



Recruitment Enhancement Tool for Researchers: *Learning from the experience of people who have taken part in research*

This document is a recruitment enhancement tool, designed for use by research professionals who are in the process of setting up a clinical research study. The information contained in this document is based on feedback from over 7,000 research participants between 2015 and 2020 via the Participant in Research Experience Survey. The survey is produced by the NIHR Clinical Research Network Eastern.

The information in this document comes directly from people who have taken part in a research study, their words, their experiences and their ideas for improvement.

The aim of the document is to give the researcher a better understanding of what is important to the participant during the delivery of the research, so that they might design their research study with this in mind. It is important to design a study which gives participants a good experience to ensure recruitment and retention to the study is successful.

Giving research delivery teams a voice

Research delivery staff can be important influencers. Consider providing a way for them to feedback their comments and suggestions on how to improve future study design and delivery.

Information about the study

Information is very important to participants. This includes information about their own health, test results and understanding where they are in the study and whether the study has finished. Many participants are also interested in the “bigger picture” and would like information about the study as a whole.

Things to consider

- How will you provide regular updates on the progress of the study? Will you provide it to the research teams so that they can pass it on to the participants, or will you update the participants directly?
- Could you provide one or more of the following?
 - Newsletter (through the post, by email or through a website)
 - Postcard
 - A one off or regular phone call from a member of the research team.
 - Text message (this might include a link to a website or newsletter)
 - Using a smartphone App
 - Through a range of methods to suit the needs of the participant

- Consider how and when contact details such as email and postal address and phone numbers will be collected and stored, in line with GDPR requirements.
- Ensure that all updates are provided in easy to understand language, and in a format that allows the research participants to access and understand it.
- How often will you provide updates?
- When designing the research study, ensure that there is an opportunity at each stage of the trial for participants to ask questions.

“I was given step by step on my progress in a kind and understanding way. Not rushed, my questions were answered in the best way possible”

- Consider how you will keep participants informed of the stage they are at in the research study and whether the research or their participation in the research has come to an end.
- Could you send a postcard or letter to acknowledge the end of the study and to say thank you, or could a member of the team arrange a phone call?

Feeding back the results of the research study

Whilst some research participants do not wish to know the results of the research they took part in, a larger proportion are interested and feel it is important to have access to this information. It is also important to the majority of participants to receive the results of any tests they are given.

Things to consider

- If the results won't be made available to participants, ensure this is explained at the beginning and end of the trial.
- Make sure the research team knows how the results will be made available so that they can tell the participants at the start of the trial and remind them during or at the end of the trial.
- Make it easy for participants to find the results of the study and make it available in a variety of formats, e.g. website, by post or email etc.
- Provide the results in an easy to understand format, free of jargon and medical terminology.
- Ensure the results are available in other languages, large format, plain English etc.
- Read the NHS Research Health Authority's #MakeItPublic Strategy to understand requirements and expectations around making the results of research available to the study participants and the public. You can access the strategy via their website www.hra.nhs.uk

Explaining the study and receiving consent

It is important to make information as accessible as possible

Things to consider

- Provide the research staff with simple to understand patient information so that they can use this to explain the study to the participant during the consent process. This could be a printed information sheet, a link to a website and/or a video to explain the study. Can you offer alternative communication methods to support the research team?
- It is important to have the information in a format which can be taken away by the participant so that they can refer to it at a later date. This is particularly important when information is given to the participant at a stressful time or when they are very unwell and unable to retain the information.
- Provide the information in other languages and other formats so that patients are not excluded. This might include translations, large print and audio or visual formats. Consider accessibility for colour blind or dyslexic participants.
- The language used should be mindful of participants with low literacy levels.
- The information should explain exactly what will be expected of the participant so that they can make an informed choice on whether to take part in the research. This should include how many appointments and how often, the procedures involved e.g. blood pressure, x-rays, bloods etc
- If consent is required from the participant at a time when they are particularly unwell or stressed, consider the need for a second appointment so that they have time to absorb the information given and have the opportunity to discuss it with their health professional again.

Can technology improve participant experience?

It is important for the NHS to continue to develop the use of technology, however, we must not forget that many people are still more comfortable using paper rather than online content.

Things to consider

- When using technology, it is important to offer alternative methods such as paper versions so that nobody is excluded.
- Consider using technology to deliver your research study. The following have been suggested by participants:
 - Provide information using email, websites and video links.
 - Feedback results using text messages, links to websites or email.
 - Offer virtual appointments through video calls or by telephone to cut down on the number of visits to hospital, avoid hospital parking and reduce travel.

What to consider regarding appointments:

The survey demonstrates that a flexible approach to appointments provides participants with a better experience of taking part in research. This includes where, when and how often appointments take place.

Things to consider

- In light of the COVID-19 pandemic, consider whether you can reduce the number of face to face appointments by offering virtual appointments. This will also reduce the need for travel and parking.
- Consider reducing the number of face to face appointments by feeding back test results via telephone, email or letter.

“Local appointments, less appointments or telephone or skype appointments would have made it easier”

- Remember that, despite the move to more online appointments, some participants still prefer face to face contact with their healthcare provider if given the choice.
- Appointments should, where possible, be flexible and alternative times and dates offered. This would allow participants to:
 - Attend appointments outside of work or school, in the evening or at weekends
 - Avoid the rush hour congestion
 - Attend the hospital at times when the car park is less busy
 - Allow participants to attend appointments that meet their individual health needs, e.g. a person with a chronic respiratory condition may have difficulty arriving for an early morning appointment
 - People using public transport would need appointments that fall within the timetable for that transport. Older people can only use their bus passes after 9.30am.
 - Offer hospital transport or refer to voluntary transport providers for support in attending appointments.

“Car parking is a nightmare, parking charges are a nightmare, it took ages to park”

- Consider whether it is possible to offer appointments in the participant’s home.
- Where possible, arrange all appointments and procedures in one day to reduce the number of times the participant is required to attend hospital.
- Ensure the participant is able to get to the appointment and if not offer hospital transport or make arrangements through your Trusts volunteer driver scheme if you have one.

“You could have made it easier by providing transport”

- Could any of the appointments and/or procedures e.g. bloods, take place in a clinic closer to where the participant lives?
- Could blood sampling or other monitoring be carried out by the participant themselves?
- Ensure that clear guidance is offered to participants prior to appointments to avoid confusion e.g. whether they should be nil by mouth, whether they should take their medication before the appointment etc.
- If medication is needed as part of the study, if possible, ensure this is readily available in advance so the participant does not have long waits at the pharmacy.
- Consider whether the medication can be delivered to their home.

“There were occasions when the drug wasn’t ready and I had to wait up to 2 hours without being notified of the reason for the delay”

- Send the participant a text message or email the day before their appointment to remind them.

- Ensure the participant knows where to attend for their appointment, provide directions, a map or offer to meet them if necessary.

Make it clear how to access further help and support

Making it clear where to go for help and support during the research trial is important reassurance to the participant and can help alleviate concerns.

Things to consider

- The participant should always be provided with a contact name and number for the research team, to reassure them that there is help and assistance available, should they need it. This may include an emergency contact.

“It was comforting to know that if I had any problems or questions that I could contact the team direct by phone or email”

- Are you able to offer contact information so that participants can get in touch with someone on your team should they wish to?
- Ensure that clear guidance is available to offer to participants prior to appointments to avoid confusion e.g. whether they should be nil by mouth, take their medication before the appointment etc.
- Ensure further support and information is available to participants who are expected to carry out procedures at home (self swab tests, finger prick tests, recording measurements, completing diaries etc).
- Make it clear whether payment for time and travel will be offered and how this can be accessed. This will improve access to research trials for people on low incomes. Does your Trust offer subsidised or free parking for research participants?

Giving feedback

- It's important to give participants an opportunity to feedback their experiences. Consider an appropriate time to give out the Participant in Research Experience Survey. For more information visit the patient experience page of CRN Eastern's Hub Home Site: <https://sites.google.com/nih.ac.uk/crneasternhubhome/hub-home>

For free advice please contact the **NIHR Research Design Service East of England:**

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Or complete the client enquiry form: <https://rds-roe.nihr.ac.uk/contact-us/client-enquiry-form/>

For further information on the CRN Eastern Participant in Research in Research Experience Survey please contact:

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Thank you to the research delivery staff who gave out the Participant in Research Experience Survey over the past few years and to the 1000's of participants who have completed the survey. This has enabled us to produce this comprehensive information sheet so that we can learn from participant experience and improve the way we deliver research.

“Being on a research trial has been a wonderful experience. Apart from the fact that the drug being trialed has prolonged my life, it has also made me feel that I am doing something worthwhile”