Examining how best to meet patients’ information needs along the clinical trial continuum—beginning understanding what a clinical trial is, progressing to the process of enrolling and, finally, understanding the patient’s response to the trial—can help to better alignment with clinical research and clinical trial participation. Researchers have an opportunity to consider improved ways of ensuring key patient questions get answered along this continuum.

**STAGE 1**
GATHER INFORMATION ABOUT CLINICAL RESEARCH
Individual is in the healthcare system

- 56% of patients indicated that they would discuss clinical trial opportunities with their physician or HCP before seeking a clinical trial location.

**Stage 1 Key Communication Opportunities for a Patient’s Clinical Trial Journey**

- **GATHER INFORMATION ABOUT CLINICAL RESEARCH**
  - Individual has completed/ended participation in a trial
  - Key Patient/Trial Participant Questions
    - What is the purpose of the trial?
    - Who is enrolling the trial?
    - How will the investigational product being tested work?
    - How will the investigational product be given to me?
    - What is the expected time during the trial?
    - What happens after the trial?
    - How will you contact me about the trial?
  - Current Methods of Information Exchange
    - Informed consent form (ICF)
    - Sponsor-arranged educational interventions
    - Sponsor’s own trial websites
    - Information submitted to patient advocacy groups
    - Reimbursement of expenses
    - Informed consent form
  - Opportunities to Improve Communication
    - Publicly accessible educational resources on research
    - Discussions with treating physician on clinical research as a potential option

**STAGE 2**
CONSIDER CLINICAL TRIAL PARTICIPATION
Individual considers and decides about specific trial participation

- 81% of patients said that knowing the potential risks and benefits of the trial before considering participation

**Stage 2 Key Patient/Trial Participant Questions**

- What should I do if something goes wrong?
- What should I expect if I am well?
- What if I am expected to continue treatment?
- What if I am not expected to continue treatment?
- What will I need to do before and after the trial?
- How will I be compensated for my time and trouble?
- What happens when the trial ends?
- What if I disagree with the trial staff or want to get involved in the trial?

**Stage 2 Key Communication Opportunities for a Patient’s Clinical Trial Journey**

- **CONSIDER CLINICAL TRIAL PARTICIPATION**
  - Key Patient/Trial Participant Questions
    - How will the investigational product be given to me?
    - When and where can I find more information about the clinical trial results?
    - When will my access to the investigational product end?
    - Am I responding to the investigational product?
    - Are there opportunities for completing tests remotely or at a local lab?
    - What will the experience look and feel like?
    - When is my next visit and what can I expect?
    - What does it mean to participate in a clinical trial and what does the experience look like?
    - What is the purpose of clinical trials and how do they work?
    - What was the overall outcome of the trial?
    - What should I know before trying other treatments?
    - Where is my lab/test data?
    - Did I receive the investigational product during the trial?
    - Are other trials available?
  - Current Methods of Information Exchange
    - Government-sponsored clinical trial registries
    - Reimbursement of expenses (e.g., travel, lodging)
    - Recruitment of patients in clinical trial settings
    - Informed consent form
    - Updates on the status and progression of the overall trial
    - Downloadable and hard copy trial guide and visit schedule
  - Opportunities to Improve Communication
    - Publicly accessible educational resources on research
    - Discussions with treating physician on clinical research as a potential option

**STAGE 3**
PARTICIPATE IN A CLINICAL TRIAL
Individual enters and participates in a trial

- 52% of patients want overall clinical trial statistics and visit calendar data/results

**Stage 3 Key Communication Opportunities for a Patient’s Clinical Trial Journey**

- **PARTICIPATE IN A CLINICAL TRIAL**
  - Key Patient/Trial Participant Questions
    - What is the difference between placebo and standard of care?
    - What is the purpose of clinical trials and how do they work?
    - What does it mean to participate in a clinical trial and what does the experience look like?
    - What is the difference between placebo and standard of care?
    - What questions should I ask my doctor?
    - Will the investigational product be available on the market?
    - How will the investigational product being tested work?
    - How will the investigational product be given to me?
  - Current Methods of Information Exchange
    - Government-sponsored clinical trial registries
    - Recruitment of patients in clinical trial settings
    - Informed consent form
    - Updates on the status and progression of the overall trial
    - Downloadable and hard copy trial guide and visit schedule
  - Opportunities to Improve Communication
    - Publicly accessible educational resources on research
    - Discussions with treating physician on clinical research as a potential option

**STAGE 4**
CONTINUE HEALTHCARE JOURNEY
Individual has completed/ended participation in a trial

- 83% of patients want overall clinical trial statistics and visit calendar data/results

**Stage 4 Key Communication Opportunities for a Patient’s Clinical Trial Journey**

- **CONTINUE HEALTHCARE JOURNEY**
  - Key Patient/Trial Participant Questions
    - What questions should I ask my doctor?
    - How will participation in this trial impact my daily life?
    - How does the investigational product being tested work?
    - Who is overseeing the trial?
    - What will it measure?
    - What is the purpose of the trial?
    - What was the overall outcome of the trial?
    - Will I be able to obtain my lab/test data during the trial?
    - What was the experience of other patients?
    - What will be the goal of the trial?
    - How will the investigational product be given to me?
    - How will I be compensated for my time and trouble?
    - What happens after the trial?
    - What is the difference between placebo and standard of care?
    - What should I do if something goes wrong?
    - When and where can I find more information about the clinical trial results?
  - Current Methods of Information Exchange
    - Government-sponsored clinical trial registries
    - Recruitment of patients in clinical trial settings
    - Informed consent form
    - Updates on the status and progression of the overall trial
    - Downloadable and hard copy trial guide and visit schedule
    - Sponsors’ own trial websites
    - Information submitted to patient advocacy groups
    - Reimbursement of expenses
    - Informed consent form
  - Opportunities to Improve Communication
    - Publicly accessible educational resources on research
    - Discussions with treating physician on clinical research as a potential option

Read more about TransCelerate’s proposal to improve information exchange with patients throughout their clinical trial journey in a paper published in *TIRS,* Improving Information Exchange with Clinical Trial Participants: A Proposal for Industry. 

[http://dx.doi.org/10.1186%2F1745-6691-8-6](http://dx.doi.org/10.1186%2F1745-6691-8-6)