report and our responses to your comments immediately - it can be labelled final or 'next draft' if you have more to send but want CQC to see it tomorrow after which there might be more to comment on. Up to you.

Best wishes
[redacted]

From: [redacted]
Sent: 03 November 2017 17:25
To: 'David.Hicks@gosh.nhs.uk'
Subject: RE: Gastroenterology report

Thanks David
This is really helpfully set out and I'll work through with the review team the comments towards a formal response as swiftly as I can for you.

In the interim there are a few immediate things that popped out which I have commented on below as you might be able to provide the clarifications/evidence (or be reassured)

Pg 8, 3.8 Noted, thank you, also Pg 9 para 3.11 - we'll ensure this all ties up with cohort 1 and 2. Some of the uncertainty around numbers (including those selected for review to comply with the CQC request) was because we did not get to see [redacted] close out report which might have made a lot of the numbers and processes clearer.

I don't believe that there was a 'close out' report from [redacted]. I have the presentation that went to the Board and have been through everything in the Gastro Review folder on the K drive. I asked [redacted] and neither of them can remember a final report being delivered

> Pg 9 para 3.9 yes completely understand and we will find some suitable words

Pg 9 para 3.12 yes - referenced above - [redacted] apparently wrote a detailed report when she left the service. I did ask [redacted] for it twice but he was unable to find it, and I put a note and reminder to you and [redacted] (attached) but it has not appeared. I think it would have been seen by the Trust Board so maybe [redacted] can supply it and we can be absolutely definitive.

Ref. Answer above

P 10 para 3.15 /16- we mentioned this statement in this way because of the response it engendered in those we spoke to who had read it who did not consider it was based on the totality of cases reviewed. We saw a table providing details of the cohort 1 and 2 cases reviewed by the visiting consultants dated August 2016 which included an overview assessment of harm but did not see the extrapolation of these judgements to the statement nor the process of agreeing it within the trust/ CQC/ NHSE. That paper /board advice would be helpful to see if you could arrange for that. The definition of harm for patients who have been on long term, perhaps unnecessary treatment, is potentially complex including psychosocial as well as physical problems; the NPSA table may not fully address the specific issues and the patients selected were, we understood, relatively recently diagnosed. As those who spoke to us about it had not all seen our report they considered the 'review' cited to include the RCPCH one, or the independent panel review as these were referenced in the same external statement. We have not seen whether the 300 cases reviewed as requested by CQC were also assessed for harm and included in the statement and if so how that judgement was moderated .

These are the figures which we have been agreeing with [redacted]

P 12 para 5.1.4 Noted. we will amend wording to respect confidentiality issues. The communications strategy at the time would be very helpful to see, please.

P 13 para 5.1.6 Apologies - I understood that [redacted] was initially appointed for a one year contract term, great that he is permanent.

P.15 para 5.2.4 Thank you for the ambassador detail, that is helpful and encouraging and I expect we will include it

P.16 - The follow up independent review does not have to be conducted by the RCPCH - it is the Trust's /commissioner's choice but we would be very happy to come back on a similar independent basis if invited. This would hopefully enable the good progress being made to be confirmed as embedded, and a line drawn under historical problems. It's still a bit early to do that now but you're aware that had been our intention.

P21 para 5.3.18 Thank you for the detail about the relocation and it is great that there is tangible progress. At the time of our review visit in June-July the decision whether it was Sky or Squirrel was not clear to staff and the timescale was consequently not certain, hence our comment and recommendation, which can now perhaps be seen as a 'quick win' already achieved by the trust. .

P23 para 5.5.1 Noted but this is not unique to a specialist centre and requires good dialogue with referring clinicians and additional support from the in house social work team to actively contact colleagues in the child's home authority.

P23 para 5.5.1 Thank you - I have checked our notes from the previous review in 2015 and acknowledge the separate review which did indeed feed into the action planning form our recommendations. We can remove that statement

P24 para 5.5.5 Thank you for pointing this out. We have not seen [redacted] report; It might be helpful to see it as we can then ensure that our report stays within scope

I now have a copy of [redacted] report - are we happy to share it?

P27 para 5.6.9 and others relating to complaints - we will check these through as it is clear that numbers have dropped (but also there are fewer patients being referred). There was a predictable temporary rise during the changes in early 2016 and complaints was the main trigger for our 2015 review.

P 34 para 5.10.7 - I don't think we heard about the CNS for adolescents, apologies if we missed this - do they see many gastro patients?

I am not sure about this

P 50 survey feedback. Apologies - will remove name. Are you happy that we include the responses verbatim?

For you to agree

Obviously this just a few of the elements, but if you're able to source those additional bits of info we can get the formal reply to you

as soon as possible

With best wishes, have a good weekend

[redacted]

From: [redacted]
Sent: 03 November 2017 14:13
To: [redacted]
Subject: Gastroenterology report

Dear [redacted]

Please find our collated responses to the draft RCPCH Paediatric Gastroenterology report.

The original text from you is to the left and our comments on the right.

If I could just explain one comment I think it would be valuable.

[redacted]

I am sure we can agree on an alternative wording with the same meaning.

Other than that I feel that you will need a little time to absorb our views and that a subsequent conversation or Meeting would be invaluable.

Thank you for your help and support thus far and I look forward to hearing from you.

Best Wishes

David

Dr David Hicks Interim Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229

<image001.png><image002.jpg>

From: [redacted]
Sent: 01 December 2017 15:58
To: David Hicks
Cc: [redacted]
Subject: RE: RCPCH Gastro Network [redacted]

Dear David,

It was good to discuss these issues at the November CQRM.

Gastroenterology:
I am glad that at last you have the report from the RCPCH. I am happy having waited this long to see the final agreed version and see no benefit in seeing a draft version. As we discussed once we have the report we will have the opportunity to make some decisions and hopefully move on regarding reopening to admissions more widely as well as how the GOSH services fits in across London.

[redacted]

From: [redacted]
Sent: 02 November 2017 15:57
To: [redacted]
Subject: RCPCH Gastro Network [redacted]

Dear [redacted]

Firstly I should let you know that the RCPCH Report from their visit in July is now with us.

Whilst the Executive Summary is a document we are keen to share with anyone since it recognises the great improvements made over the last 18 months the body of the report is in parts gossipy and without evidence relying too much we believe on the comments of individuals who were interviewed by the college.

We are in discussions with RCPCH to suggest amendments whilst the college believe that they must report what was said to them.

I am happy to share the Executive Summary with you therefore at this time or if you can wait I can provide you with the final agreed version.

Secondly I have been out to meet with the [redacted] both Luton & Dunstable and Barts. Conversation centred around where GOSH finds itself in relation to matters such as RCPCH report, the television and media productions and how we wish to engage and contribute fully to the paediatric gastroenterology network for London (which is also one of the suggestions of the RCPCH draft report).

Colleagues in Luton & Dunstable [redacted] and Barts (Alastair Chesser) can feed back to you separately as to their impression of our meetings which I believe were constructive, positive and illuminating particularly around the pathways for the children we are unable to accept at this time.

[redacted]

You know [redacted] that I am always happy to speak to you and if the above does not make sense as I had intended it to then please do

not hesitate to contact me.
Best Wishes

David

Dr David Hicks Interim Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229

From: Peter Steer
Sent: 04 December 2017 11:16
To: David Hicks; Andrew Long; [redacted]
Subject: RCPCH Follow up Review
Attachments: RCPCH follow up review.pdf

Follow Up Flag: Follow up
Flag Status: Flagged

My 'scratch notes' on draft 2 for your information.

Thanks
Peter

Peter Steer
CEO

From: Andrew Long
Sent: 04 December 2017 11:57
To: Peter Steer
Cc: David Hicks; [redacted]
Subject: Re: RCPCH Follow up Review

Thanks Peter

Andrew

Sent from my iPhone

On 4 Dec 2017, at 11:15, Peter Steer <Peter.Steer@gosh.nhs.uk> wrote:

> My 'scratch notes' on draft 2 for your information.
>
> Thanks
> Peter
>
> Peter Steer
> CEO
> <RCPCH follow up review.pdf>

Great Ormond Street Hospital for Children NHS Foundation Trust

David Harris
Sent by email: David.Harris@cqc.org.uk

Great Ormond Street
London WC1N 3JH

T: +44 (0)20 7405 9200
www.gosh.nhs.uk

1 December 2017

Dear David

I am writing to follow up on the issues raised at the Gastroenterology panel meeting on 24 November and the subsequent email from you on 29 November, where you state:

"My understanding was that the Trust was saying at the meeting that there was harm but the Trust had decided it did not meet the DoC threshold and therefore there was no statutory requirement to follow the regulation. The Trust was unable to state or provide documentation as to how that conclusion was arrived at and you would need to speak to Dr Vinod Diwakar for clarification.

"Our panel's view was that there did appear to be harm within the formal definition and that the DoC regulations should have been, but were not followed."

We have reviewed the documentation recording the Trust's actions during this time and in the context of the Duty of Candour, have outlined the extensive work we initiated and conducted with yourselves and external national and international experts in the field to assess harm to patients.

Chronology of the Review

I attach a document (Attachment 1) that we have shared with you previously (in our letter to [redacted] on 31 July 2017 – sent to [redacted] by email) which outlines a chronology of events. As you know, the investigation into this area of the Gastroenterology service was initiated by GOSH. GOSH acted upon its conclusions, firstly by commissioning the Clinician Report and then by commissioning other experts to review the treatment of other patients:

Stage One: RCPCH Service Review - August 2015
In 2015 GOSH commissioned a Service Review by the RCPCH of its Gastroenterology service. It was carried out in May - June 2015 and a report was produced, dated August 2015. Among a number of broader issues, the report did raise concerns over potential over-diagnosis and over-treatment (raised in a letter from the RCPCH, dated 22 July 2015). The RCPCH Service Review did not reach any final conclusions rather it urged that the relevant matters be further investigated.

Stage Two: Clinician Report - February 2016
GOSH took the concerns raised by the RCPCH extremely seriously and consequently its Medical Director at the time (Dr Vinod Diwakar) commissioned a Clinician Report to be produced by 5 external Panel members ("the Panel"). The Panel acted very quickly and produced a report, the Clinician Report, on 5 February 2016.

The Panel was instructed to review the treatment of a sample of 40 patients. It reviewed the treatment of patients and after reviewing the case notes of 18 patients it concluded that further action was required, based on serious concerns caused by the case notes of 14 of these 18 patients. These indicated that there were grounds for investigating in further detail.

Stage Three (**Reviews by third party experts, Spring & Summer 2016)**
In response to the Clinician Report and in consultation with CQC, NHSI and NHSE, GOSH commissioned independent paediatric gastroenterologists to produce in-depth case note reviews of the treatment of the 14 specific cases highlighted by the Panel. T[redacted] Independent histopathology reviews were also conducted for each of the 14.

Additionally, all 14 patients' care management was reviewed face-to-face in clinic by an external gastroenterologist.

GOSH also commissioned external consultant gastroenterologists to review in clinic the care management of:

i) 42 patients on either immunosuppressants or steroid therapy without a diagnosis that unquestionably required such treatment (i.e. children without IBD or post bone marrow transplant or dermatological conditions on immune-modulation), ensuring all children on drug treatments that required consideration were included
ii) a random sample of 20 per cent of all patients within the service.

Stage Four: RCPCH Returns for an invited follow-up review – July 2017
GOSH commissioned the RCPCH to carry out a further follow-up review, to ensure that the service to patients is of a consistent high quality. A copy of the final report will be sent to you shortly.

In addition to the above actions taken by the Trust to review and assess levels of harm, CQC are also aware from meetings attended by Professor Baker and the documents requested and sent that:

- GOSH has implemented stronger leadership and more robust governance across the service;
- Protocols are being revised to streamline decision-making and improve care;
- GOSH has produced externally peer reviewed guidelines and protocols for gastroenterology conditions – except Eosinophilic Lower Gastroenterology Disease and complex food allergies, where there is no consensus regarding treatment. In regard to these conditions, GOSH does not routinely accept patients suspected of having these conditions;
- All treatment plans are agreed and signed-off by a multi-disciplinary team ("MDT") meeting and patients with perplexing symptoms or significant psychosocial factors are discussed and treatment agreed at a complex care MDT meeting;
- GOSH limited referrals into the department to only those patients who were:
  o Referrals from a paediatric gastroenterologist at another tertiary trust with suspected IBD in children under the age of 6;
  o Referrals from a paediatric gastroenterologist at another tertiary trust for chronic intestinal pseudo-obstruction;
  o Referrals from a paediatric gastroenterologist at another tertiary trust for patients with intestinal failure;
  o Patients with autoimmune disease leading to bone marrow transplant;
  o Existing gastroenterology patients under GOSH.
- The Trust Board has been fully informed throughout the review process of the findings and have agreed the actions being taken.

<u>Assessment of harm</u>

The chronology above highlights the seriousness with which we undertook our duty to assess harm and protect patients. But we believe that it is essential for the CQC to be reminded of the complexities of this clinical area (as acknowledged by Professor Baker – please see below):

- EGID is one of the most rare and complex conditions in the field of gastroenterology. There is no national or international consensus about how it ought to be treated or the best way to manage patients (acknowledged by the external expert reviewers). Nor was any consensus been reached by the reviewers of GOSH treatment as to what constituted over-treatment of patients diagnosed with EGID.
- As a tertiary and quaternary referral centre, only the most complex of cases are referred to GOSH who, by their very nature, constitute a unique sub-set of patients who manifest persistent and perplexing problems in one of the most complex areas of gastroenterology. These patients' cases are complex either by nature of their existing co-morbidity or because of the severity or chronicity of their gastrointestinal presentation. Many have been thoroughly investigated at other centres and may well have a combination of functional and social factors, and cover a wide range of children of varying ages and disabilities. Previous work has shown that the coding complexity of these patients are at significant variance with other peer tertiary gastroenterology providers across the country.

In this context, the assessment of harm is extremely complicated. It requires careful assessment from external clinicians who are expert in this field so as to ensure independence and application of the necessary understanding of this complex group of patients.

The assessment of harm applied by the Trust was based upon the in-depth case reviews of the treatment of the 14 cases (cohort 1) and the review of clinical care by the external clinicians of the cohort 1 patients and the 42 patients (cohort 2).

I have attached the terms of reference applied by the case reviewers for the 14 patients as evidence that moderate, severe and prolonged psychological harm was requested to be assessed (Attachment 2). On the request of Professor Baker, we sent him all of the 14 case review reports on 12 August 2016 (5) and 2nd September 2016 (9).

Patients in cohort 2 (the 42 patients) were also reviewed face-to-face in clinic by an external gastroenterologist and the level of harm considered and assessed during this consultation.

Attachment 3 documents the findings of these reviews for each patient. The findings from these reviews were risk assessed to determine whether there was moderate, severe or prolonged psychological harm.

In summary, the entire review process found that:

- In a small number of cases children have received unnecessary endoscopies and exclusion diets, and drug treatments have been questioned.
- No concerns were raised in relation to the random sample of 20% of the service's wider cohort of patients.
- No evidence of serious or significant physical harm caused to patients was found in the course of an extensive and in-depth review process.
- No consensus was reached in regard to whether over-treatment took place or not.
- Some children have missed some schooling as a result of their treatment.
- Reviewers did find that there was insufficient consideration of psychosocial factors when treating some patients. To address this we have increased the psychological support delivered to patients in the service, to ensure all children receive holistic care tailored to their individual needs. This has included recruiting a dedicated psychologist to support the service.

In the summary document sent to Professor Baker on 12 August 2016 (Attachment 4) the Trust states that the external consultants who saw these patients concluded that none of these patients suffered moderate or severe physical harm. The document does state that 4 patients have some evidence of potential psychosocial harm and that "*conclusions on the 4 patients with potential prolonged psychosocial harm will be clarified and the medical director will meet with these families informing and conversing with patients, families and clinicians in an open and transparent manner*."

We understand that you may have concerns about the wording in Attachment 3 with phrases such as *'psychological welfare affected'* and *'significant psychosocial impact'*. Our understanding is that these are summary phrases used on a working document for managers in assessing the level of harm in patients.

We have spoken with Dr Vinod Diwakar, former medical director of the trust, who was managing this process at the time. His recollection is that none of the patients identified in Attachment 4 suffered 'prolonged psychological harm' which was caused primarily by the actions of our clinicians. (It should be noted that Dr Diwakar left the trust at the end of December 2016 and has not re-visited the review records since that time.)

Dr Diwakar has explained that in some cases there were complex safeguarding issues relating to fabricated and induced illness. Decisions about what to share with carers would have been dealt with through a full biopsychosocial assessment of all the issues by a multiagency, multidisciplinary team involving both GOSH and local clinicians. GOSH's guiding principle throughout would have been to safeguard the best interests of the child. It would not have been appropriate to record detailed personal clinical, psychological or social data relating to individual patients in a summary management record.

We believe that we have been open and transparent with all patients and indeed Dr Diwakar assured the Board that the Duty of Candour had been complied with. Recognising the importance of producing further evidence to this, we propose as a next step to review the case notes and safeguarding records for 5 patients (patients A,E,R,A1 and I9 in Attachment 3). We will keep you informed of the progress of this work.

Duty of Candour

The Trust is committed to its duties under Regulation 20 (Duty of Candour) of the Health and Social Care Act. The general statutory duty (regulation 20(1)) is to 'act in an open and transparent' way. The Trust has kept the Royal College of Paediatrics and Child Health fully informed. The Trust communicated regularly with NHS England and disclosed all documents including correspondence covering the various components of the review to the Care Quality Commission.

There is the specific duty (20(2)) to individual patients to formally notify them when an incident has occurred which has resulted, or could result in the future, in harm above a certain threshold. Families with children whose care we were asking to be externally reviewed were informed that the Trust was conducting a review of the Gastroenterology service which included a review of how we manage their care. We told them that we were concerned that we have identified some differences in approaches to the management of complex and difficult to diagnose gastroenterology conditions. We told them specifically that concerns had been raised about an unusual concentration of rare and uncommon diagnoses and that, in some cases, we were concerned that more endoscopies were being carried out than might be required and more powerful drugs used than by some other services in the UK. We were very clear that to ensure we were operating a safe effective service that we wanted the management of their child to be reviewed by a consultant from a specialist hospital in another part of the UK. (Please note - you have seen these template letters.)

We believe that we undertook a comprehensive communication process throughout the review with our patients, parents and carers, referrers and regulators as well as with the general public. Despite the findings of the external reviewers that moderate and severe harm was not evident, there was a finding of unnecessary endoscopies and exclusion diets, and drug treatments were questioned. On the basis of this finding, we established open and transparent communication channels with the patients and parents affected as follows:

- Initially, families whose children were being reviewed were invited to have a further discussion with our PALS and the Divisional Director of the service. They were subsequently seen by an independent external Paediatric Gastroenterologist in clinic and changes to assessment and treatment were agreed and communicated in the appointment.
- Families whose children's case notes were reviewed in detail (cohort 1) were offered appointments to discuss the reports. Three families took up the offer and were told directly whether experts thought that their child had received treatment that differed from the practice of other Gastroenterologists in the UK.
- Every patient under the Gastroenterology service was informed of the outcomes of the broader review.
- A Listening Event was held on 15 July 2017. All patients and parents who were informed of the outcome of the external review in December 2016 were invited to attend the event. Twenty-two parents and siblings plus 6 patients (aged 6 to 15 years) attended the event, and there were 20 GOSH staff present on the day. External facilitators (Kantar Public) were used to explore four themes: communication of information, the "emotional journey", facilities and relationships/interactions with staff. The gastroenterology team was well represented at the event. A report and recommendations was produced which is being used to shape improvement work within the department. I attach a copy of the findings of this report for your information (Attachment 5).

Your initial judgements around the Duty of Candour

At our meeting of 24 November and in your subsequent email to me, you have not presented any new or additional evidence to support your current judgement about our compliance with the Duty of Candour. We are concerned by this as we believe that the external reviews we have instigated (conducted by international and national experts) and our extensive communications with patients and parents demonstrates that we were committed to ensuring that we carefully assessed whether harm had been caused by the actions of GOSH clinicians. We have also kept the CQC (Professor Ted Baker and Nicola Wise), NHS Improvement and NHS England informed of our actions and findings throughout the review process.

At the meeting on 24 November you indicated that the CQC had 'moved on' from its previous involvement with the GOSH Gastroenterology Review. We are disappointed and concerned by this as Professor Baker (as a senior representative of the CQC) sat around the table with the Trust, NHSI and NHSE, asked searching questions on our handling of the review and of our application of the DoC and received letters attaching numerous documents to assure him and your organisation of the process followed. I have attached copies of these letters sent by email and courier (Attachments 6 and 7).

We understand and accept that it is the Trust's responsibility to maintain compliance with the DoC. However, at no time was the Trust advised by the CQC that the process we followed, the judgements reached and the approach to our application of the DoC was problematic or at risk of non-compliance. From this, we do not believe it is inappropriate for us to have reached the conclusion that your organisation was assured by our actions and that our approach was in line with the requirements under the Duty of Candour.

This view was supported by the letter received from Professor Baker on 26 October 2016 which stated:

"Having reviewed the extensive information that you provided; both in paper format and also via your recent presentation material, we do not require any further information from you at this stage. It is clear from the information provided that this is a complex clinical area, with levels of ambiguity amongst this professional field, with a spectrum of views and evidence as to the treatments.

"We note the extent to which you have sought both national and international review of these cases and thank you for your open approach in relation to this matter."

We believe that we have conducted a comprehensive review of our Gastroenterology service. In light of the complexities of the patients treated and the lack of international guidelines or consensus on EGID, we have sought independent, expert advice throughout the review and maintained an open and transparent dialogue with our patients, parents, carers, referrers, commissioner and regulators.

Our approach to informing and supporting our patients, parents and carers has not been rigidly defined just by the outcome of the assessment of harm. We have carefully considered the findings from the external case reviews and consultants. Despite there being no finding of moderate or severe harm to patients, we have accepted the findings that patients were over-treated and in line with our general duty under the Duty of Candour, ensured that patient, parents and carers have been kept informed, and offered opportunities to receive information about the findings of the review in relation to their care. We have also worked hard to learn from mistakes made, though restructuring the gastroenterology team, producing externally peer reviewed guidelines and protocols for gastroenterology conditions and holding a listening event with our patients, parents, carers and staff.

I hope this provides you with the evidence and assurance you are seeking in this complex area. I will keep you informed of the independent review of the four gastroenterology patients highlighted above.

Yours sincerely

[redacted]
[redacted]**y**

Gastro Investigation Status Report

Progress in the last week:

- Letter sent to Vin for clarification on his March 2016 confidential document
- Investigated request to use five-digit codes to establish EC / EGID numbers at GOSH – not possible in England
- Response to [redacted] drafted
- Received draft response from [redacted] to the BIJ on [redacted]
- Meeting held on managing internal and public comms at time of broadcast

Next steps:

- Send letter to Amazing
- Chase Vin for response
- Advise [redacted]on his response
- Draft letter to ITV commissioners (and maybe head of BIJ) expressing concerns about the approach being taken
- Investigate responses to questions below

Current outstanding questions:

1. Please could you tell me what the Research Directorate is, and please could we have a copy of their review into the informed consent for trials of immune suppressing agents in children without IBD in GOSH gastro?

   I understand from The Urgent Actions Report sent to NHSE from GOSH in March 2016, (you have a copy) that trials were reallocated to other principle and chief investigators, and publication and presentation of papers was held back.

   What is the current status on this?

2. Any news on the Royal College's latest report?

3. I saw this come through on someone else's FOI yesterday. Is the increase due to the gastro review?
   https://www.whatdotheyknow.com/request/325599/response/808005/attach/3/FOIRQ3124.pdf?cookie_passthrough=1

   If so,
   - is it over and above the additional Gastro Review costs reported in GOSH's Annual Reports?
   - why is finding numbers and information on the scale of the problem now so difficult for GOSH?

Month	Agency Spend
Apr-15	£50,008
May-15	£232,707
Jun-15	£109,111
Jul-15	£258,767
Aug-15	£159,215
Sep-15	£170,765
Oct-15	£367,623
Nov-15	£391,148
Dec-15	£595,165
Jan-16	£532,337
Feb-16	£593,086
Mar-16	£1,068,587
Total	£4,650,763

Please Note: During 2015/16 the Trust was required to source additional temporary staff to validate referral to treatment information which resulted in an increase in expenditure on agency staff. The Trust maintained full compliance with the Monitor published rates for agency staff during 2015/16.

4. we have uncovered a conflict between the information provided to us and that given to NHSEngland with regards to the numbers of "higher risk" children who were reviewed. We do not understand how and why a cohort of 345 "higher risk" patients, who NHSE was told in March 2016 would be prioritised for review, was reduced to just 42 patients later that month.

We've previously highlighted that at least one patient on immunosuppressants [redacted] was not reviewed, indicating GOSH's claim that "all children on drug treatment that required consideration" is not accurate.

From the data we now have it appears [redacted] was just one of 303 "higher risk" patients not reviewed, or not prioritised for review.

I'd be grateful if you could explain, as soon as possible, how the 345 came to be reduced to 42.

[redacted]

From: [redacted]
Sent: 02 October 2017 19:28
To: Peter Steer; [redacted] David Hicks; Andrew Long; [redacted]
[redacted]
Cc: [redacted]
Subject: Gastro Update
Attachments: Gastro Investigation Status Report.docx; H[redacted]docx

Follow Up Flag: Follow up
Flag Status: Flagged

Hi All

Ahead of tomorrow's meeting, I wanted to share an update on where we are with the gastro investigation and a proposed draft letter to [redacted]at Amazing (see attached for both).

I would like to answer the BIJ response but this is complicated as we need guidance from Vin on this.

See you tomorrow morning
Best
[redacted]

[redacted]
[redacted]
Great Ormond Street Hospital and Children's Charity

[redacted]
[redacted]

[redacted]

From: Elizabeth Jackson
Sent: 22 August 2017 14:30
To: David Hicks
Subject: RE: Gastro Review

Follow Up Flag: Follow up
Flag Status: Flagged

Do we need to ask [redacted] to send current benchmarking data from ICN ?

Liz

From: David Hicks
Sent: 22 August 2017 13:28
To: Elizabeth Jackson
Subject: FW: Gastro Review

FYI,

Best Wishes,
David

From: [redacted]
Sent: 19 August 2017 13:11
To: David Hicks
Subject: RE: Gastro Review

Dear David
Thank you for your note - I'll respond as best I can….

1. This was just to emphasise that we didn't look at casenotes, and we didn't see any comparative work on outcomes - although I presume you subscribe to Civil-eyes and ICN we didn't see the data driving any quality initiatives or similar like the surgeons do. [redacted] often explains that a service needs to monitor three things - System Process and Outcomes - we always look at the first two and sometimes on review the data about the third one is harder to evidence. But that's OK. If you have any benchmark material I'd be happy to include it but suspect that might come once the networks are set up as we did feel that UK comparisons are legitimate - not everything they are doing is so rare .
2. The further review was because although things seem to be safe and controlled at the moment, many interviewees were unsure whether it was sustainable or if with increased activity and possible relaxing of the MDT the consultants might revert to old habits. A quick check in 12-18 months time should confirm whether the change is embedded, but we are not suggesting that the doctors should feel they are still working under scrutiny.
3. We have made lots of comments in the report on the strength of the current clinical leadership, the openness and trust that has been established with the team in recent months and the encouragement for this to continue in order to support [redacted] -- hence the proposal for a chair or similar individual with external gravitas to build the network and reframe the perception of the unit so it doesn't all fall on your successor !
4. ICN is mentioned in the report - we have not seen any benchmark data (nothing recent on my netsearch not the GOSH website) and interestingly nobody except the IBD consultants mentioned it at all. I guess it's

more relevant to an international audience? We have however strengthened the recommendation to include rolling out the principles to other divisions and teams.

The report's with the reviewers (although [redacted] is up a mountain in France) then hopefully goes to QA next week - they have 5 working days to respond so depending upon what they all say we should be on target to get it to you in draft at the end of August/first week in September.

We have not seen any of the board papers around the management of the casenote review, etc as that's really history and I wasn't planning to go into detail on that in a publishable report, but let me know if you think we need that for completeness. I think in our conversations we've covered the areas of ongoing concern that were raised with us. Two people have agreed to send me specific details which I will pass on and hopefully they will correlate with the list [redacted] is preparing.

With best wishes

[redacted]

[redacted]
[redacted]
RCPCH *Leading the Way in Child Health*
5-11 Theobald's Road London WC1X 8SH
[redacted]
[redacted]

From: [redacted]
Sent: 17 August 2017 16:46
To: [redacted]
Subject: Gastro Review

Dear [redacted]

Thank you for our recent telephone conversation.

Your information and advice is as ever much appreciated

I have reviewed the draft of the invited review you have kindly shared with me and I was wondering if I could clarify and suggest the addition of a couple of items please.

These are under the heading of progress

1. The service improvement is noted but the team is unable to comment on outcomes. I assume this is because a more in depth case note review in this area would be required and that the team did not have the time and resource to do this.
2. The penultimate bullet points suggests that there should be further clinical review of cases 12 months after the lifting of case restrictions which I think will lead the team to view that the team is still 'under review'. Whist l I accept that the intention is to note further progress and that I have no objection of another look at the service in the time period suggested, I was the one that you return for the most recent visit, then I wonder if it could be clarified that this is a suggestion rather than a requirement.
3. If there could be some comment in the paper of the quality of the clinical leadership provided, even if only to compare with that observed in initial review, then this would be appreciated
4. As I discussed with you on the phone the team's membership of the 'improving care now initiative' and out excellent position through benchmarking could be recognised and this would be appreciated.

Thank you for your anticipated help and comments on this.

Best Wishes

David

Dr David Hicks Interim Executive Medical Director

Level 3 | Paul O'Gorman Building | Great Ormond Street Children's Hospital NHS Foundation Trust | London | WC1N 3JH
Tel: 020 7405 9200 ext 5257| Fax: 020 7813 8229

[redacted]

From: [redacted]
Sent: 28 June 2017 12:43
To: Andrew Long; [redacted]
Cc: David Hicks
Subject: [redacted]
Attachments: [redacted] Right of Reply 270616 .pdf; [redacted] Right of Reply 280616.pdf

Follow Up Flag: Follow up
Flag Status: Flagged

Dear Andrew [redacted]

Attached are the rights of reply that have been drafted [redacted] regarding the forthcoming ITV documentary about our gastroenterology department. I believe David has briefed Andrew on this.

[redacted]

I am very concerned about what would be the best way to share these with them – and am aware they need to see them sooner rather than later.

I am on leave tomorrow and Friday (unfortunately) but have some availability this afternoon.

Very happy to discuss.

Best wishes

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

From: David Hicks
Sent: 11 July 2017 11:33
To: Andrew Long
Subject: RE: Gastro Documentary Deadlines

Follow Up Flag: Follow up
Flag Status: Flagged

thank you Andrew.
Appreciated,

Best Wishes,
David

From: Andrew Long
Sent: 11 July 2017 11:32
To: David Hicks
Subject: FW: Gastro Documentary Deadlines

Dear David

These are the people that I think you should contact:

[redacted]

Dr Alistair Chesser, Medical Director at Barts and the London (020 7377 7000). [redacted] Dr Sandhia Naik [redacted] Again, you could take the line that the MD's have moved on however Dr Naik has raised major concerns in a public documentary and since we cannot trace any correspondence between them and ourselves we just wished to make sure that their lines of governance and the need to inform the CQC/GMC have been complied with fully.

[redacted]

We might think about Southampton [redacted] however I would leave that for the current time until our Comms team have spoken to them.

Let me know if you need any more info!

BWs

Andrew

Dr Andrew Long
Responsible Officer
Consultant Paediatrician and Associate Medical Director
Great Ormond Street Hospital
55 Great Ormond Street
London WC1N 3JH

Tel: 020 7405 9200 ext 1294/5257
Email: andrew.long@gosh.nhs.uk

[redacted]

Dear All

Please see below the confirmations on deadline extensions, as requested.

Best wishes
[redacted]

[redacted]

[redacted]

On 10 Jul 2017, at 4:02 pm, [redacted] > wrote:

Hi [redacted]
Yes my understanding was that the response was due back a week after the originally agreed date of 11th July - ie the 18th.
We did give that deadline in our second letter to you [redacted]
Best wishes
[redacted]

[redacted]
The Bureau of Investigative Journalism
Acorn House
314-320 Gray's Inn Road
London WC1X 8DP
[redacted]

On 10 July 2017 at 11:41, [redacted] > wrote:

> Dear All
>
> Please can I request written confirmation from you that we were given a one-week extension of our deadline on right to reply – ie Tuesday 18 July?
>
> I discussed this with both [redacted] on the phone but it would be helpful to have this in writing.

Please can you also confirm that this applies to all six right of replies submitted, [redacted]

Best wishes

[redacted]

[redacted]

If you have received this communication in error please notify us immediately by return email, and delete this email and all attachments immediately. This email is for the exclusive use of the intended recipient and may contain information that is privileged, confidential and exempt from disclosure under applicable law. If you are not the intended recipient please note that any form of disclosure, distribution, copying or use of this communication or the information in it or any attachments is strictly prohibited and may be unlawful. The views or opinions are solely those of the author of this email, and do not represent those of the Great Ormond Street Hospital Children's Charity unless specifically stated.

[redacted]

From: Cymbeline Moore
Sent: 13 April 2018 13:01
To: Peter Steer; Anna Ferrant; [redacted] Matthew Shaw; Andrew Long
Cc: [redacted]
Subject: CQC full copy to ITV

Follow Up Flag: Follow up
Flag Status: Flagged

Dear all

Please find below the full copy of the letter Ted Baker send to ITV.

BW

Cym

From: [redacted]
Sent: 12 April 2018 16:58
To: [redacted]
Subject: RE: ITV Exposure on EGID at GOSH

Hello [redacted]

Thanks very much for your letter. Please find below a response from our Chief Inspector of Hospitals, Prof Ted Baker.

If you need anything else, please let me know.

All the best,

[redacted]

[redacted]
Care Quality Commission
[redacted]
Email: [redacted]

****

Thursday 12 April 2018

Dear [redacted]

Thank you for your letter dated 30 March 2018 and for giving the Care Quality Commission (CQC) the opportunity to respond to the allegations against Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), which will be subject to your ITV Exposure documentary to be broadcast on 18 April 2018.

To begin with, I think it will helpful to outline CQC's role as the quality regulator of health and adult social care in England. Our purpose is to ensure that people receive safe, high quality and compassionate care and to encourage services to improve. There are a number of ways that we do this, including through our monitoring of services, our inspections, our enforcement powers, and by using our independent voice.
Our regulation of providers is underpinned by the 'fundamental standards', which are set in regulations (the Health and Social Care Act 2008 {Regulated Activities} Regulations 2014). When we inspect providers we assess them against these regulations using five tests of quality. We determine whether services are safe, effective, caring, responsive and well-led.

Providers have a legal responsibility to ensure they are open and transparent with patients and families and carers about their care and treatment, including when something goes wrong. In cases of serious harm in particular, they are required to provide support and apologise: this is called the 'duty of candour' requirement. Providers must assure CQC and others that they are meeting this regulation appropriately and CQC ensures that they do so through its monitoring and inspection work. I encourage you to read the information on our website about this: http://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-20-duty-candour.

We encourage providers to review their performance using our regulations as a guide. How well they conduct such a review is an indication of how well led they are. When providers commission external reviews in response to concerns within their services, CQC will maintain an interest in these activities as part of its monitoring activities and it will expect to be kept informed on key findings and of the implementation of any recommendations; however, CQC does not supervise or direct this process. Terms of reference for clinical reviews are a matter for agreement between the trust and the reviewer, which in the scenario that you have detailed in your letter, would be a matter been GOSH and the Royal College of Paediatrics and Child Health. When we inspect providers we assess how well the review has been conducted and whether learning and improvement have taken place.

With regards to CQC's regulation of GOSH, CQC last inspected this provider in January 2018 and published the report on this on 6 April 2018.
This inspection assessed how 'well-led' the trust was and inspected two of its core services: surgery and its outpatient department. These two core services had been selected because CQC's previous inspection in April and May 2015 had rated both of them as Requires Improvement.

CQC's inspection in January 2018 led GOSH's surgery care being rated as Requires Improvement again and its outpatient care being rated as Good.

CQC's inspection of how 'well-led' GOSH, which included a review of its duty of candour, led to the trust being rated as Requires Improvement.
I encourage you to read this report, including the accompanying evidence appendix, which can be found on our website: http://www.cqc.org.uk/provider/RP4/reports

You have mentioned that your documentary will focus on GOSH's gastroenterology department and specifically, on how GOSH has cared for patients with confirmed or suspected eosinophilic gastrointestinal disease (EGID), including the reviews GOSH commissioned on this and its communication with patients and their families.

As the quality regulator, CQC has been liaising with GOSH on its progress with implementing the recommendations from these, as part of its wider monitoring of the trust. As part of our regulatory work, we have emphasised the importance of being open and honest to patients and their families or carers.
However and for the reasons explained above, CQC has not been involved in defining "the scope of the review and their [the trust's] approach to duty of candour", as you have stated incorrectly in your letter. Our assessment of how well-led GOSH is in our recent inspection report includes an assessment of this review, as well as other evidence.

While there is no regulatory requirement for CQC to approve or assess communications issued by healthcare providers, if we detect an apparent error or deliberate intention from a provider to misinform its patients or other groups, then we would raise this with the provider and seek clarification, especially given their 'duty of candour'.

In December 2016 GOSH assured us that it had not identified long-term harm and had fully complied with its obligations under the duty of candour requirement. We have now fully investigated the alleged breach of the duty of candour requirement, which you have referred to in your letter. This included interviews with senior staff at the trust and a detailed review of the case notes of patients who had been identified as coming to harm.

Following this, we have not found GOSH to be in breach of the duty of candour requirement, as stated in the regulation. Although we did not find a breach of the duty of candour, our latest inspection report includes judgements and observations about how GOSH was found to apply learning from incidents and reviews, how there were missed opportunities to engage with local stakeholders and have open and positive relationships with them, and how it was found to be defensive when challenged on performance and safety.

We continue to monitor GOSH as part of our wider regulation of this trust and to take action in the best interests of patients and their families or carers. This includes ensuring that the trust applies its learnings from its reviews on its gastroenterology care and addresses the concerns that we identified on our most recent inspection of its services.

If anyone has concerns about the care provided by GOSH – or indeed any provider of healthcare in England – in the lead up to or following the broadcast of your programme, I encourage you to refer them to CQC so that these can be passed on to the relevant inspection team. Details on how to contact CQC are available on our website: http://www.cqc.org.uk/contact-us.

I trust that you will find this a helpful response to your letter. If you have any further questions or additional information to share, I advise you to make these known via our media team in the first instance.

Yours sincerely,

Professor Edward Baker
Chief Inspector of Hospitals
Care Quality Commission

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From: [redacted]
Sent: 10 April 2018 10:10
To: [redacted]
Subject: RE: ITV Exposure on EGID at GOSH

Please be advised that for scheduling reasons the documentary will now transmit on 18th April 2018.

We will still need any response you wish to make by the 12th April.

Many thanks

[redacted]

Amazing Productions
[redacted]
[redacted]

[redacted]
[redacted]
[redacted]
[redacted]

From: [redacted]
Sent: 30 March 2018 13:48
To: [redacted]
Subject: ITV Exposure on EGID at GOSH
Importance: High

Please see attached an outline of the programme we are making and an invitation for the CQC to respond by the 12th April.

Many thanks

[redacted]