

Reader Group Evaluation Report



November - December 2019
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Executive Summary

The Reader Group is overseen by the Engagement Team at NHS Leeds CCG, and allows organisations to collect feedback from patients, members of the public and NHS staff about patient literature they have produced.

Members of the reader group ensure that the content and layout of the resources are accessible for patients, checking for any spelling and grammar mistakes or unexplained medical jargon. After observing that a small number of the group provide feedback for each document, usually 10-12 responses despite there being 120 signed up to the reader group, we aimed to find out some of the reasons why this may be happening.

The survey was sent out to the 120 members of the Reader Group, with the option to complete it via an online survey or by post. The survey consisted of a series of questions to ascertain how confident members of the Reader Group feel when reviewing documents, how easy and convenient they find the process, and what aspects of it they feel could be improved.

31 people responded to the survey:

- People told us that a lack of reports and final versions of documents from organisations was something that needed improving.
- People told us that they thought a face-to-face meeting at least once a year would be beneficial, to ensure everyone is confident with their role as a Reader Group member, as well as to discuss any potential improvements.
- People told us that the feedback surveys should have slightly fewer questions (between seven and 11).
- People also told us that work, or a lack of time, prevented them from responding to a lot of the documents they are sent to review.

In response to this feedback, a meeting will be arranged with members of the Engagement Team to discuss how we can address the issues raised, with the intention of working with members of the Reader Group to improve the process in the coming year.

Background

The Reader Group was established by the Engagement team at NHS Leeds Clinical Commissioning Group based on evidence suggesting that involving patients and the public can help us produce more effective literature.

The group is made up of patients, members of the public and NHS staff. Reader Group members receive several documents to review each month, and use prompts to assist them in providing feedback. Their responsibility is to ensure that the literature is accessible for patients, with no unexplained medical jargon, a clear layout and no spelling or grammar errors.

The group can feedback via an online survey, or alternatively they can request to receive the documents by post. There is a typical turnaround time of around two weeks, to allow sufficient time for the group to respond, particularly those who participate by post.

Once the feedback has been collected, a member of the Engagement team will send this feedback to the organisation along with a short report template to fill in. The report will include a summary of the key themes and recommendations from the feedback, as well as how the organisation will address the suggested improvements. Ideally, this report will be completed by the requesting organisation within a month of receiving the feedback, along with the final, amended versions of the literature, so that this can be shared with the Reader Group.

The decision to evaluate the Reader Group process was based on the low number of people providing feedback for each document. Each document was typically reviewed by no more than 10 people out of the 116 people signed up to the group. As a team, we wanted to determine why the majority of members choose not to participate.

The evaluation survey was put together following a series of discussions between members of the Engagement team, with questions that aimed to gauge people's confidence when reviewing documents and what aspects of the process they feel needs improving. The evaluation survey was sent to the group to complete, with the option to receive the survey by post. A turnaround time of three weeks allowed plenty of time to respond, both online and by post, and especially during the beginning of the busy Christmas period.

What did people tell us?

This section outlines what members of the Reader Group told us in the Evaluation Survey. 31 out of 116 people responded.

Over 90% of people (28 out of 31) felt either **'very'** or **'quite confident'** when providing feedback on a document.

'I feel confident that the information would be used to improve the documents and hence the service.'

'Instructions are understood and feel confident of making adequate input.'

'I feel very much out of depth with some of the documents.'

However, some people felt less confident, noting that there are often lots of **unexplained medical terms** in the literature they review.

'At times we need help with the technical terminology.'

The most common feedback was that members of the Reader Group do not often see how their contributions have made a difference. 44.8% of people (13) **'rarely'** or **'never'** see how their feedback has been used.

'More feedback, we never get to hear whether the suggestions are acceptable or used or rejected.'

'Never informed whether the author has taken up any of the suggested changes which means there is no personal satisfaction to be gained from giving up time to support this project.'

When asked about the number of documents sent through for review:

- **80%** of people (24) think the number of documents we send them to review is **'about right'**.
- **62%** of people (19) would prefer **7 to 11 questions** to answer when reviewing literature.
- **73%** of people (22) find the online survey **easy to use**, however it has been noted that sometimes certain questions are irrelevant to the type of document being reviewed.

'It is easy to follow, it saves having to download forms and less time consuming.'

'Often the standard question doesn't quite match the subject matter.'

Over 58% of people (17) felt that **training** would be useful.

'Things to look out for, how feedback helps, why documents and information is important and what it brings to the NHS.'

'What is its objective, how the reader group should indicate amendments to text/graphics, how and if amendments to documents/leaflets are followed up, what the amended document looks like.'

Some reasons for choosing not to feedback on a document include **work**, and being involved in other **volunteering commitments**. Others noted a **lack of understanding** about the medical condition or subject matter.

'Not familiar with the subject being asked about.'

'If I don't understand the condition I don't send feedback.'

'The use of words that we do not often come across.'

Over 96% of people (29) felt that a 'welcome' document would be useful.

'Very important indicator of inclusion.'

'It would encourage membership and make them feel their input can make a real difference.'

Some of the additional suggestions for improvements were:

'A six-monthly or annual meeting with an agenda at a convenient location.'

'Encourage people to comment by sending out a thank you note from the requestor showing the changes that have been made. We are doing this to help the NHS free of charge.'

Key themes and recommendations





Themes identified	Recommendations
Not receiving reports from organisations to show how Reader Group feedback has been used, or the amended documents.	To think as a team about how we can ensure organisations know this is a requirement for using the Reader Group. Despite making this clear in initial communication, most reports and final versions of literature are still not received.
A welcome/introductory document for new members would be useful.	To prepare a welcome document – a side of A4 with information about what is expected from reader group members, or an email – to send out when future members join.
Members would prefer slightly fewer questions when providing feedback (between 7 and 11).	Make sure irrelevant questions are removed from the survey wherever necessary (e.g. if the document is a GP letter, remove the question about whether it is eye-catching). Consider as a team to what extent the survey can be shortened.
Introduce a face-to-face meeting once or twice a year to ensure everyone knows what is expected of them, potentially with training included.	Arrange a face-to-face meeting with members of the Reader Group before Spring 2020, to discuss their role, what is expected of them, what can be expected from the organisations, as well as a chance to talk about any further improvements that can be made.
Some members are concerned that they do not have enough medical experience or knowledge to properly feedback on the literature.	Ensure all reader group members are aware that they do not need to know about a particular medical topic to review a document. If a document is unclear, then the organisation needs to amend it so it is accessible to everyone. If members do not understand a document, this is very valuable feedback that the organisation needs to be aware of. Will be discussed further with Engagement Team.

What happens next?

Following the survey, the feedback and report will be shared with the Reader Group, with further updates within 6 months to show the improvements that have been made. The feedback received will be taken on board with the intention of improving the group throughout 2020. A meeting will be arranged with members of the Engagement Team to discuss how we can address the issues that have been identified, particularly the lack of reports and final versions of documents from requesting organisations.

Appendices

Appendix A – Feedback from the survey

1. How confident do you feel when providing feedback on documents?				
			Response Percent	Response Total
1	Very confident		54.84%	17
2	Quite confident		35.48%	11
3	Somewhat confident		6.45%	2
4	Not at all confident		3.23%	1
Tell us why:				
1	Used to such type of analysis in my previous career, but not in the medical field. But assume the documentation would be in layman terms.			
2	I have spent my career writing and proof reading documents and web pages. I have also spent many years working to improve accessibility of digital resources.			
3	ut we never get feedback on our comments			
4	During my career I was a teacher of English, a Local Education Advisory Teacher for English, a consultant for the government's National Literacy Strategy and a university lecturer in the Education Dept. I believe I can communicate well in writing.			
5	Happy to give detailed feedback			
6	I had a previous life editing/writing			
7	Not always easy to recall the content of document under examination when answering questions			
8	Apart from some medical terminology, I have a great deal of experience and understanding of English grammar, sentence structure, spelling and document layout.			
9	Years of experience as a proof reader and the mother of a 33 year old with severe learning difficulties.			
10	As long as I have time and the documents are in a readable format			
11	I have a nursing background plus I worked in a senior role at CCG prior to retirement			

1. How confident do you feel when providing feedback on documents?

		Response Percent	Response Total
	and this role involved reviewing legal and regulatory policy documents including documents for patients and carers		
12	The format of the review documents and questions works well for me - I prefer digital. Plus I've got some background in this kind of activity so I'm happy with it.		
13	We are not restricted - we have the opportunity to provide comments.		
14	We both had careers in the NHS caring professions. Communicating successfully was essential to us both.		
15	I do not know whether others are thinking along the same lines as I am. I do not get feedback as to my comments.		
16	We get very little feedback on most of our comments.		
17	Sometimes my personal lack of experience or knowledge of a particular condition makes it harder to judge impact on reader who has this		
18	I find it easy to adopt a lay perspective because I am a patient and have had no detailed engagement with the NHS in a professional capacity. I used to work pre early retirement on the drafting and production of documents, and quality was scrutinised by a range of stakeholders in high profile contexts. I am less confident with accessibility of document issues but assume this is a bit of a specialist area for which you have arrangements in place.		
19	I am a proof reader and the mother of a daughter with severe learning difficulties which helps		
20	Confident about my amendments/corrections, not confident they are acted upon.		
21	To be honest I am not the cleverest		
22	HCPs must value the service as they continue to submit documentation.		
23	At times we need help with the technical terminology but when we are at home we would have to contact the office to find out what they were meaning.		
24	I feel confident that the information would be used to improve the documents and hence the service.		
25	I am providing feedback from a user perspective.		
26	Instructions are understood and feel confident of making adequate input		

2. How do you feel about the number of documents that are sent to you to review?

			Response Percent	Response Total
1	Too many		6.67%	2
2	About right		80.00%	24
3	Not enough		13.33%	4

3. How many questions would you prefer to answer when reviewing a document?

		Response Percent	Response Total

3. How many questions would you prefer to answer when reviewing a document?

			Response Percent	Response Total
1	1-3		0.00%	0
2	3-5		6.45%	2
3	5-7		6.45%	2
4	7-9		22.58%	7
5	9-11		38.71%	12
6	11-13		9.68%	3
7	13-15		6.45%	2
8	15+		9.68%	3

4. Do you find the online survey easy to use for providing feedback on a document?

			Response Percent	Response Total
1	Yes		73.33%	22
2	No		26.67%	8

Comments:

1	Not done on line yet
2	You do not think open enough if there is anything that you feel is not right then you should be able to add the comments directly to the document under review
3	Much easier all in one place
4	I always request a paper copy so do not use the online survey
5	But sometimes it can be hard to explain in a short sentence
6	Although sometimes the answers are a little restrictive, would be good to always have a free text box to add commentary if the answers don't quite fit what you want to say.
7	Yes - as I have access to a laptop computer, but I can imagine it would be difficult to take part using a SmartPhone, as often you need two screens open at the same time.
8	I am unable to read papers on the computer. I prefer to see papers in 'black and white paper'.
9	IF we have any coment it would be far easier to mark up a word copy for the people to read what you saying.
10	Often the standard question doesn't quite match the subject matter
11	Its very simple and easy. Some overlap in questions perhaps but I just say see above or whatever.
12	Much better than having to mess around with incompatible file types, scanning documents or the postal service
13	It all depends on the amount of comment that you want to give.
14	Would also like a comment box to highlight words that might need making simpler for those with lesser reading ability

4. Do you find the online survey easy to use for providing feedback on a document?

		Response Percent	Response Total
15	I do not use it		
16	The document should be supplied in a format that can be changed in a different colour so the changes are easily spotted and changed on the original.		
17	It is easy to follow, it saves having to download forms and less time consuming.		

5. Do you feel that any training would be useful for reader group members?

		Response Percent	Response Total
1	Yes	58.62%	17
2	No	41.38%	12

If yes, what sort of things would you like to be covered in that training?

1	Can't answer, no experience
2	I don't know who the other members are so can't comment on this.
3	How to access the document easily and to be able to edit it online using either a different font size or font colour
4	For myself no, and I would assume most who signed up for this will be aware what's expected of them, maybe it's something you can ask new members
5	How many people comprise the reader group What is its objective How the reader group should indicate amendments to text/graphics How and if amendments to documents/leaflets are followed up What the amended document looks like
6	If you are asking members of the public to comment who have no NHS training they may need to have some input into corporate style wording.
7	This would depend upon the level of prior experience both as a patient receiving such information or from previous/present work where review of such documents has been part of their role
8	I personally feel okay but I could see that some others might benefit from this. It might be a good opportunity for reviewers to meet and discuss ideas too - maybe a workshop style event would be really positive and allow for some training in the system and sharing of learnings. I'd be happy to contribute.
9	Yes, to make sure that everyone has the same understanding about appropriate content, channel, tone, accessibility etc.
10	undecided
11	What is expected of the readers.
12	Going through with the originator so that both sides see first hand the changes that are proposed and the final version is completed in one go, which helps both sides.
13	It's not the reader group members who need training, it's the survey writers! There are several standard questions which are sometimes hard to apply to the specific material
14	Perhaps. You know the group and the responses, and any recurring points made that might not be appropriate. But a reader thinks there are for some reason so no harm in taking the mix.
15	Not for myself but perhaps for those who are not working in a corporate environment

5. Do you feel that any training would be useful for reader group members?

		Response Percent	Response Total
16	Things to look out for How feedback helps Why documents and information is important and what it brings to the NHS		
17	It all depends on the detail of the leaflet		
18	- Instructions on how to show amendments/corrections and if there is a specific format - What is the criteria for joining the group or leaving it		
19	Just think you should make it clear experience in reading would be a real advantage and good spelling ,		
20	Particularly for those who are not NHS employed as some terminology and subject matter may be confusing		
21	The documents that contain technical terms of any sort should be reviewed by a group of members to ease the changes that may be required.		
22	I'm not sure what sort of training would be provided, but I'd be happy to attend if needed.		


6. Is there anything that sometimes stops you from providing feedback? (e.g. not having enough time, busy with work, etc.)

		Response Percent	Response Total
1	Open-Ended Question	100.00%	31
1	18/11/2019 10:31 AM ID: 131117917	As above, not involved in one on line yet	
2	18/11/2019 11:26 AM ID: 131121426	I think I missed one due to lack of time.	
3	18/11/2019 12:12 PM ID: 131121518	Not familiar with the subject being asked about	
4	18/11/2019 12:44 PM ID: 131128005	No	
5	18/11/2019 12:51 PM ID: 131129352	Na	
6	18/11/2019 13:02 PM ID: 131130105	Yep. Not enough time or thinking that you may have enough readers with actual personal experience of the topic.	
7	18/11/2019 13:10 PM ID: 131130674	See earlier comments please	
8	18/11/2019 15:53 PM ID: 131144940	Not an area I have an interest in	
9	18/11/2019 16:20 PM ID: 131145773	No	
10	18/11/2019 18:52 PM ID: 131158600	Not enough time. My role is extremely busy and am off site for huge parts of my working week. My inbox at times is overwhelming as no-one calls anymore with a quick query, they email instead. A 2 week turnaround may mean I only have one opportunity to go through emails and sadly the reader group sometimes has to take a back seat to other, urgent, emails.	
11	18/11/2019 19:42 PM ID: 131161437	Quite involved in other CCG and NHS patient engagement	

6. Is there anything that sometimes stops you from providing feedback? (e.g. not having enough time, busy with work, etc.)

			Response Percent	Response Total
12	18/11/2019 20:50 PM ID: 131164901	Out of the country on holiday		
13	18/11/2019 22:33 PM ID: 131169260	not having enough knowledge of the subject matter		
14	19/11/2019 10:57 AM ID: 131177711	Yes, I've so far received about 6 and only managed to complete 1 mainly because I got busy with work. I have found that unless I do it straight away, it's easy for it to fall off my radar. Maybe a reminder 1 or 2 days before the deadline would be good, a friendly nudge of course.		
15	19/11/2019 14:53 PM ID: 131207171	Personally, it would be better to be invited to give feedback on documents once every so often - rather than several at once, as they may land with me at a time which is not convenient.		
16	21/11/2019 14:07 PM ID: 131325617	No, we can usually fit it in		
17	25/11/2019 14:31 PM ID: 131489205	No		
18	25/11/2019 16:56 PM ID: 131500013	Not enough knowledge of the subject being sent for review. As commented above going through it with the originator would save time all round then as patients we can say we have had an input. Nearly all do not the different ways of getting copies of the document, whether it in a different languages or different colour for those who are colourblind.		
19	26/11/2019 09:12 AM ID: 131531157	How busy I am at a particular period		
20	27/11/2019 11:44 AM ID: 131603936	No		
21	28/11/2019 09:07 AM ID: 131646780	other work commitments taking precedence - limited access to WiFi as a mobile worker		
22	29/11/2019 11:22 AM ID: 131710333	Time to do it		
23	29/11/2019 15:52 PM ID: 131725991	Not knowing enough about the subject		
24	29/11/2019 22:13 PM ID: 131740679	Yes, timing of them being sent out for review-can we have regular timings for them, eg on a Monday, as they currently come in ad hoc and get lost among my other email/spam-if I know they may be coming on a certain day or the week/month I can keep an active look out for their arrival		
25	02/12/2019 13:48 PM ID: 131818174	No		
26	05/12/2019 14:52 PM ID: 132135391	No but if I don't understand the condition I don't send feedback		
27	05/12/2019 16:26 PM ID: 132142875	As my role is mobile - I have missed commenting on a couple of documents due to work commitments and lack of availability of WiFi from the locations I am working.		
28	05/12/2019 22:58 PM ID: 132158978	The use of words that we do not often come across.		
29	06/12/2019 19:32 PM ID: 132201556	No		
30	09/12/2019 11:30 AM ID: 132259893	Being busy at work is the main reason. When I'm at home I'm rarely on the computer anyway.		
31	09/12/2019 21:35 PM ID: 132308446	I have huge other voluntary work commitments time wise		






7. Do you think a 'welcome' document posted or emailed to new members, providing them with more information about the group, would be beneficial?

			Response Percent	Response Total
1	Yes		96.67%	29
2	No		3.33%	1

Comments:

1	18/11/2019 11:26 AM ID: 131121426	I think a terms of reference might be helpful too. What sort of comments are within the remit of the group or should we say things like 'this should be discussed with a practitioner and not sent out as a standard letter' ?
2	18/11/2019 12:12 PM ID: 131121518	Encourage people to comment by sending out a thank you note from the requestor showing the changes that have been made. We are doing this to help the NHS free of charge.
3	18/11/2019 12:51 PM ID: 131129352	Very good idea
4	18/11/2019 15:53 PM ID: 131144940	Maybe
5	18/11/2019 16:20 PM ID: 131145773	It could contain information about the make up of the reader group
6	18/11/2019 18:52 PM ID: 131158600	It's always nice to feel welcomed and wanted.
7	19/11/2019 10:57 AM ID: 131177711	Definitely could see the benefit of this - covering what to expect, how it works. Although it is fairly self explanatory.
8	19/11/2019 14:53 PM ID: 131207171	I seem to have been automatically enrolled. I enjoy taking part, but it was not properly explained why I was receiving these emails.
9	21/11/2019 14:07 PM ID: 131325617	Very important indicator of inclusion
10	25/11/2019 14:31 PM ID: 131489205	Training, some pointers might help.
11	27/11/2019 11:44 AM ID: 131603936	Maybe it would but does it really matter. People are being asked to respond to documents. The responses will collectively help you, at least I assume they do.
12	28/11/2019 09:07 AM ID: 131646780	It seems disjointed as I have no idea who is involved with the Reader Group
13	29/11/2019 11:22 AM ID: 131710333	People just get added to the reader group without a proper introduction, it'd be great to be able to have bit more explanation and certainly would make people feel more of 'a part of the reader group'
14	29/11/2019 15:52 PM ID: 131725991	This goes for the writer as well as there should be certain things on every leaflet irrespective of the subject
15	05/12/2019 16:26 PM ID: 132142875	it would encourage membership and make them feel their input can make a real difference.
16	06/12/2019 19:32 PM ID: 132201556	Members would know what they are taking on.
17	09/12/2019 11:30 AM ID: 132259893	I don't know how many members there currently are in the reader group but the numbers responding seem low. Although I admit that I've not responded to that many myself.

8. Do you feel that you get to see how your feedback has made a difference?

			Response Percent	Response Total
1	Always		3.45%	1
2	Quite often		10.34%	3
3	Sometimes		41.38%	12
4	Rarely		20.69%	6
5	Never		24.14%	7

9. Are there any other ways we could improve the reader group?

		Response Percent	Response Total
1	Open-Ended Question	100.00%	25
1	This is probably something that only the organisers can answer. Are you getting the sort of feedback and responses that you want? Do the comments from the reader group have validity? Many of my responses say the same thing about providing the information in digital format to allow the reader to access the information in a way that is relevant for them. This removes the 'do you want this in another format'? question as if it is correctly structured and written a user can manipulate a digital document so that they could for example, listen to it or read it with size 32 font - whatever their requirements are. In addition to this some of the documents would be very helpful to be in 'easy read' format. It might also be helpful if these weren't anonymous so that if necessary you could ask for more information!		
2	By getting leaflets from all the other CCG's so that there is less duplication as some of them seem to be nationwide items and not just local ones it could help everyone, not just the Leeds area and all it costs us is time. There should be certain things on all leaflets whereby comments from patients not in the reader group, can be sent to When reviewing a letter from the GP it should be checked by people at a much senior level due to various legal requirements.		
3	As a new member I cannot yet respond to questions 8 and 9. I took a guess for question 2! A face to face meeting would be appreciated.		
4	Na		
5	See earlier comment		
6	Tell the reader group if amendments have been acted upon Has our feedback been relevant/useful Tell the group if certain amendments might alter the meaning of some medical terminology		
7	Never informed whether the author has taken up any of the suggested changes which means there is no personal satisfaction to be gained from giving up time to support this project.		
8	Clear information - 1) who end reader is to be, 2) purpose of message 3) as well as yes/no give space for comments		
9	No		
10	I looked at one of the recent reports showing what had been taken on board and I was quite surprised at how little was changed, especially as the whole range of feedback was included and it was obvious how extensive that was. Maybe that process could be looked at? I wasn't involved in giving feedback for that particular project but I think that if I had been, I might have been disappointed at the changes then made by the requester. Maybe more narrative added about why certain comments weren't taken on board?		
11	Outcomes following the feedback we provide.		

9. Are there any other ways we could improve the reader group?

		Response Percent	Response Total
12	How about a six-monthly or annual meeting with an agenda at a convenient location		
13	More feedback, we never get to hear whether the suggestions are acceptable or used or rejected.		
14	Get the members together with the originator to do the review and it could be done in one go by having it modified as things are agreed.		
15	Put a final question asking about the actual survey and whether it worked well or not in getting useful information		
16	If it works at your end I would not worry about it over much. Its simple and easy, provides an opportunity to contribute and presumably is helpful to you and the authors of the documents. If you are worried about specif issues, why not ask us about them?		
17	Informing members if their suggestions have been taken up would give some satisfaction and make the role feel worthwhile		
18	It'd be great to meet other members and support each other.		
19	If it is a complicated subject then a small number being brought together could help tremendously. Sorry, I cannot give an example but one that could be helped by having a physician to answer any questions.		
20	<ul style="list-style-type: none"> - Introduce members of the group to each other via a face-to-face meeting - Instruct the group on your objectives - Describe how you require documents to be amended and methods to be used - Feedback amended documents/leaflets 		
21	<p>I think it is so important I feel very much out of my depth with some of the documents. And not been the brainiest I struggle with you ask about grammar Think may be I should not be part of the group</p>		
22	Clear instructions to those submitting documentation would be good - almost all those sent through have the same issues i.e. headings without capital letters except for the first word, inappropriate font sizes, not well spaced out, black print on a white background, unexplained medical terminology, spelling inaccuracies etc. Would a bullet point guide be useful to send to those submitting resources so they could amend these parts first and then resubmit for sending out to the Reader Group for final approval? This may then encourage members to continue to read them without feeling they are simply repeating the same comments each time.		
23	There should be a one day introduction to explain some of the requirements that are needed in the review.		
24	An occasional meeting to get to know each other.		
25	I can't think of any improvements that could be made.		