



## Recruitment Enhancement Tool for Research Delivery Teams: *Learning from the experience of people who have taken part in research*

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This document is a recruitment enhancement tool, designed for use by research delivery teams. The information 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 and delivered annually by research teams across the Eastern region.

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 research staff a better understanding of what is important to research participants and provide ideas for improvements to the service provided. Improving participant experience will help to ensure successful recruitment and retention to studies.

### **Your voice is important too!**

Research delivery staff can be influencers. Feeding back comments and suggestions from research participants on how to improve study delivery may not result in changes to the current study protocol but it could influence future study design.

### **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**

- Good communication with participants is important throughout the study.
- Find out whether the national study team will be providing regular updates about the study. Consider how you might pass on this information to your participants. You could provide one or more of the following:
  - Research Study Newsletter (through the post, by email or website)
  - Postcard
  - A one off or regular phone call from a member of the research delivery 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, postal address and phone numbers for texting will be collected and how they will be stored, in line with your Trusts GDPR policy.

- 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.
- Consider how often and when you will provide updates.
- Give the participant some idea at the outset how long the study is likely to last.
- Ensure that participants are offered the opportunity at every stage of the trial to ask questions.
- You could attend the CRN Eastern Communications in Research training, contact [crneastern.training@nih.ac.uk](mailto:crneastern.training@nih.ac.uk) for more information.

*“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 results

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 most participants to receive the results of any tests they have.

#### Things to consider

- If scans, bloods or other procedures are carried out as part of the research study, clearly explain how and when the results of these procedures will be provided to the participant. If the participant will not be provided with these results, ensure this is also clearly explained.
- Provide the participant with information about how and when the results of the research they took part in will be published. You could remind them at the end of the research study.
- If the results of the study won't be made available to the participant, ensure this is explained at the beginning and end of the trial.
- 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](http://www.hra.nhs.uk)

### Explaining the study and receiving consent

It is important to make information as accessible as possible

#### Things to consider

- To support the use of the patient information sheet when explaining the research to the participant, consider whether a website, video link, picture cards or other forms of communication are also available to further enhance understanding.

- If you feel alternative communication methods are needed (e.g. large print, pictorial, audio, translation etc) contact the study team to request this.
- 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 could be either printed or provided electronically. 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.
- Be mindful of low literacy levels when explaining the study.
- 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 the number of appointments, the procedures involved (bloods, x-ray, blood pressure, throat swabs etc) and how often these will be done.
- If consent is required from the participant at a time when they are particularly unwell or stressed, consider the need for a second appointment. This would enable them to better absorb the information given and have the opportunity to discuss it with their health professional again.
- Consider whether consent can be given virtually.
- You could attend the CRN Eastern Informed Consent training, contact [crneastern.training@nhr.ac.uk](mailto:crneastern.training@nhr.ac.uk) for more information.

### Can technology improve participant experience?

It is important for the NHS to continue to develop the use of technology, however, we must be careful not to exclude people who are more comfortable using paper rather than online content.

#### Things to consider

- When using technology it is important to offer alternative methods, where possible, such as paper versions so that nobody is excluded.
- The use of technology may be required as part of the study. Be mindful that some participants will need additional help and support to use it.
- If participants do not have access to technology, consider offering other methods so they are not excluded. For example, if the study involves recording diary entries online, consider whether a member of staff can record their entry via a telephone call.
- Consider whether you can use technology to provide information (email, website, video links) or to feedback individual results and study results (text messages, links to websites, email).
- Could you use technology to offer virtual appointments (video calls, telephone)?

### 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.

***“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 delivery team, to reassure them that there is help and assistance available, should they need it. This should include an emergency contact for out of hours.
- Share the contact details of the national study team with the participant if this is available.
- 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).

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

- 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?

## Some final thoughts from research participants

These points are taken from survey comments left by research participants and demonstrate the importance of giving patients the opportunity to take part in research.

### Things to consider

- Participants often take part in research because they want to give something back to the NHS. Whilst some know that the research will not benefit them, particularly if they are in palliative care, they are still glad of the opportunity to take part and help others.

*“I felt it was valuable and important to take part, in order to further research and benefit others in the future as I am benefiting from others participation in the past”*

- Participant experience is improved when seeing the same clinicians and familiar faces during the course of the study and many appreciate building relationships with the clinical staff.
- Feedback suggests that participants would appreciate the opportunity to talk to other participants who are taking part in the same study, to share experiences and get support.
- Many participants feel a benefit from taking part in research, feeling useful and taking comfort in feeling needed and valued by the clinical staff, even though often the research does not benefit them personally.

*“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”*

## 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>

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**For further information** on the CRN Eastern Participant 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.

*“The friendliness of absolutely everyone was amazing. It made you feel like they really care and I cannot express the gratitude I feel and how much it benefits your health to think that someone cares”*