A scoping review was conducted to assess the existing evidence in research literature relevant to the following three research questions:

1. Do people want to know the findings and impact of the research they have been involved in?
2. What do people want during their involvement in research?
3. What criteria would participants use to rate their experience of being involved in research?

**Method**

We searched Google Scholar using the following terms: ‘health [service] research’, ‘patient involvement/participation/experience in [health] research’, ‘communicating research results/findings to patients’ and ‘criterion evaluating health research participation/involvement experience’. We conducted our initial cursory search separately and altogether identified thirty-two potential papers. However, after conversing with one another we made decisions regarding whether it was necessary to exclude several of these articles based on our criteria. In discussion with RL we made the decision to distinguish (for this phase of the review) between patients as ‘participants’ in research and patients who are ‘involved’ in research, for example, influencing research design. We only included the former in this review. We also excluded articles focusing specifically on providing feedback on the patient’s individual clinical results (e.g. whether their condition had improved) as this was not directly relevant to the type of research being undertaken as part of the Care Opinion cohort. We also initially excluded those that did not incorporate ‘patients’ specifically as participants, however, we relaxed our criteria and accommodated one article that employed both patient and public participants. With these criteria applied, we identified eleven papers relevant to our investigation, although very few addressed all three of the research questions collectively.

**Results**

Of the eleven included articles, ten were empirical clinical research articles, six of which incorporated qualitative methods, typically surveys or interviews, alongside one quantitative questionnaire and three mixed method designs; six of the investigations were executed in the UK, two in the US (one jointly in the US and Canada) and one in Malawi, and one failed to specify. The remaining article was a systematic review, *What potential research participants want to know about research: A systematic review*, encapsulating fourteen studies taken from various countries aiming to establish empirical evidence about the kind of information patients want receive before, during and after participation in health research5. Only two of the articles contained in this review were published prior to the year 2000, thus it was concluded that the research findings reflect those of present day. In some respects, the literature was fairly limited, hence inferences were made based on the available evidence and these will be specified throughout the review.

**Research Question 1:**

We begin by addressing the first research question of whether or not patients who have participated in research want to know the findings and impact of this research. There exists a high volume of literature indicating that patients do wish to be informed of the findings of research to which they have contributed1,2,3,5,6. In one qualitative study investigating the experiences in research of patients with rheumatic conditions, patients did not explicitly communicate the desire to be informed of the research findings, however, the reported frustration exhibited by those that did not receive feedback led us to infer that these patients would have liked to and perhaps expected to be enlightened about the findings of the research9. An additional qualitative study revealed that very few participants were given the opportunity to request the findings of research they had partaken in, but the authors later acknowledged and discussed the conceivable benefits of informing them4. Essentially, according to existing publications patients generally do want to know the findings of research they have participated in and it is the responsibility of the researcher to ensure this a possibility. Few investigations directly report patients’ desire to know the impact of research, however, two studies comment on the altruistic motivations of patients to participate6,7, and thus it can be inferred that these individuals feasibly would want to know whether or not the research has had a positive outcome on its intended audience.

A recurrent theme in the literature is the significance of the format in which the research findings are communicated to patients. The preferences for this appear to be unique and personal to the individual, hence a recommendation for researchers is to tailor the format of dissemination of the findings to the participant’s requests. In a quantitative questionnaire of heart attack rehabilitation patients, 80% indicated that they wished to be informed of the research findings via a letter form, 18% in a meeting and 12% by email or online – several wanted to be informed via two distinct means2. One plausible explanation for the differences that exist among patients in their preferences for the format of obtaining the findings is the sensitivity or personal relevance of the research topic. To illustrate, in a epidemiologic research study of paediatric brain tumour, while all mothers articulated the desire to be informed of the research findings, patient mothers were more inclined to request additional information and a personal telephone call as opposed to control mothers (those of children absent of brain tumours) whom were less concerned with this1. Thus, it is logical to suppose that participants with a personal connection to the research topic under investigation will want to be informed of the findings in a more personalised manner.

**Research Question 2:**

Current research outputs for what participants expect from their experience of research involvement has tended to cluster around three themes. The first recurrent theme was feeling that researchers respect6,9.Participants reported feeling that respect was shown to them by taking the time to establish a trusting relationship with the research team and feeling that the team will listen when participants have something to contribute6. Interviews with adolescent participants further revealed a worry that respect would not be given to their perspectives or concerns because of age differences between them and the research group9.. In such cases participants may want reassurance that respect will be afforded to them regardless of intergroup differences.

The second theme to emerge from the literature was the clear communication of information throughout the participation process4,6,9,10,11. Prior to participation, potential participants report wanting adequate information regarding the study such that they feel their consent is fully informed4, and noted that such information should be presented in written mediums, such as on the consent form6. Throughout participation also, participants say they want to feel continually informed about the progression of research. A systematic review of studies on what information participants want to be informed of found pooled statistically significant evidence indicating participants want to be informed of the aims, length, voluntariness, risks, benefits and confidentiality of the study. Furthermore, two papers identified grey areas of information dispersal, with young participants sometimes feeling unsure if a treatment had comprised standard clinical care or research participation9, and participants involved in an acute emergency RCT being unable to give informed consent due to the mental distress they were in and the immediacy of the care11. In such cases, participants were still happy to have taken part in the research, since either treatment would be expected to improve their condition but affirmed that they would want adequate study information to be disclosed to them as soon as they would be able to understand and retain it.

The final theme in the data regards participants wanting the quality of the healthcare afforded to them for the duration of research to be consistent with, or potentially better than, standard healthcare7,8,10,11. One paper, interviewing research participants in Malawi8, noted that the statutory healthcare system participants would otherwise be treated in is under-staffed and under-funded, meaning some aspects of healthcare, such as follow-ups, are often missed; in such cases research participation is seen as advantageous as the university-associated clinicians afford them more time to assess their condition at more regular intervals. In UK-based research, a similar trend is evident, with mental health patients noting that the time to discuss their healthcare and previous experiences with someone outside of their standard care team was beneficial to their wellbeing10, and experimental group participants in clinical research described the advantages to taking new, often shorter, treatment regimens contained in research7.

**Research Question 3:**

The survey and interview questions used in research were explicitly stated in three of the papers we reviewed. These items might provide some suggestions for how a criterion evaluating the participation experience might be constructed. First, survey-based research offer examples of the kinds of questions which are currently being used in the understanding of participation experiences. Assessments of the overall quality of the participation experience have been completed using either an open-ended question about the experience10. Qualitative papers used a 5-point Likert scale, or a 10-point rating scale, to rate the likelihood participants will recommend participation to friends and family, how well-informed participants felt they were in preparation for the study from the information provided on the consent form, and whether they felt pressured or rushed into participation by researchers6.

No research was found which attempted to develop or empirically validate criterion to assess the experience of research participation. However, further potential criterion from the remaining literature can be inferred from participants’ descriptions of what mattered to them during research participation, as summarised in the preceding paragraphs. In the attached literature scoping table, inferred criterion have been demarcated using italics. As participants often reported improvements to the quality of care during research participation as an advantage of involvement7,8,10 a criterion could be asked whether their involvement felt consistent with, or identifiably different from standard healthcare in terms of consultation frequency and length, duration of treatment and development of knowledge relevant to their healthcare. If so, a further item could ask, did such differences feel beneficial to their wellbeing? Perceptions of researchers’ respect towards participants could be assessed via Likert-scale ratings of whether participants felt able to voice disagreements with researchers9, whether participation has impacted their relationship to their care providers7, if the conduct of researchers and the process of the study felt appropriate3,11, and whether they trusted researchers to handle their care effectively7,8. Finally, participant’s access to information can be assessed by asking whether they felt adequately informed about the topic area prior to and during participation5.

To summarise, research evidence strongly suggests that, when patients participate in health service research, they want to know the general findings they helped to produce. It was further noted that, though the preferred means of dissemination were inconsistent across studies, the more personally relevant the research was, the more likely participants were to want an individualised form such as a phone call. Although empirical evidence cannot be gathered with regards to patient interest in the impact of research, considering their interest in the results, and the frequently reported altruistic motive behind participation, it can arguably be inferred that they do. Evidence on what participants want during their involvement formed around three main themes: to feel respected by researchers, to feel well informed about the research process before, during and after their involvement, and to receive healthcare consistent with, or potentially better than, the standard clinical care they would otherwise receive. Finally, a literature base of development and validation of evaluation criterion for the participation experience does not appear to exist. However, future research attempting to develop such criterion would likely benefit from examining the surveys and questionnaires currently being used in individual research, and the topics which it will be important to assess can partly be inferred from what participants report wanting during involvement.

**References**

1) Bunin, G. R., Kazak, A. E., & Mitelman, O. (1996) Informing subjects of epidemiologic study results. Children's Cancer Group. *Pediatrics, 97*(4), 486-491.

2) Dalal, H., Wingham, J., Pritchard, C., Northey, S., Evans, P., Taylor, R. S., & Campbell, J. (2010) Communicating the results of research: how do participants of a cardiac rehabilitation RCT prefer to be informed? *Health Expectation, 13*(3), 323–330. <https://doi.org/10.1111/j.1369-7625.2009.00580.x>

3) Elbourne, D. (1987). Subjects' views about participation in a randomized controlled trial. *Journal of Reproductive and Infant Psychology, 5*(1), 3–8. <https://doi.org/10.1080/02646838708403468>

4) Fernandez, C. V., Kodish, E., Taweel, S., Shurin, S., & Weijer, C. (2003). Disclosure of the right of research participants to receive research results: An analysis of consent forms in the Children’s Oncology Group. *Cancer, 97*(11), 2904-2909. <https://doi.org/10.1002/cncr.11391>

5) Kirkby, H. M., Calvert, M., Draper, H., Keeley, T., & Wilson, S. (2012). What potential research participants want to know about research: A systematic review. *BMJ Open, 2*(3). <https://doi.org/10.1136/bmjopen-2011-000509>

6) Kost, R. G., Lee, L. M., Yessis, J., Wesley, R. A., Henderson, D. K., Coller, B. S. (2013). Assessing participant-centred outcomes to improve clinical research. *The New England Journal of Medicine, 369*(23), 2179-2181. <https://doi.org/10.1056/NEJMp1311461>

7) McGrath-Lone, L., Ward, H., & Schoenborn, C. (2015). The effects of cancer research participation on patient experience: A mixed-methods analysis. *European Journal of Cancer Care, 25*(6), 1056-1064. [https://doi.org/10.1111/ecc.12336](https://owa.bradfordhospitals.nhs.uk/owa/UrlBlockedError.aspx)

8) Mfutso-Bengo, J., Ndebele, P., Jumbe, V., Mkunthi, M., Masiye, F., Molyneux, S., & Molyneux, M. (2008). Why do individuals agree to enrol in clinical trials? A qualitative study of health research participation in Blantyre, Malawi. *Malawi Medical Journal, 20*(2), 37-41. <https://doi.org/10.4314.mmj.v20i2.10898>

9) Parsons, S., Thomson, W., Cresswell, K., Starling, S., & McDonagh, J.E. (2018). What do young people with rheumatic conditions in the UK think about research involvement? A qualitative study. *Pediatric Rheumatology, 16*(1), 35. [https://doi.org/10.1186/s12969-018-0251-z](https://owa.bradfordhospitals.nhs.uk/owa/UrlBlockedError.aspx)

10) Taylor, P. J., Awenat, Y., Gooding, P., Johnson, J., Pratt, D., & Tarrier, N. (2010). The Subjective Experience of Participation in Schizophrenia Research: A Practical and Ethical Issue. *The Journal of Nervous and Mental Disease, 198*(5), 343-348. [https://doi.org/10.1097/NMD.0b013e3181da8545](https://owa.bradfordhospitals.nhs.uk/owa/UrlBlockedError.aspx)

11) Tutton, E., Achten, J., Lamb, S.E., Willett, K., & Costa, M. L. (2018). Participation in a trial in the emergency situation: a qualitative study of patient experience in the UK WOLLF trial. *Trials, 19*(1), 328. [https://doi.org/10.1186/s13063-018-2722-4](https://owa.bradfordhospitals.nhs.uk/owa/UrlBlockedError.aspx)

**Acknowledgments and disclaimer**

*This research was funded by the National Institute for Health Research (NIHR) Yorkshire and Humber Patient Safety Translational Research Centre (NIHR Yorkshire and Humber PSTRC). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.*