


BMJ Open What are the benefits and risks of sharing patients' diagnostic radiological images with them? A cross-sectional study of the perceptions of patients and clinicians in the UK

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ABSTRACT

Objectives The objective for this work was to assess clinical experts' and patients' opinions on the benefits and risks of sharing patients' diagnostic radiological images with them.

Setting This study was conducted outside of the primary and secondary care settings. Clinical experts were recruited at a UK national imaging and oncology conference, and patients were recruited via social media.

Participants 121 clinical experts and 282 patients completed the study. A further 73 patient and 10 clinical expert responses were discounted due to item non-response. Individuals were required to be a minimum of 18 years of age at the time of participation.

Primary and secondary outcome measures This study was exploratory in nature. As such, the outcomes to be measured for demonstration of the successful completion of this study were generated organically through the process of the investigation itself. These were: (1) the delineation of the benefits available from, and the risks posed by, widening access to diagnostic radiological images; (2) establishment of the level and nature of demand for access to diagnostic radiological images; and (3) the identification of stakeholder requirements for accessing available benefit from diagnostic radiological images.

Results 403 usable questionnaires were returned consisting of responses from clinical experts (n=121) and patients (n=282). Both groups acknowledge the potential benefits of this practice. Examples included facilitating communication, promoting patient engagement and supporting patients in accepting health information shared with them. However, both groups also recognised risks associated with image sharing, such as the potential for patients to be upset or confused by their images.

Conclusions There is a demand from patients for access to their diagnostic radiological images alongside acknowledgement from clinical experts that there may be benefits available from this. However, due to the acknowledged risks, there is also a need to carefully manage this interaction.

Trial registration number 187752.

Strengths and limitations of this study

- This study received a good level of response.
- Cross-sectional study of both patients' and clinicians' attitudes.
- Self-administered questionnaires entail the risk of respondent misinterpretation of questions.
- The sampling strategy for the patient survey may have excluded certain groups.
- As a snowballing approach to sampling was used to recruit respondents, the denominator for the samples was not defined.

INTRODUCTION

Traditionally, the field of medical imaging has experienced ongoing transformation as a result of advances in the technological landscape. A current pertinent case in point is the medical technology and cybersecurity company Sectra's share with anyone function, enabling picture archiving and communication system (PACS) managers to distribute images to anybody who has a laptop, an internet connection and the relevant access rights.¹ PACS are commonly used within radiology departments for the storage and transfer of medical imaging data.

These capabilities are particularly important in the contemporary political climate, which has seen a drive towards promoting engagement and the sharing of patients' data with them. In April 2018, NHS England announced that the number of patients who signed up to view their records or order repeat prescriptions had risen 42% to nearly 14 million.²

Hence, emerging technological capability and rising levels of patient access to their medical data³ suggest that demand from patients to access their diagnostic radiological images online will increase. However,



little work exists that considers the benefits and risks of such processes. Consequently, it is not clear that there is a rationale for this practice that extends beyond the existing capability, nor that there has been explicit thought given to what the implications of sharing patients' diagnostic radiological images with them might be. This work sets out to address this gap with the objective of assessing clinical experts' and patients' opinions on the benefits and risks of sharing patients' diagnostic radiological images with them.

METHODS

A cross-sectional study was conducted to gather opinions using self-administered questionnaires. The questionnaires contained questions that were common to both patients and clinical experts, as well as additional questions specific to each group (see online supplementary appendix 1). The patient questionnaire was open for 4 weeks (7 May 19–3 June 19) and was distributed via social media. The initial share was via Facebook but was snowballed by participants to LinkedIn and, potentially, to other platforms. While this may have influenced the results by promoting responses from technically literate individuals, this medium was chosen as it allowed for a high number of potential participants to be reached. The expert questionnaire was distributed at the UK Radiology and Oncology Congress 2017.⁴ For the purposes of this research, clinical experts consisted of individuals who work within the healthcare system and interact with imaging as a core element of their role. Most of the clinical experts were patient facing; a small number had specialised in research, training or management.

Both questionnaires included a series of statements of potential benefits and risks of patients being shown their imaging during consultations, followed by Likert-style response options asking participants to rate their levels of agreement with these. Potential benefits and risks were based on: a literature review previously undertaken by the authors⁵; a patient and public engagement and involvement (PPEI) exercise undertaken at the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Northwest London Exchange Network⁶; existing behavioural⁷; and communication⁸ theoretical frameworks identified as germane to the study.

Clinical experts were specifically asked to indicate their level of professional experience. The patient questionnaire was adaptive and asked slightly differently worded questions dependent on the participant responses. It established: whether the participant had undergone imaging; whether they saw their imaging/would have liked to see their imaging and why; their age group; and whether they considered themselves to be expert patients.

Quantitative data analysis used descriptive and inferential statistics including Kruskal Wallis H tests and Mann-Whitney U tests.

Table 1 Patient age

What is your age? (years)	
18–24	9 (3.19%)
25–34	86 (30.49%)
35–44	108 (38.29%)
45–54	27 (9.57%)
55 and over	51 (18.08%)
I do not want to reveal my age	1 (0.35%)

Patient and public involvement

A PPEI exercise undertaken at the NIHR CLAHRC Northwest London Exchange Network⁶ at the inception of the study. This process contributed to the methodological approach and influenced the design of the data collection instruments.

RESULTS

Respondent demographics and characteristics

A total of 355 responses were returned for the patient questionnaire. Of these, 73 responses were excluded due to missing data, meaning that just over 20% of respondents began but did not complete the survey. None of the data from these surveys was used. Therefore, 282 questionnaires were considered as below. While individuals under the age of 18 years were excluded from this research, all other age categories received some level of response. The modal age category was 35–44 years (table 1). This may have been a consequence of the sampling strategy and may have skewed the results as Miles *et al*⁹ assert that younger individuals are more likely to access their radiology results online. Most respondents did not consider themselves to be expert patients (table 2). The majority of respondents (95%, n=267) indicated that they had had previous imaging (table 2). Of these, 81% (n=217) stated that they had seen their images (table 2).

For the clinical experts' questionnaire, a total of 131 responses were returned. Of these, 10 responses were excluded due to missing data. Therefore, 121

Table 2 Levels of patient experience

	Yes (n (%))	No (n (%))	Unsure (n (%))
An expert patient is a person with a long-term illness whose knowledge enables them to play a role in its management. ¹⁶	75 (26.6)	174 (61.7)	33 (11.7)
Do you consider yourself to be an expert patient?			
Have you had radiological images (eg, X-rays, CT scans and MRI) taken in the past?	267 (94.68)	14 (4.96)	1 (0.35)
Did you see your radiological images?	217 (81.27)	41 (15.36)	9 (3.37)

Table 3 Distribution of clinical experts by professional role

What is your professional role?	
Clinical	93 (76.86%)
Technical	3 (2.48%)
Other	25 (20.66%)

questionnaires were considered as below. Respondents considered themselves to work in a variety of roles: 77% (n=93) held clinical roles; 2% (n=3) held technical roles; 20% (n=25) responded ‘other’ (table 3). Participants who responded other were broadly involved in service management or ‘academic’ roles, although one radiographer also identified their role as ‘other’. A range of experience levels were represented in the survey. The most populated groups were 0–5 years (29%, n=36) and more than 25 years (21%, n=26), respectively (table 4).

Demand for image access

A percentage of 94.3 (n=266) of patient participants surveyed wanted/would like to see their diagnostic radiological images (table 5). Only 2% (n=5) did not want to see their images, while 4% (n=11) were unsure (table 5). Patients who wanted to see their images gave reasons such as: ‘To understand what had happened to me’.

Perceived benefits

Patient (figure 1) and expert (figure 2) respondents indicated broad agreement with the proposed benefits of radiological image sharing. In all instances, those who selected either ‘agree’ or ‘strongly agree’ outnumbered those who had selected the other response options combined.

Questions on potential benefits were collapsed into themes in order to facilitate the organisation and logical structure of the data and to assist with the identification of patterns in the responses. The correlation of questions within these themes was tested with a Spearman rank correlation test. The themes were as follows:

- ▶ Contribution to knowledge and understanding.
- ▶ Contribution to communication.
- ▶ Contribution to engagement.

Thereafter, groups were compared with one another for each theme (online supplementary appendix 2).

Table 4 Distribution of clinical experts by years of professional experience

How many years’ experience do you have in your professional field?	
0–5	36 (29.75%)
5–10	16 (13.22%)
10–15	19 (15.70%)
15–20	13 (10.74%)
20–25	11 (9.09%)
More than 25	26 (21.49%)

Table 5 Patient desire to see images

Did you want/would you like/have liked to see your radiological images?	
Yes	266 (94.32%)
No	5 (1.77%)
Unsure	11 (3.9%)

Contribution to knowledge and understanding

This theme encompassed the understanding and recollection of health information. These questions had a strong positive correlation for both groups (patient R=0.703; expert R=0.652), and the association was significant at the 0.001 level. One respondent noted ‘helpful for understanding and is also interesting’.

Contribution to communication

This theme encompassed speaking with clinicians and asking questions. These questions had a strong positive correlation for the patient group (R=0.724) and moderate for the expert group (R=0.371). The association for both groups was significant at the 0.001 level. Comments included that seeing the image ‘was helpful when explaining my treatment’.

Contribution to engagement

This theme encompassed acceptance of health information, following care plans, management of patient’s own health and the promotion of partnership working. These questions had a strong positive correlation for patient respondents with R values ranging from 0.525 to 0.695 and a weak to moderate correlation for experts with R values ranging from 0.000 to 0.592. The association for both groups was significant at the 0.001 level. One patient remarked ‘I like knowing what the issues are’.

Perceived risks

Patient (figure 3) and expert (figure 4) respondents indicated broad disagreement with the proposed risks of radiological image sharing. In all instances for patients, those who selected either ‘disagree’ or ‘strongly disagree’ outnumbered those who had selected the other response options combined. The clinical experts were more nuanced, but, in all cases, the majority either ‘disagreed’ or ‘strongly disagreed’ with the proposed risks.

Questions on potential risks were collapsed into themes in order to facilitate the organisation and logical structure of the data and to assist with the identification of patterns in the responses (online supplementary appendix 2). The themes were as follows:

- ▶ Negative emotional responses.
- ▶ Negative impact on understanding.

Thereafter, groups were compared with one another for each theme (online supplementary appendix 3).

Negative emotional responses

This theme encompassed upsetting patients and increasing their anxiety. These questions had a strong

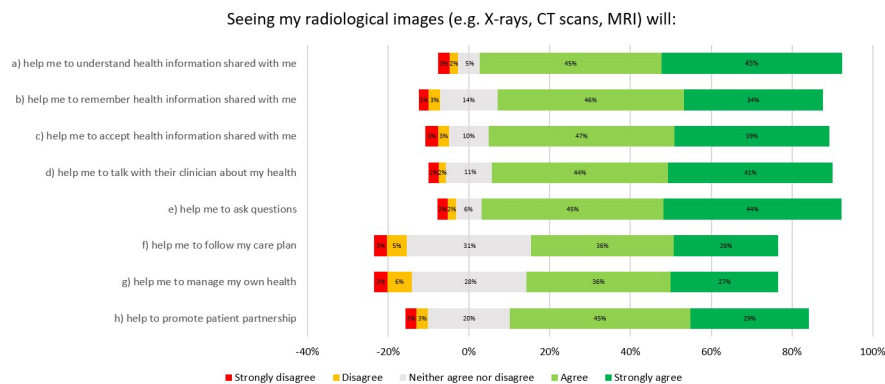


Figure 1 Patient agreement with potential benefits – deviation from neutral.

positive correlation for both groups (patient: $R=0.648$; expert: $R=0.512$). The association for both groups was significant at the 0.001 level. While clinical experts were more concerned with negative emotional impact than patients, one respondent raised concerns about people being ‘frightened and confused by seeing the images’.

Negative impact on understanding

This theme encompassed confusing patients and being difficult for them to understand. These questions had a strong positive correlation for both groups (patient: $R=0.652$; expert: $R=0.468$). The association for both groups was significant at the 0.001 level. One respondent noted ‘to some it may be beneficial, to others it may confuse’.

Support for image sharing

Levels of support for image sharing were high and 88% of patients agreed or strongly agreed that sharing images with patients was a good idea (table 6). This was only echoed by the clinical experts of whom 81% agreed or strongly agreed that sharing images with patients was a good idea (table 7). Underpinning this were high levels of agreement from both groups with proposed benefits, for patients this was 78.49% and for clinical experts it was 73.35% (figure 5).

DISCUSSION

The results demonstrate that there is broad agreement across both respondent groups on the potential benefits available from providing patients with access to their diagnostic radiological images. There is also some level of agreement on the potential risks, although this was less pronounced. Overall, there is evidence of support for this process from both surveyed groups, although there were differences in opinion regarding the implications of image sharing both between and among groups.

Similarities in opinion

Overall, both groups agreed that sharing images with patients was a good idea. Furthermore, there were strong levels of support with the vast majority of both groups agreeing with the proposed benefits. The mean level of agreement for patients was 78.49% and for clinical experts it was 73.35% (figure 5). As both groups consider that image sharing is a good idea, a question is raised regarding what the impediments to achieving this are. There are the obvious considerations such as costs, technological and other physical resource requirements, but it also raises issues such as whether there is sufficient education for clinicians to feel comfortable with participation in this interaction. There was also similarity in the mean levels of agreement with the risks, although this was less convincing. For patients, this was 5.1% and for clinical experts it was 27.76% (figure 5), which suggests that, while there

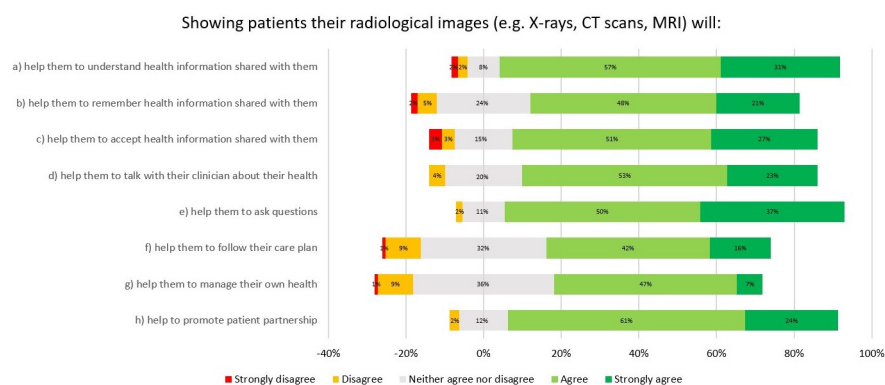


Figure 2 Clinical expert agreement with potential benefits – deviation from neutral.

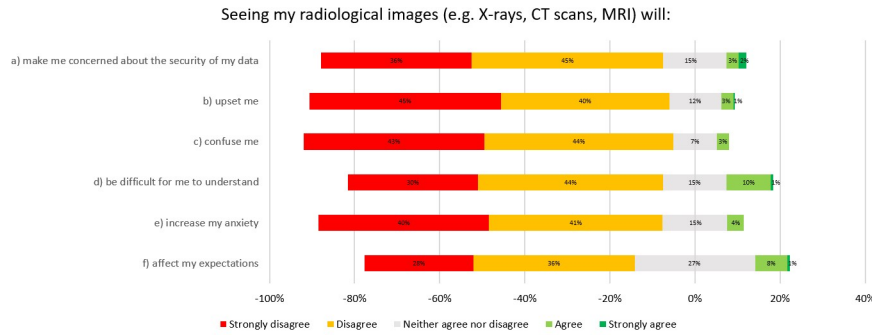


Figure 3 Patient agreement with potential risks – deviation from neutral.

is some level of concern regarding the risks addressed, patients are the less concerned group.

Differences in opinion

There were also differences between the groups. Patients mean ranked higher on the scale asking whether sharing images with patients was a good idea than clinicians did and their views also differed from clinical experts in terms of the impact on their knowledge and understanding (ranked higher), communication (ranked higher), potential for negative emotional impact (ranked lower), likelihood to confuse (ranked lower), concern regarding data security and likelihood to affect their expectations (ranked lower). This potentially suggests a throwback to the age of paternalistic medicine where doctor knows best. New thinking suggests that the patient should be given a greater opportunity to assess the risk for themselves.

There were additional differences within the groups by characteristic. In terms of patient age, the older the participants, the higher they ranked the impact of seeing imaging on the knowledge and understanding scale. In terms of the patients' experience of having experienced imaging, differences were reported by participants who had imaging and those who had not. Those who had not had imaging ranked higher on the negative emotional response scale than those who had. Finally, patients who had not seen their imaging ranked higher on the negative emotional response scale than those who had seen their imaging, although few respondents had not seen their imaging.

Comparison with prior work

To date, where there has been exploration of sharing radiological results with patients, the focus has tended to be on the interpretation of the patient's images. There are varying mechanisms for this, and a study in the USA by Lye *et al*¹⁰ found that these were complicated for patients. However, the processes do exist. The patient may be given access to the radiologist's report Lee *et al*¹¹ and one study found that half of patients with the opportunity to access their report would do so.¹² However, questions have been raised regarding the patients' ability to interpret and use these data meaningfully so several methods of enabling its meaningful use have been proposed. One suggestion is that the patient be given an explanation by either the referring clinician or the radiologist. In such cases, patients have been found to prefer to receive the results from the referring clinician.¹³

There are arguments, however, to support the radiologist role in this process. Liao and Lee¹³ note that there is the potential to raise the profile of radiologists with the general public. This correlates with the work of Lee *et al*,¹⁰ who highlight such interactions as providing the potential for the evolution of the patient–radiologist relationship and for radiologists to become active partners in their patients' care.¹⁰ Both of these solutions, however, have resource implications for clinicians. One way to overcome resource shortages may be found in the work of Cook *et al*,¹⁴ who explored the potential of an online system to annotate clinical terms with lay definitions. Not only would this reduce the requirement for clinician

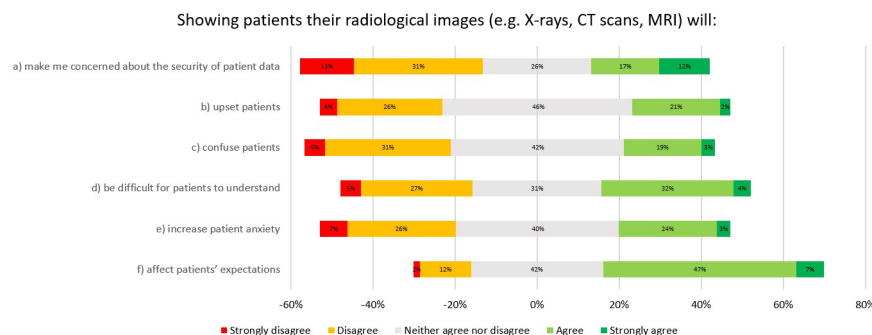


Figure 4 Clinical expert agreement with potential risks – deviation from neutral.

**Table 6** Patient agreement that image sharing is a good idea

Sharing radiological images with patients is:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
A good idea	4 (1.41%)	3 (1.06%)	28 (9.92%)	121 (42.9%)	126 (44.68%)

input, but it was found to have the potential to improve patient understanding of these data. None of these studies directly address the question of patients' attitudes to the benefits and risks of viewing the images themselves.

However, a study by Halaska *et al*¹⁵ considers patient attitudes about viewing their radiology images online preintervention. This paper reports results of a sample of 105 patients treated at UHealth who lived in Colorado. Some of the findings of Halaska *et al*'s¹⁵ paper are supported through the research reported here. However, Halaska *et al*¹⁵ consider attitudes towards online sharing of images, whereas this research considers direct sharing within a consultation. This research also broadens the work undertaken by Halaska *et al*¹⁵ by considering a UK sample, a broader population, both preintervention and postintervention, and includes a comparison of patient attitudes with those of clinical experts.

Implications of findings

Patient access to their diagnostic radiological images is set to increase, and there is a need to consider how to facilitate this in a meaningful and safe way. This work suggests that consideration is needed regarding whom the images are being shared with, whether the individual wants to see them and what benefit that individual might receive from exposure to their images. It also raises issues such as what training or other resources may be needed to do this.

Limitations

Self-administered questionnaires entail inherent limitations. These include the risk of respondent misinterpretation of questions and limited scope to explore deeper factors underlying attitudes. An attempt was made to mitigate these factors. The former by piloting the questionnaire to assess ease of understanding, the latter by following up the questionnaires with semistructured interviews to gain further depth of understanding. It is also acknowledged that some demographic data that were not collected, such as respondent gender, may have been valuable. There was also the potential for response bias since it is possible that individuals who respond to surveys about their healthcare may be more likely to want to see their images (and have had images) and thus may not be representative of the population. Finally, the sampling strategy for the patient survey may have excluded certain

groups. This potential limitation was accepted on the basis of the increase in the numbers of potential participants which it enabled.

CONCLUSION

Advancing technologies are providing increasingly frequent and convenient opportunities to share patients' medical images with them. With growing technological awareness among the general population, there may be an increase in the number of patients making use of this access. This work builds on existing anecdotal views that patients want to see their images by providing evidence to support this and further suggests that there is, in fact, broad support for this process from both the clinical expert and the patient community. Finally, this work identifies what the benefits and risks of this interaction might be.

Several benefits of sharing images with patients were identified. The most pertinent of these were the opportunity to: improve patient knowledge and enhance their understanding of health information; support the patient–clinician communication process; promote patient engagement and empowerment; and encourage positive healthy behavioural change. However, a number of potential risks were also identified. These risks surrounded concerns regarding the potential to elicit negative emotional responses from patients; the risk that patients would not understand their imaging; and logistical issues.

These results raise a number of important questions for consideration. For example, via which media is it appropriate to share images with patients, for example, face-to-face, or online portals? Does this interaction create legal or ethical issues that need to be addressed? What educational requirements are there for both clinicians and patients in order to facilitate this process and what accompanying information needs to be given to patients to support them to make it meaningful?

It is important, therefore, that as patient access to their diagnostic radiological images becomes more commonplace, this process is carefully managed in order to promote access to available benefits while mitigating potential risks. To this end, further research is required to

Table 7 Clinical expert agreement that image sharing is a good idea

Sharing radiological images with patients is:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
A good idea	1 (0.83%)	0 (0%)	21 (17.36%)	69 (57.02%)	30 (24.79%)

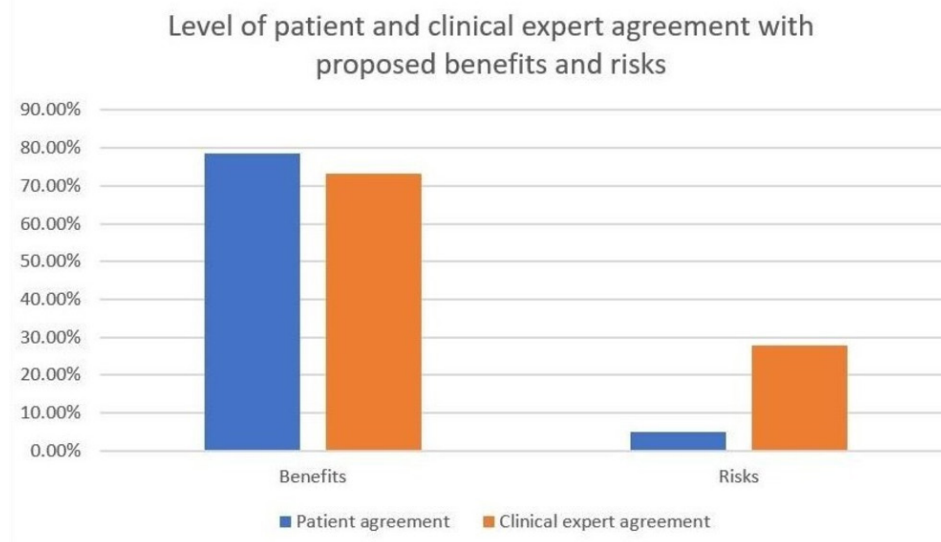


Figure 5 Level of patient and clinical expert agreement with proposed benefits and risks.

explore how these benefits and risks might be effectively managed.

RECOMMENDATIONS

This work represents a cross-sectional assessment of expert and patient attitudes towards the sharing of images with patients. It is recognised that these findings will not be generalisable. This is particularly true in the context of the rapidly changing political and technological environment. Further research will be needed to confirm the broader applicability of these findings. Additionally, recognising the limitations of this questionnaire, further research is needed to clarify the attitudes and beliefs underpinning participants' responses in order to deepen understanding of these factors as well as to incorporate further participants for some less well represented groups.

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