Supplemental Digital Data 2: Qualitative Analysis of Focus groups; Part 1: Analysis of Focus Groups #1 and #2 (adult focus groups).

Recommended Content for Transition Letters between Pediatric and Adult Gastrointestinal Care

Content Analysis Report

Prepared by Dennis Newhook, CRU Qualitative Analyst, September 5, 2019

Dataset: Transcripts from two separate focus groups of adult Gastroenterologists: Ottawa group (n=5); Montreal (n=6)

Guiding Research Question(s): 1) What information is required in a letter when transferring a pediatric patient to adult care

Report Contents: Three summary tables (1. Possible letter content, 2. Appearance/functionality, 3. Other considerations) including exemplar participant quotes where useful. *Note: cells marked by an asterisk (*) indicate content that was discussed by multiple participants or was emphasized as being absolutely necessary.*

Supplemental Digital Data 2, Part 1, Table 1. Possible letter content prioritized by importance *(i.e., must include and could include)*

Content Area	Important (*"must include"* or *"bare minimum"*)	Possible (*"could include"* or *"nice to have" or "supplemental"*)	Exemplar Quotes	Notes
Demographics	Age			Little discussion as to what should be included in demographics (other than age)
Diagnosis	*Date (year) of diagnosis			These items came up a lot and were discussed in both focus groups
	*Disease type			
	*Localisation			
	*Phenotype			
		Montreal classification		
		Onset		
	Initial presentation at diagnosis	Initial presentation at diagnosis	1.1. *"Perhaps a brief overview of the initial symptoms at presentation. Because sometimes it is nice to know when there is a relapse, what it was initially."* 1.2. *"how the disease presented initially"*	Disagreement as to importance of receiving the initial symptoms at diagnosis in the transition letter
Therapeutic history: Medication	*Name & dose	Dose		
	*Dates/timing (start and ending)			Starting dose and tapering also mentioned as not important
	*Reasons for stopping (e.g., side effects, compliance)			This came up several times in both transcripts
	*Complications or side effects		1.3. *"So complications like metabolic, did they experience adrenal deficiency, delayed secondary growth, osteoporosis"* *"Were there side effects? What were those side effects? And again often, they are not able to provide the answers themselves."*	Complications were discussed in reference to treatments but also in relation to the disease itself. It was not always clear.
	Exposure (number of steroids, number of courses)			
	Compliance		1.4. *"Something about the compliance, like sometimes it stopped because they didn't show up for their appointments or they weren't taking the injections, especially for this age group, it's important to know if there was issues leading to*	Some disagreement as to how important compliance issues are to the transition letter vs being communicated in supplemental material.

			that, when you see them the first time so you can be more aggressive in your interaction." 1.5. *"Like, to me, it's also helpful to know the compliance stuff…. But if they've had compliance issues in the past for medications"* 1.6 *"What I need to know is more like medication compliance… So, for me, compliance is a big thing if you already know."* 1.7. "*To me, compliance is the biggest thing. If they've had issues, it's nice to know."* 1.8. *"I mean, there are lots of circumstances. Sometimes it's financial, for instance. They can't afford their drugs, and so that's the issue, is the problem why they're not well-controlled or whatever. You're going to put that in."*	
Therapeutic history: Surgeries	*Type and dates/timing	Details of procedures	1.9. *"Well, if you're going to put surgery…"ileocecal resection with 30 centimeters of ileum removed." And then, if you are putting down the location of the disease, so if it's colonic involvement to say what percentage of the bowel is involved. So, that way, if there's 2 percent of colon involved, I know down the road I'm not going to have to do surveillance colonoscopies."*	
Imaging Scopes	All endoscopes		1.10. *"…it is important that I [receive] the largest range possible. A range of the most details possible so that I can see the progression… so for me, all the endoscopes if that is possible."*	Mixed opinions on usefulness of all scopes. Opinions ranged from all, to the relevant ones, to first and last. Emphasis was on endoscopes but colonoscopy was also mentioned.
	First and last endoscopy		1.11. *"If one led to a surgery, it would be worth knowing"*	
	First and last **colonoscopy**			
Imaging Radiology	Most recent MRI	MRIs that show stenosis	1.12. *"At least the last exam that was done so that we know where we are starting from. Did it fluctuate over time, over three MRI's – I don't need to know that."*	
	All abdominal x-rays			Possibly a joke (laughter indicated in the transcript)

		Bone density		
		CT-scan		
Pathology reports	Pathology reports		1.13. *"The pathology reports also; you want to see the variations in the disease too"* 1.14. *"Because it is easier in ulcerating colitis for example, versus Crohn's. So if we said' well it is pancolitis and mayo 3, it took four words and we already have all the information. Versus Crohn's – there is an ileal presentation and I describe it then, doing a SES-CD becomes more complex. That's about it."* 1.15. *"Ideally, if there are deep ulcers and stenosis, it would fun it they told us. Because that relevant. Otherwise, just little [inaudible 0:27:34. 9] we don't care, it is active."* 1.16. *"It's critically important that we have the path…"*	
Complications	Severe or significant complications			Complications were discussed in relation to interventions (e.g., meds) but also to the disease itself. Not always clarified in the text.
	All complication history		1.17. *"He had viral meningitis, pneumonia, something that is going to prevent us from…."*	
Current status of patient "snapshot"	Patient's condition at time letter was written/last consultation		1.18. *So, the last snapshot of what the patient was like at last consultation. Both clinical and biochemical presentation* 1.19. *"how the patient is doing now"* 1.20. *"What is important in all of this and we are saying it again, is that one of the essential roles of a letter, is that it allows for triage the relative urgency or not of seeing this young patient. So we need to know his condition at the time the letter was written."*	Purpose of which is to triage
	Date of last (most recent) consultation			
Other medical history/comorbidities	*Allergies	E.g., Allergies, Ankylosing spondylitis, and therapies, history of C. Diff.		Some disagreement regarding the importance of allergies
Other	Priority rating (for triage)			

		Date for initial consult	1.21. *"A check-box to say at least it's your request that you want them to be seen within a certain period of time."*	
		Psychosocial description (cognitive disorders, comments on personality, whether patient lives independently, school status, employment status)	1.22. *"One detail that I think is important, well, not important to put in here, so that you are not overloading the information. We are just talking, but it is to know what I expect as an individual. Because often, they do not come alone, they come with their parents most often. And how many young people, often young men, they are just passive, they do not talk. And you engage the discussion with the parents. But I think that this is important, I am just mentioning it. Perhaps a bit on the patient's personality. A young extrovert who answers questions correctly and who is independent."* 1.23. *"Not only the psychological elements, but his progression, evolution under various therapies, his fears, apprehensions. In short, everything that is going to help forge confidence, his understanding of the disease, his family and how they are. It doesn't have to be a two-page essay that goes on and on, but just a few sentences about who is this individual. I find that very useful when it is included. It allows me to get prepared and conduct the interview which is often with one or two parents when I see them for the first time."*	
	*Complications associated with the condition itself			
	Drug use (e.g., cigarettes, cannabis)	Drug use (e.g., cigarettes, cannabis)	1.24. *"But smoking you have to, no? I think that's important."* 1.25. *"But I would put that as supplemental. I mean, it's not core."*	Some discussion as to the appropriateness of including "sensitive" information (drug use) given multiple audiences of letter
Vaccination status		Pretesting before biologics (whether x-ray and PPD was done)	1.26. *"Well we do want it. You can always find it in the vaccination booklet."* 1.27. *"that can be interesting to have"* 1.28. *"if the PPD is done, lung x-rays – this will save them some time if they are transitioning to*	Importance seemed to depend on whether or not the patient is on a biologic; assumption that these things have been done if on biologic; interesting to have if patient is not on biologic

			a new therapy, even during the transition period, because not all patients are well controlled prior to transition" 1.29. *"I don't really care when it was done, I would just want to know that it was done. I would assume that if they are on a biologic, that it was done, I wouldn't mind knowing still the hepatitis vaccination, the status, to make sure that it's done, so if something crops up, I can flip back the chart and find it."* 1.30. *"We usually repeat it. Like, if they haven't been on biologics, we'll have to usually do it. I assume it's negative if they're on biologics. So, I don't think you need to put it. I think it's extra."*	Date of x-ray and PPD mentioned as not important
Labs	Most recent labs	Labs	1.31. *"Yes, no labs."* 1.32. *"The labs are always the same. What we need to know is that in March 2017 the patient had severe neutropenia at 400 neutros, and we stopped [inaudible 0:18:47. 4] at that point. You know, the major chapters. We might not need the whole batch of labs."* 1.33. *"which labs were done last, the last results"* 1.34. *"PA: Yes, and again the labs. The antibodies, dosages if any, residual rates, antibodies, things like… PD: The levels, the antibodies depending on which drugs he took. PA: Right."*	Participants expressed various opinions regarding usefulness of labs. Comments ranged from "no labs" to needing the "last [lab] results"
	Biologic medication serum levels (most recent)	Biologic medication serum levels (all)	1.35. *"No, for me, the last one, like on the current dose, is good …you know, the dose was adjusted because the level was low or whatever level was. That's good to have, but I don't need like every level that was ever done, just if there's any change that was made because of it."* 1.36. *"But to know what the level is the last time you checked and if you've made changes because of levels that you've done before."*	Some disagreement as to usefulness of all levels in the transition letter, but most recent levels seemed important

			1.37. *"I'll be honest. I don't mind having…if it's not onerous…to have different levels, because it helps to put it in perspective"* 1.38. *"Patient had a level of X, and therefore dose optimization was required." I find that important.*	
		Viral infection	1.39. *"Hep A, B, C, CMV, EBV, varicella."* 1.40. *"it's at the time of their diagnosis, which is often many years ago. So, I must say I don't find that paragraph all that helpful."*	
		Faecal calprotectin	1.41. *"Again, more recent, most recent. And actually, that one would be helpful to know if you've synced it with their inflammatory disease, if you've noticed it's high when their inflammatory disease is high."*	

** Cells marked by an asterisk indicate content that was discussed by multiple participants or was emphasized as being absolutely necessary*

Supplemental Digital Data 2, Part 1, Table 2. Comments pertaining to appearance of letter

Appearance	Summarized Participant Feedback	Exemplar Quotes
General comments	• Bullet points can be helpful	
Sections/Headings	• Box of antecedents • Medication details: Display using bullet points, include dates • Sections should be divided for easy navigation	1.42. *"Yes, but it is still good to have before the history, right away in the box of antecedents and you see it. Because if the antecedents are very small, you are reassured. If we have like half a page of antecedents."*
Chronology	Chronology/Chronological time line came up as a preferred way of organizing and receiving patient information/history	1.43. *"It can be chronological because sometimes it is easier for the person writing this down, telling the story. Rather than just trying to place things in different spots, it is easier to tell the story."* 1.44. *"Yeah, and I don't think to me it matters if you put it in a list or in a text as long as it makes sense. They tried this, you know. And the way, the chronological way it happened."*
Length	Some participants expressed acceptance that the letter may have to be long to capture the complexity of the case/history	1.45. *"There is also an advantage is receiving something that is complete and detailed from the very outset. Because we can digitalize, rather than having sheets of paper rather than seeing the patient and wait for data while he is in front of you."* 1.46. *"That is the beauty of having, well these are almost summaries in themselves with: 'Dear Doctor, I am entrusting this young patient for management'. And everything is there. If the objective is to have just a short sheet with a summary coming afterwards, sometimes this can be harmful in-patient management I think."* 1.47. *"I want to get everything."* 1.48. *"I mean, to me, if it's not incredibly onerous upon the pediatrician referring, I prefer longer…longer to the point that it's pertinent, longer or shorter depending on what's pertinent…but a longer letter, if pertinent, would not make me in any way unhappy."*
Title	Some participants expressed that it is helpful if the letter is identified specifically as a transition letter	1.49. *"it helps enormously"*

Supplemental Digital Data 2, Part 1, Table 3. Other considerations/recommendations

Other considerations	Summarized Participant Feedback	Exemplar Quotes/Notes
Who are the recipients/audience	• Receiving physician • Family doctor • Patient • Other specialists if concomitant pathologies (e.g., rheumatologist)	Some discussion as to the appropriateness of including "sensitive" information (e.g., sexual orientation, sexually active status, drug use) given that parents may also be receiving/opening the letter
How is the letter shared/method of delivery	• Fax and Email • Two methods to ensure delivery • Concerns about email because of junk mail/filters	1.50. *"I agree with the fact that there would be two ways to be sure you receive it. I think that a fax is fine, but I would also opt for the email version."* 1.51. *"Yes, both is better because sometimes your email goes into the junk mail, could just be by accident. You really need the second one."*
Observations based on review of existing tool	Last visit section and progression missing	
	Vaccination status missing	
	Pretesting before biologics missing	
	Missing dates of when medications were stopped and why	
	Missing information on procedures	
	Lifestyle habits are missing	
	Missing disease progression	1.52. *"There isn't that much room for disease progression. It is more like the ASA meds. But to have an idea if he is hard to control, not hard to control, that is taken care of properly, but we want to have a better idea of drugs, more text."*
	Missing most recent blood tests	
	Missing current status of patient	1.53. *"By itself, it is not completely sufficient. Because it doesn't tell you how the patient is doing now. That is important for classification when you are going to see him."*
	Has useful sections	1.54. *"It's actually a good backbone. It's a fairly good backbone. I think it just needs a bit more detail."*
	A narrative account, chronology of events is missing	
Purpose of the transition letter	Allows recipient to gauge when they have to see the child	
Attachments to the letter	The first and last endoscope. The pathology. Surgery if any. Results of the x-rays that are relevant. Entero-MRI. Last clinic notes from previous doctor.	

Supplemental Digital Data 2: Qualitative Analysis of Focus groups; Part 2: Analysis of Focus Group #3 (paediatric focus group).

Recommended Content for Transition Letters between Pediatric and Adult Gastrointestinal Care

Content Analysis Report

Prepared by Dennis Newhook, CRU Qualitative Analyst, April 21, 2020

Dataset: Transcript from one focus group of **Pediatric** Gastroenterologists (6 participants)

Guiding Research Question(s): What information is required in a transition letter when transferring a patient from pediatric to adult care?

Report Contents:

Table 1. Possible letter content by importance (i.e., must include vs could include)
Table 2. Other considerations (e.g., audience, delivery mode, etc.)
Table 3. Pediatric GI comments in relation to Adult GI focus group & NASPGHAN template

Note: cells/text marked by an asterisk (*) in the table indicate content that was discussed by multiple participants or was emphasized as being absolutely necessary.

Supplemental Digital Data 2, Part 2, Table 1. Possible letter content by importance *(e.g., must include, could include)*

Content Area	Important (*"must include"* or *"bare minimum required"*)	Possible (*"could include", "nice to have" or "supplemental"*)	Notes/Summary	Exemplar Quotes
Diagnosis	Date of diagnosis			
	*Initial presentation at diagnosis		One participant defined this as diagnostic scopes, radiology, severity, and PDCAI/PUCAI score at diagnosis	2.1. *"So, really the disease. The initial presenting major symptomatology."* *"I do like to summarize what they were like at the beginning, what they presented with, how sick they were, etcetera"*
Therapeutic history: Medication	Medication history with starting and ending dates (including serum biologic levels)	Dates/timing (start and ending)	Some variation in the amount of medication history deemed important to include; most discussion revolved around biologics; dates for some meds were not deemed absolutely important	2.2. *"I think the one thing that we sometimes add, again non-specific start and stop treatment dates, but for biologic therapy, we would tend to go more into detail."* 2.3. *"I will put all the medication, beginning and ending so I will put you know, title, this medication and all the medications they had beginning and ending."* 2.4. *"Especially if the biologic therapy's induction was a bit out of the standard. So if it's acute severe UC, we'll speak of how it's given accelerated, like zero one four or a ten milligram per kilo, so it's probably one of the things that we would add."*
	History of immune modulator use and any concomitant therapy			
	Steroid responsive/dependent or refractory		Participant excludes start and stop dates	
	Last course of prednisone			
	Induction and maintenance therapy, the initial ones, and really what happened along the way (did they fail?)			
		Biologic work up dates (IGRA, chest x-ray, TB skin test)	Variation in opinion re: TB testing	2.5. *"Because you would need to have submitted that to start biologics anyway so I just assume they wouldn't need that detailed of information."* 2.6. *"I put the TB, but I'm not putting the X-ray, and I didn't put the date of the TB, because definitely it's before I started*

				the medication. But if it was redone, then I will put it. But no, they don't..."
Imaging Scopes	Diagnostic scopes			
	Number and date of endoscopies			
Imaging Radiology	Radiology reports			
Complications	Any hospitalizations			
***Current status of patient "snapshot"**	*Status: stable/controlled or not stable/uncontrolled at the time of transfer *Brief synopsis of present condition and current medication (including recent levels if using biologics)		mentioned as important for triage	2.7. *"I like to start with a brief synopsis of what the patient's like now."* 2.8. *"I like up front to have details about the treatment they're on, you know for the biologics, including recent levels sort of thing."*
Other medical history/comorbidities	• Allergies • Rheumatologist • Dermatologist • Anemia • Bone health	Rheumatology reports		
	• Pertinent family history • Family history of disease/genetic predisposition		no discussion of what constituted "pertinent" history	
Other Considerations	*Psychosocial description and handling of sensitive information (and patient consent)		Seen as important information for adult GI but some concerns about sharing all information with patient and/or parents; also suggestions that patient is informed/consenting to what content is shared in a letter	2.9. *"Yeah smoking, and even like you know, I have a lot of difficult families… is there abuse, anything going on in the family that you may not want to include. So, I do like the idea of just having a separate snapshot that's not, you know, the patient doesn't need as detailed of a summary as a physician will need taking over care… I think that psychosocial aspect is very important to the adult doctor."* 2.10. *"So, I actually explain to them [patients] that the transition letter would always include these things and how do they feel about that. And if they're uncomfortable, that they think that the family might, other people might see, then that goes in an email to […] whoever is likely to be going to see the patient. And that's how I've dealt with that because it's obviously important information that needs to be passed across."*

				2.11. *"We kind of need the consent, I think the important thing is that you need to discuss these sensitive issues, like you, and you need to have the consent of the patient to put it in the letter. Otherwise, if you don't have the consent you could say that this section will be discussed with the physician at the time of the next appointment."*
	Compliance		Similar to psychosocial description, some participants expressed concern that compliance may be sensitive information depending on audience of letter	2.12. *"…I think with compliance it's very important."* 2.13. *"and then I was finding I had some children who were having issues with compliance that I felt I needed to, you know, call the adult GI doctor, you know, you were getting the letters back and you're getting Cc'd trying to give a little bit more background information that maybe I hadn't provided on that transition of care. So, I've been putting in like a summary of that now moving forward. But, I think it's an important piece to add."* 2.14. "*But there are some patients and we would call it a sensitive issue but really what it is, is I like to be able to explain to the adult doctor, when the escalation of therapy has been slower than I wanted. You know. So if I wanted anti-TNF at the time of diagnosis, and it took me two and a half years, and by that time, the bowel had strictured. I don't know why but I want them to know that it wasn't me, you know, not treating them. And so I put that in my letter and I'm uncomfortable, those parents seeing that in writing. Because I think you know, it may be too hard for them to see it in writing."*
		Statement regarding linear growth		2.15. *"And I guess, you know maybe, the most important thing I think is when somebody is constitutionally short, or maybe constitutional pubertal delay that we just, you know explain that. So they're not thinking that they have to make them grow."*
	Core of evolution			
	Weight and Height at last visit		Only mentioned by one participant	
Vaccination status	Vaccination required		Varied opinion related to importance of vaccine status; general comments	2.15. *"Our west coast docs quite like to know if they've had their flu vaccine, so I sometimes add that in… I tend to put in the live vaccine status, whether they've had them."*
		Vaccination not really required		2.16. *"I routinely don't"* 2.17. *"By exception, chart by selection."*

			suggest that it is not always important	2.18. *"I guess if it was, yeah like a varicella who was indeterminate but I started."* 2.19. *"If there was anything glaring. You know a TB test that was questionable, we'd put in, or sorry a varicella history. But if not, we don't really, too much."*
Labs	Status of TPMT, Hepatitis A, B & C, EBV, CMV, and varicella			
	latest blood work that was available or anything that was off somewhere along the way			
	Biologic levels (latest levels at what dose)			
	Current labs including faecal calprotectin			
		Viral serology		2.20. *"I give current labs, including CALPRO if it's available. I actually don't include such detail on their sort of viral serology. I think we're pretty careful about checking that before we start biologics but I don't, I don't summarize the immunization status for the adult doctor."*
		Vit D levels		

Supplemental Digital Data 2, Part 2, Table 2. Other considerations/recommendations

Other considerations	Summarized Participant Feedback	Exemplar Quotes/Notes
Who are the recipients/audience	• Patient: empowers patient; useful for patient to have incase receiving GI loses documents; useful if patient relocated during the transition; avoids a trip to archives	2.21. *"Yeah when we started a track program that we were actually, to empower also the patient. And also to, for the first visit, if the adult GI was busy, busy, busy, and lost the document, then at least they are able to bring their own letter. And if they move or if they didn't have a family doctor at the time of the transition, they also have the letter. Instead of the step back, coming to the archives, I think the letter in print and everything."*
	• When mailed to patient, patient is the addressee, not the parent(s)	2.22. *"I do mail the summary to the patient. The letter is not addressed to the parents, it's addressed to the patient. So then after I don't have the control."*
	• Multiple audiences (patient, parents, adult GI) poses a challenge regarding the inclusion of sensitive information (e.g., noncompliance) • Primary care physician, another potential recipient • Other possible recipients: specialists, e.g., rheumatologist	2.23 *"I would say that for some patients, I'm completely comfortable that they get a copy. But there are some patients and we would call it a sensitive issue but really what it is, is I like to be able to explain to the adult doctor, when the escalation of therapy has been slower than I wanted. You know. So if I wanted anti-TNF at the time of diagnosis, and it took me two and a half years, and by that time, the bowel had strictured. I don't know why but I want them to know that it wasn't me, you know, not treating them. And so I put that in my letter and I'm uncomfortable, those parents seeing that in writing. Because I think you know, it may be too hard for them to see it in writing. That yes, you would have given this... yeah. So those letters I do not send to the families."*
	• Choice of recipients of physical or faxed copies influenced by use of electronic medical records and who already has access if required	2.24. *"I don't really care if the parents get it or not because if they want they can go to medical records and get it anyway. However, I've sent them just that snapshot, that one page summary. And I've never had anyone come back and say you know, I want the whole letter. I tell them, you know the doc's getting the summary letter and the whole package, and they'll be sent the snapshot and they can use that to go over their health centre in the future. And I've never had anyone say no, no, I want the whole great big dictation. I mean if they want it, they go to medical records anyway."* 2.25. *"The accepting physician, the primary care physician, and then the patient gets a snapshot summary."* 2.26. *"What about the other specialists that the patient sees. Say a rheumatologist, to let them know that we're transitioning them to adult GI. Is it of value for the… Let's say if they're really active, would you cc them?"* 2.27. *"I've also photocopied and sent the last, the discharge summary from rheumatology, so that everybody has that."*

		2.28. *"So I guess I'm a little bit torn because for me all the other providers are on Epic at G.O and I don't know that they want a whole bunch of inbox stuff, if they care, it's right there anyway."*
How is the letter shared/method of delivery	• Fax • Email • Mail • In some cases, participants reported hand-delivery of physical copies	2.29. *"I'm never going to send it by email . . . So, you know they get a fax."* 2.30. *"I don't send paper copies, we just fax."* 2.31. *"sometimes we would email a copy of our letter"* 2.32 *"So we tend to fax and send the paper copy currently because I don't think they have a secure email."* 2.33. *"So if they don't have a fax number they want it sent to, then it comes up and the medical records at our place just knows to send them by mail."*
Purpose of the transition letter/Triage	Agreement among participants that transition letter should indicate degree of urgency; if extreme urgency, then emails are sent directly to physician	2.34. *"I do specify. And if they need to be seen earlier I'll email the physician... especially in these cases where I think they need to be scoped… The way that I send referrals in it's a check box that I have to put. Like it will say urgent, non-urgent, semi-urgent."* 2.35. *"There are cases where if the patient turned 18 for example in March or April, and they really want to meet the adult GI doctor before post-secondary education begins, we would specify that on the letter, to please see before they go off in September. So the family tends to like that."* 2.36. *"First of all the regular paper consult of the province, we have a stamp. And on that stamp it is written zero to three months and three to six months. Okay, and then have a cover fax and on this it's written stable, not stable patient. So, there's two ways that the triage is done for the one receiving it. And then if you need to like, quicker than zero to three months so they say put zero to three months they will sit at three months, so then the agreement is that you call or you email the doctor, to discuss the patient right away."*
Need for surveillance colonoscopy	Suggestion that adult GI should know whether or not surveillance scopes were discussed with patient	2.37. *"To avoid any surprise that the first visit, because they could actually talk about it in the first visit and we never talk about it … sometimes as I am doing the summary I realize, oh my God I didn't talk about it. And I will put it in the summary that I didn't discuss, I forgot, or I didn't have time to discuss this…"*
Attachments to the letter	Growth chart	2.38. *"And we always have appended a growth chart I would say when we, send."* 2.39. *"Yeah, I include the growth chart as well."*
	Discharge summary	
	Capsule endoscopy	

	Other specialists' letters (or last letter or letters when ongoing issue – not a single visit) Substantial rheumatological history/consults (at least last letter)	2.40. *"I don't include if it was just a one time they saw dermatology, but if it was like an active issue, yes they're followed by rheumatology along with me. I'll follow up with that letter, it's pertinent."* 2.41. *"I think rheum is probably the biggest one."*
	• Labs and investigations • Flow sheet of blood test	2.42. *"All the labs and the investigations I say just see document that are adjoined to the letter."* 2.43. *"So I will send the flow sheet with the [inaudible 0:23:27.5] that's included and Infliximab and adalimumab levels with the package."*
Referring pediatric GI requests	• Acknowledgement from adult GI that he/she is accepting the patient • Estimate of when the patient will be seen • Notification once the patient has been seen by adult GI (only one letter required)	

Supplemental Digital Data 2, Part 2, Table 3. Pediatric GI comments in relation to Adult focus group and NASPGHAN template

Pediatric GI comments in relation to Adult GI focus group findings	Vaccination reporting difference	2.44. *"So one thing that I read in here that I don't do very often is the vaccination history. I think everything else kind of fit like the pertinent…"*
	Drug-related testing results	2.45. *"They talked about drug levels but I didn't see the actual TPMT and I didn't see, I don't know if they're talking about 6-TG and 6-MMP as drug levels but, I'll tend to include those as well. The last one I have, so really it's any kind of drug related testing I've done, I'll include in the letter."* 2.46. *"I always, always put it, you know because always you know we get kind of a standard beginning, when you have a new patient, you do this, this, this. So I'm always putting the value. I was surprised by actually the amount of information, I thought they would need less than this. But this is what actually I cover when I am doing the summary."*
	Surprise that there was little focus on initial presentation	2.47. *"I was a little surprised that they didn't seem very interested in the initial presentation. But you know, that's ok, I'm still going to put that in the letter."* 2.48. *"It's the same in the west. The west coast are exactly the same. They didn't care really how they presented."*
	Details regarding complications of earlier therapies	2.49. *"they seem to really want to know about complications of earlier therapies. And I guess you know I can see that actually. They want to make sure they were told if someone had a bad effect of an earlier therapy. So I will, I mean I think I would usually do that, but they make a big thing of it, it seems to me."* 2.50. *"I think it's because, you know they have to live with the same patient until they are 50, 60, and sometimes you know if you fail and then you have to reuse a medication then you want to make sure you're not making any mistake, you know, 20 years down the road, your memory, and the patient memory, you know if the child received it at eight years old they won't remember even at 18 that they got that."*
	Vaccination status	2.51 *"Their attitude towards vaccination status, it seems like it was a bit mixed. I mean I like the comments that say we don't really need it, they can always look at their vaccination booklet. And that's sort of true."*
	Surprise at details requested	2.52. *"I love how they commented on they want long letters. Like comprehensive."* 2.53. *"And then it's their choice to decide if they read it or not."* 2.54. *"the sense is that they want a good overall summary kind of thing. And, I think that's nice."*
	Missing content: growth, family history	2.55. *"Well we talked about how we usually put in something about growth, I don't know."*

		2.56. *"I guess the other area sort of that I didn't see very much that they wanted, family history. And I guess I thought that was, especially if it's an immune based family, if there's a lot of IBD in the family."* 2.57. *"Or glandular carcinoma, colon cancer, these sorts of things, I usually put that in."* 2.58. *"I also put the family history in the summary, because of all this. I think it's...yeah, maybe it's surprising that it wasn't mentioned at some point."*
Observations based on review of existing NASPGHAN template	Not a lot of direct comments; overall regarded as a brief summary, maybe useful to patient as a snapshot, not sufficient as a template transfer letter	2.59. *"This is a brief medical summary, but it doesn't replace the letter and the core of the evolution."* 2.60. *"Cause this is the other extreme, simplistic."* 2.61. *"I don't think anyone thought that that was the transfer."* 2.62. *"Should be given to the patient, so it's actually a summary for the patient."*

Supplemental Digital Data 2: Qualitative Analysis of Focus groups; Part 3: Analysis of Focus Group #4 (combined adult and paediatric focus group).

Recommended Content for Transition Letters between Pediatric and Adult Gastrointestinal Care

Content Analysis Report

Prepared by Dennis Newhook, Qualitative Analyst, July 29, 2020

Dataset: Transcript from one combined focus group of **Pediatric and Adult** Gastroenterologists (n=15), sampled from Stage 1 and 2

Guiding Research Question(s): What information is required in a transition letter when transferring a patient from pediatric to adult care?

Report Contents:

Table 1. Summarized participant feedback on draft template letter by content areas
Table 2. Other considerations/recommendations
Table 3. Summarized feedback on suggested attachments to template letter

Supplemental Digital Data 2, Part 3, Table 1. Summarized participant feedback on draft template letter by content areas

Content Area	Summarized feedback
Demographics	General agreement expressed; no further comments provided
Diagnosis and Phenotype	• phenotype at diagnosis important
Comorbidities	General agreement expressed; no further comments provided
Allergies	General agreement expressed; no further comments provided
Medication Current & Historic	• details for current therapies may be more important than historic
Biologics	• focus on *reason* for biologic failure (mechanism); dates not as important
Corticosteroids	• detail of failure for steroids not as important as for biologics • dates not important
Surgeries Historic	• focus on hospitalization for obstructive symptoms *(see note in hospitalizations below)*
History/Initial presentation	General agreement expressed; no further comments provided
Current Status	General agreement expressed; no further comments provided
Imagine: Endoscopies	General agreement expressed; no further comments provided
Imaging: Radiology	• focus on first/initial and most recent • history of CTs and x-ray (interested in repeated radiology exposure)
Labs: previous	General agreement expressed; no further comments provided
Labs: recent investigations	General agreement expressed; no further comments provided
Hospitalizations	• focus should be on hospitalizations for obstructive symptoms and surgery; date of surgery, length of bowel resected (if available), any complications related to that surgery • list of ALL hospitalizations not necessarily important
Complications	• consider adding reminder for inclusion of **ophthalmology** • infectious complications important to adult GIs • shingles of interest; ENT-related infections; chronic sinusitis • some disagreement about importance of including all infections and some concern about accessing this information in patient file
Family History	• collected by adult GIs anyway so didn't seem absolutely necessary • adult GIs would appreciate highlighting family history of **IBD** and **cancer**
Immunization History	• may not be very important (considered ok if biologics had been prescribed) • could be an addendum • difficult to track • discussion around CAG guidelines
Psychosocial	• living situation: family unit vs independent (psychosocial risk factors) • family conflict issues of interest • compliance issues *(could go here or as adherence in treatment section)*

Supplemental Digital Data 2, Part 3, Table 2. Other considerations/recommendations

Other considerations	Summarized Participant Feedback
Letter recipients and inclusion of sensitive information	• patient should receive a copy (up to patient if he/she chooses to involve parents) • agreement that patient should receive the letter (not the parents) • sensitive information could be excluded from letter and shared privately with adult GI • inclusion of sensitive information could be discussed with patient beforehand
Mode of delivery	• two modes of delivery good if urgent (e.g., email and fax; or follow up with phone call) • move to paperless systems (electronic modes preferred) • variation in use of EMR systems making e-transfer of data difficult/impossible • hard copies by mail still preferred by some
Pediatric gastroenterologist requests	• agreement that notification should be sent that patient has been accepted by adult GI including a target of when patient will be seen • letter following consultation
Adult gastroenterologist requests	No additional comments provided
General concerns about the amount of work to prepare the letter	• concern from adult side that the letter is too much work for pediatric side • concern from pediatric side that there is no remuneration for time spent preparing letter
Growth chart	• not seen as important; would not be useful to adult GIs • mention of whether or not growth was affected by the IBD would be useful (or if significant growth delay)
Urgency of transfer/timing of transfer	• lengthy discussion about interaction between urgency, age/DOB, and time frames/wait times • concerns about pediatric GIs not being able to see patients after they turn 18 years of age • avoid having patient present to adult emergency departments

Supplemental Digital Data 2, Part 3, Table 3. Summarized feedback on suggested attachments to template letter

Possible Attachments	Summarized Participant Feedback
Hospitalization discharge summaries	• not always relevant • noteworthy cases could be included (e.g., hospitalizations that involved surgery)