

Name of document: Leeds Teaching Hospitals Trust – CCG letter to patient
Contact: Steve Laville, Leeds West CCG

Patient reader group - Feedback Report

Brief

Patients were sent the draft patient letter and email which outlined the purpose of the project and the leaflet. They were asked to comment on the letter from a patient perspective. The email was sent to NHS Leeds West CCG Patient Network members. We received **26** responses.

Responses

1	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • In what circumstances do the consultants feel that the patient does not need to be seen and why? • Things could be missed. • It's very concerning – if GP has referred to the consultant there must be some reason why. It feels like it would be disregarding the GPs recommendations. • How might this affect a patient who is extremely ill and the consultant has not seen the patient?
2	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Remove 'time' from the last sentence. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • Will the consultant be named? Some patients have multiple referrals and may be confused as to which one this letter relates. • Is this intended for use when a referral has been rejected as inappropriate? If so, will the GP be able to access information on LCR if the hospital letter has not arrived when the patient calls? My experience is it can take weeks for the letter to be typed, signed and posted.
3	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Add date that the letter is written underneath the hospital details. • Add 'decision' to second section "the consultant will write to your GP explaining this decision".

	<ul style="list-style-type: none"> • Final sentence as “from the date of this letter” to the end of the sentence. • “Remove “time”. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None
4	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Add name of GP in first sentence: “Your GP, NAME OF GP’. • Change “3” to “three”. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None.
5	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • Whilst not being the most polished letter there is actually nothing that a patient could take exception to as long as the reason for referring back is acceptable to the individual and the GP. • The fly in the ointment could be the deplorably inefficient postal service from LTHT. • It would be interesting to know what percentage of DNAs happen because the letter arrives after the date of the appointment. • The wording of the letter is acceptable but the system might be flawed.
6	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • I fully appreciate the Trust can't hold an appointment with the patient merely to tell them they don't require a referral, but I think it would be preferable if, at a minimum, the letter contained some personalised content to show that the consultant had actually reviewed the right referral before coming to this conclusion. Something like: <p><i>“We will be advising your GP that your symptoms [of xyz] can be safely managed via [medication a/procedure b]. Your GP will order repeat tests after six months and advise us if your symptoms have changed. [or some appropriate follow-on actions].</i></p> <p><i>Your GP will be asked to make an appointment with you to discuss the next steps in your treatment but please contact your surgery if you do not hear from them within three weeks.”</i></p>

	<p><u>General feedback:</u></p> <ul style="list-style-type: none"> • It's very short. Too short, given for many patients this will be a very distressing outcome. • The letter comes across as utterly unfeeling (not unusual for LTHT, I have to say) and contains no specifics other than yet another wait for information - when the patient receives this they could have been waiting for months for a response from the hospital I would guess. • Could the patient then be invited to contact PALS if they want further reassurance? • This is a very upsetting letter - most people will not be reassured that the consultant doesn't feel their symptoms are serious, because their GP (who they know and generally trust) has indicated that they are.
7	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • In paragraph 1 insert "by him/her" after "clinical decision". • Paragraph 2 a space is required between "write" and "to". • The last sentence remove "time". <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I would be very unhappy if any clinical decisions were made without sight of me, a bit like the G.P telephone consultations from which the wrong diagnoses can and are being made.
8	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I do have some questions and cannot respond fully until they are answered. I suffer from a complicated rheumatologic condition and frequently find that clinical decisions are often made by consultants in a different speciality to rheumatology without considering a connection to or the treatment for my main condition. SLE can affect just about any part of the body in different ways. • Is the triage consultant a specialist in the field for the referral within LTHT? • Is the full medical history of the patient being referred available and reviewed by the specialist? • If a GP sends a referral is their professional decision making being respected? • Is the triage consultant a specialist within the speciality of the referral or a centrally based generalist? • This doesn't feel very joined up in terms of seamless patient care.(No decision about me without me) • As a patient who requires a whole system approach to my care and I am certainly not alone there needs to be more detailed information about this suggested triage letter.

	<ul style="list-style-type: none"> • I am totally opposed to a single central triage where a generalist makes decisions on behalf of a specialist. • A lot of work has been done to develop whole person centred care and respect clinical freedom with respect. • I genuinely feel worried about this letter without having more information. Both primary and secondary care are overloaded but the patient should be at the centre. • Any new systems require a focus on quality and safety. Patients should be discussing the background behind the concept, not just the letter.
9	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • This is a situation where the GP has already discussed with the patient why there is a need for a consultant to become involved, so the patient will be worried about the possible seriousness of their condition. So I assume the aim is to achieve the same outcome, without seeing the patient, but not leave the patient feeling they are not receiving the treatment they need and possibly giving rise to a complaint. I feel the only way to achieve this is for the GP to mention to the patient at the outset that the referral could be dealt with in two ways, either by a clinical review by the consultant of the details the GP provides, followed by advice on what is required or an outpatient appointment. The letter can then reflect this and I would suggest the following wording: <p><i>“Your GP has sent a referral to (Department) together with the necessary information to enable us to consider if you need to attend as an outpatient. The information has been reviewed by a Consultant and on this occasion a clinical decision has been made that an appointment is not required.</i></p> <p><i>The Consultant will write to your GP explaining this, together with appropriate advice on what is required. Your GP will be contacting you to explain this in detail but if you have not heard from your GP within 3 weeks please contact the practice.”</i></p> <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None
10	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • I would suggest amending: <p><i>“The referral has been reviewed by a consultant and a clinical decision has been made that an appointment is not required.”</i></p> <ul style="list-style-type: none"> • to read: <p><i>“A consultant has reviewed the referral and has made a clinical decision that an appointment is not required.”</i></p> <ul style="list-style-type: none"> • Or similar as I feel that active sentences are generally more easily understood than passive sentences.

	<p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None.
11	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • The letter is clear and concise however, I would hope that a specific consultant's name will be placed within the letter so that, should any issues arise at a later date, there is a clear point of contact. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None.
12	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I've read the proposed letter and find that it doesn't offer confidence to the patient that they will be given any viable further support to overcome their medical condition. • It reads rather curt and unhelpful. • Surely this letter should offer support to the patient when the GP initially felt his/her patient required further investigation from the consultant? • I understand the pressure on hospitals and consultants but the letter offers neither comfort nor reassurance that the patient will receive further treatment or advice from their GP.
13	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • My suggested amendments are in bold. I hope this helps: <p><i>"Dear Title Surname</i></p> <p><i>Your GP referred you to (Department) requesting an outpatient appointment. The referral has been reviewed by a consultant and a clinical decision has been made that an appointment is not required.</i></p> <p><i>What will happen to my referral?</i></p> <p><i>The consultant will write to your GP explaining why the clinical decision was made, along with appropriate advice. Your best interests will be taken into account regarding this decision and your GP will contact you as soon as possible to discuss the consultant's review and what will happen next.</i></p>

	<p><i>Please contact your GP Practice if you do not hear anything within 3 weeks' time.</i></p> <p><i>Yours sincerely</i>"</p> <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None
14	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • Apart from being short, impersonal and no general info around the decision made, it is OK.
15	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • Whilst not being the most polished letter there is actually nothing that a patient could take exception to as long as the reason for referring back is acceptable to the individual and the GP. • The fly in the ointment could be the deplorably inefficient postal service from LTHT. • It would be interesting to know what percentage of DNAs happen because the letter arrives after the date of the appointment. • The wording of the letter is acceptable but the system might be flawed.
16	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I agree with its content, one point I would make is that a letter of explanation be sent to the patient quite soon after that first letter, say within a week.
17	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • The appropriate communication and use of language as you know is imperative

	<p>especially when carers like me have to deal with them.</p> <ul style="list-style-type: none"> • A couple of months ago I received a letter from a hospital [on behalf of my father] in which an ultrasound scan had been reported as suspicious. The family were worried that the cancerous tumour had come back. Fortunately this was not the case, and obviously the consultant and the team are going to be monitoring my father's health with further tests. They sent their sincere apologies for any confusion that may have been caused. I cannot fault this excellent team as my father's care is ongoing. The consultants are highly skilled, polite, and courteous and they gave me all the time I needed to talk to them and ask questions. Superb Healthcare, the NHS as always the best. • However the letter still raised many questions that I wanted to ask, I knew I only had to phone to ask, which I did, and got another letter. Letters on their own can raise more questions if not worded correctly or tailored with the personal touch, so the patient knows that they are being dealt with in a caring and personal way. • A purely impersonal and clinical letter is not one I would like to receive. A more personal and explanatory letter would reassure me that the team are dealing with it, they have explained briefly why and that I will get more detail when I see the GP. • Just telling someone in a clinical way that a decision has been made without giving the patient a little more detail feels like decisions are being made without the patient being involved /rejection.
18	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • I think it should be something like this: <p><i>"Dear Mx Smith....</i></p> <p><i>Your GPxxxx.....outpatient appointment. All the details of your referral have been reviewed by (oncology) Consultant Mr Joe/Jo Bloggs, whose clinical decision is that there is no need for a hospital consultant appointment. He/she feels that your condition can be safely managed by your GP in primary care.</i></p> <p><i>He/she will now write to your GP with an explanation for the decision, and give appropriate advice and full guidance for your future treatment.</i></p> <p><i>Please contact.....etc."</i></p> <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I'm appalled on two levels; firstly the action itself, which will undermine both G.P's authority and patients' confidence in their G.P. (but will, of course, save consultants' time) • Secondly, the totally impersonal, almost dismissive tone and substance of the letter, obviously written by a functionary who has no understanding of human communication and its effect on the reader.
19	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • I would suggest adding something in to explain advice as an alternative,

	<p>otherwise it seems to suggest patient is not ill and they may not contact GP: <i>i.e. "appropriate advice on how to best manage your medical condition."</i></p> <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None
20	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I am fine with the letter and how it's worded. • The fact that your doctor only usually writes a referral to the hospital consultant when you're problems are ongoing for a long time and your doctor has done everything he can for you and as a patient you want a second opinion. • I know they want to cut down on people visiting hospitals but if they will not see you what are your rights in getting a second opinion and often it puts patients at ease that something is being done.
21	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • I don't have any problem with the wording except I felt more explanation is perhaps required. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • The letter is fairly straightforward and the wording is fine but after waiting for a while expecting an appointment which is currently the case, to be told you were being passed back to your GP I would find personally pretty hard to accept particularly as the letter doesn't explain why. • I realise some patients would not understand but it is essential to give some information if after waiting weeks you are returned to your GP. I appreciate that whilst it is easier to send out a standard letter, in this kind of situation more explanation I would feel would be required. • I am more concerned as to why this letter would need to be sent out though. • In many GP practices there are some GP specialists that cover diabetes, gynaecological issues, arthritis, lung problems like COPD etc. and they only send referrals to the hospitals when necessary knowing the current situation of waiting times. • What sort of circumstances would require this type of letter being sent out as I would really like to understand who would be likely to receive such a letter?
22	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Here are some amends (in bold) I think would work better:

	<p><i>“Your GP referred you to (Department) requesting an outpatient appointment for you. The referral has been reviewed by a consultant and a clinical decision has been made that an appointment is not required at this time.</i></p> <p><i>The consultant will write to your GP explaining this, along with giving appropriate advice and guidance as to how best to proceed with your ongoing care and request your GP to contact you to discuss this.</i></p> <p><i>Please contact your GP Practice if you do not hear anything from them within 3 weeks’ time.”</i></p> <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I thought it was a very cold letter and I would be upset if I received it as it seemed to imply that I was wasting time and that whatever was wrong wasn't important enough for the referral. • It would be interesting to know how many of these letters are sent out to patients - do you have any numbers? • Once all comments have been received and decided upon could you let me have a copy of the final letter please? Be interesting to see what others thought and see the final version.
23	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Delete the word “time” in the last sentence as it is unnecessary • In the second sentence after “an appointment” add “at the Hospital”. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • I believe that patients will be upset/annoyed by not receiving an appointment as it could be construed that the case is closed. This will be before reading the next paragraph.
24	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • Include GP’s name to reassure the patient that this info is correct. • Add “in the next three weeks”. • Remove “time in the last sentence. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • None.
25	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • 1st paragraph - extend to say “<i>be assured an appointment is not needed at this time</i>” [stops the patient from thinking they are of no importance] • 2nd paragraph - <i>2the consultant will write to your GP explaining this decision along with appropriate advice to manage your condition.</i>”

	<p><u>General feedback:</u></p> <ul style="list-style-type: none"> • It is too cold and clinical. • It needs to have a softer tone. • The Consultant might also consider copying in the GP letter to the patient [reassures the patient].
26	<p><u>Formatting feedback:</u></p> <ul style="list-style-type: none"> • None. <p><u>General feedback:</u></p> <ul style="list-style-type: none"> • It is dismissing their concerns that had them referred to a consultant in the first place. • Being told that the GP will be contacted in the future along with giving the GP appropriate advice creates yet another delay for the patients and places the patient in the uncomfortable state of not being involved in their own health. • If ‘virtual consultations’ are being conducted and a letter is being sent to the patient then the advice to the GP should be copied in for the patient and if referral back to the GP should be necessary. • A simpler streamlined process.

Key Themes

- More explanation is required.
- Letter is too short and does not provide enough detail/context.
- General feel that the GP that made the recommendation is being dismissed.
- No reassurances offered to patient who had been waiting on the referral.
- Concerns about promptness of being communicated with.
- Needs more personalised information.
- A patient may well find this letter distressing.
- Clinical decisions being made without the patient being involved.
- Letter is impersonal/clinical/”cold”.

Recommendations

- All “**formatting feedback**” that require simple changes to be implemented (i.e. simple word changes/deletions, inclusion of date).
- Consider “**formatting feedback**” to include more substantial changes to wording such as what has been given by patients in the reader group. This would help address some of the issues regarding tone.
- Make the letter more personal to the patient (consultant name, GP name, any additional and relevant information).
- Send final version and responses to engagement team to forward to patients who have been involved.