Optimising Patient Research Experience Checklist

The checklist overleaf is based on themes identified in feedback collected from 4,665 clinical research participants during 2017/18 through the NIHR Clinical Research Network infrastructure. This told us what was important to people when participating in studies. The checklist is designed to be a helpful resource that can apply to a range of study types and site environment. It does not replace active patient and public involvement in study design and delivery but aims to compliment discussion on approaches that optimise patient experience.

There are **6 top tips** themes that make up the checklist:

1. Motivation
2. Research staff
3. Information
4. Intervention
5. Time
6. Access

The top tips can be used as a checklist in relation to a number of research stages by research teams, site teams and supporting staff. For example:

- Study design
- Patient information
- Budget planning
- Study roll out
- Site selection
- Site set up
- Research staff training
- Recruitment strategy
- Study management
- Site monitoring
- Study closure

Please see over the page for the full checklist →

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1 ‘Report of the Patient Research Experience Survey 2017/18’ (Golsorkhi/Steel 2018)
<table>
<thead>
<tr>
<th>The 6 top tips</th>
<th>Insight</th>
<th>We found that:</th>
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| Actively appreciate the motivation of patients for joining a study and be prepared to explain health issues. | People participate in studies for a range of individual reasons. Understanding something about a person's motivation for participating can help you to help them feel fully engaged. | In order of frequency of mentions in participant feedback, motivations were:  
  ● Altruism and improving medical knowledge  
  ● Possibility of improving own health condition  
  ● Better medical monitoring  
  ● Learning about a medical condition |
| Ensure site research staff are supported and have sufficient time to build excellent working relationships with patients taking part in the study. | The relationship with research staff is absolutely key to the experience of study participants. | What was most appreciated was staffs':  
  ● Friendliness  
  ● Professionalism  
  ● Knowledge  
  ● Approachability  
  ● Helpfulness  
  ● Respectfulness |
| Ensure the right information is available in the right place at the right time as participants proceed through the study. | Having good timely information is important to people feeling engaged in and valued as participants in a study. | The types of information important to participants were:  
  ● Quality of pre-consent information (written and verbal).  
  ● Practical timely information about the process: appointments, what to expect, where to be, when and how.  
  ● Timely updates about progress of study.  
  ● General information about the health condition.  
  ● Getting personal medical information from tests etc.  
  ● Information about study results. |
| Understand the implications of the research intervention for patients. | Involve patients in the design of the research in order to understand their perspectives early on. | ● Managing patient expectations is important.  
  ● Responding to individual patients’ experience of intervention outcomes is critical. |
| Carefully consider participant’s time on their pathway through consenting and starting a study to subsequent study ‘visits’. | People’s time given to a study is important to them and should be respected and not wasted.  
  Site walkthroughs by patient representatives help identify difficulties early on. | The issues were:  
  ● Waiting time in clinic.  
  ● Waiting time between tests.  
  ● Appointment/procedure frequency and length of time (design).  
  ● Recognition of time priorities of individual patients. |
| Consider carefully how potential participants can access your study/site and the action you can take to reach them to reach you. | The opportunity to take part in a study is an opportunity for all involved. Access is a critical factor affecting opportunity to participate. | Particular aspects of access mentioned in feedback were:  
  ● Burden of travel and parking.  
  ● Flexibility of appointment times.  
  ● Location proximity/convenience.  
  ● Disabled access (e.g. visual impairment, wheelchair access etc.). |