CISCRP

2023 Perceptions & Insights Study

Global trends in public and patient attitudes about, and experience with, clinical research.

ENGAGEMENT PREFERENCES

Introduction

Supportive services and flexible study visit options continue to play a critical role in improving access to clinical research studies, particularly among underrepresented communities.

In this report, CISCRP highlights engagement preferences for participation in clinical research studies. These findings identify important elements of participation, as well as provide a comprehensive view of receptivity to various decentralized clinical research models. The insights can help inform the design and optimize the implementation of these clinical research studies.

Receptivity to various types of **decentralized clinical study models remains high**, and the availability of options will remain key — particularly for **underrepresented communities to help increase access**.

While most are generally willing to go to a **pharmacy** for study visits, there are **concerns about facilities, data privacy, and quality of care**. Knowing pharmacy staff is **properly trained** and **optimized privacy measures** are key to increasing trust in a pharmacy setting for clinical studies.

Level of comfort with different study clinic settings is variable — with a **supermarket setting identified as least comfortable** compared to local hospitals, labs, and community health clinics.

Clinical Research Study Models

There is continued strong willingness to participate in a range of clinical study research models.

Black respondents were significantly more likely to report **'Very Willing' for all types** compared to other races.

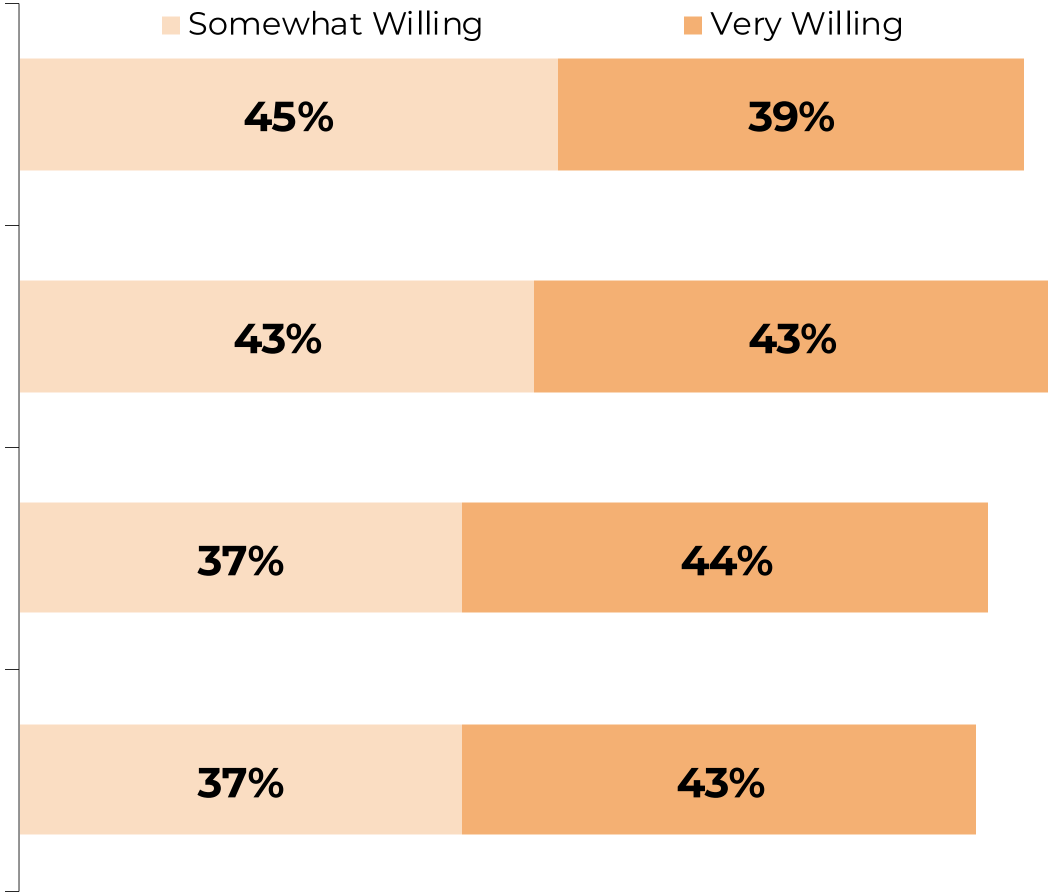
How willing would you be to participate in each of the following types of clinical research studies?

TRADITIONAL MODEL
All study visits at the clinic; seeing the study doctor and staff in-person at the clinic only

HYBRID MODEL
Some study visits at home and some visits at the clinic; seeing the study doctor sometimes via video conference at home or in person at the clinic

MOBILE NURSE MODEL
Having a nurse come to your home for all study visits and speaking to the doctor via video conference from home

REMOTE MODEL
Collecting all of your health data on your own at home using technology and only talking to the doctor/study team via video conference at home



Sample Size = 12,017 | Base: All respondents

Important Clinical Research Study Features

If you were to participate in a clinical research study, how important are the following to your participation? % indicating 'Very Important'	**Never Participated** (n=7,459)
Being provided with supporting information on the clinical research study	**47%**
Being provided with supporting information on managing my health condition in general	**45%**
Supportive services	**39%**
Availability of a clinical research study clinic in my local community or neighborhood	**36%**
Being provided the opportunity to complete a satisfaction survey on your clinical research study experience to provide feedback	**35%**
Availability of mobile applications	**34%**
Being able to review and sign study documents in an electronic format	**32%**
Availability of clinical research study information designed specifically for caregivers	**29%**
Some or all study visits conducted at my home or my office	**25%**

Hispanic and Black subgroups were more likely to cite the following as **'Very Important'** compared to non-Hispanic and White subgroups, respectively:

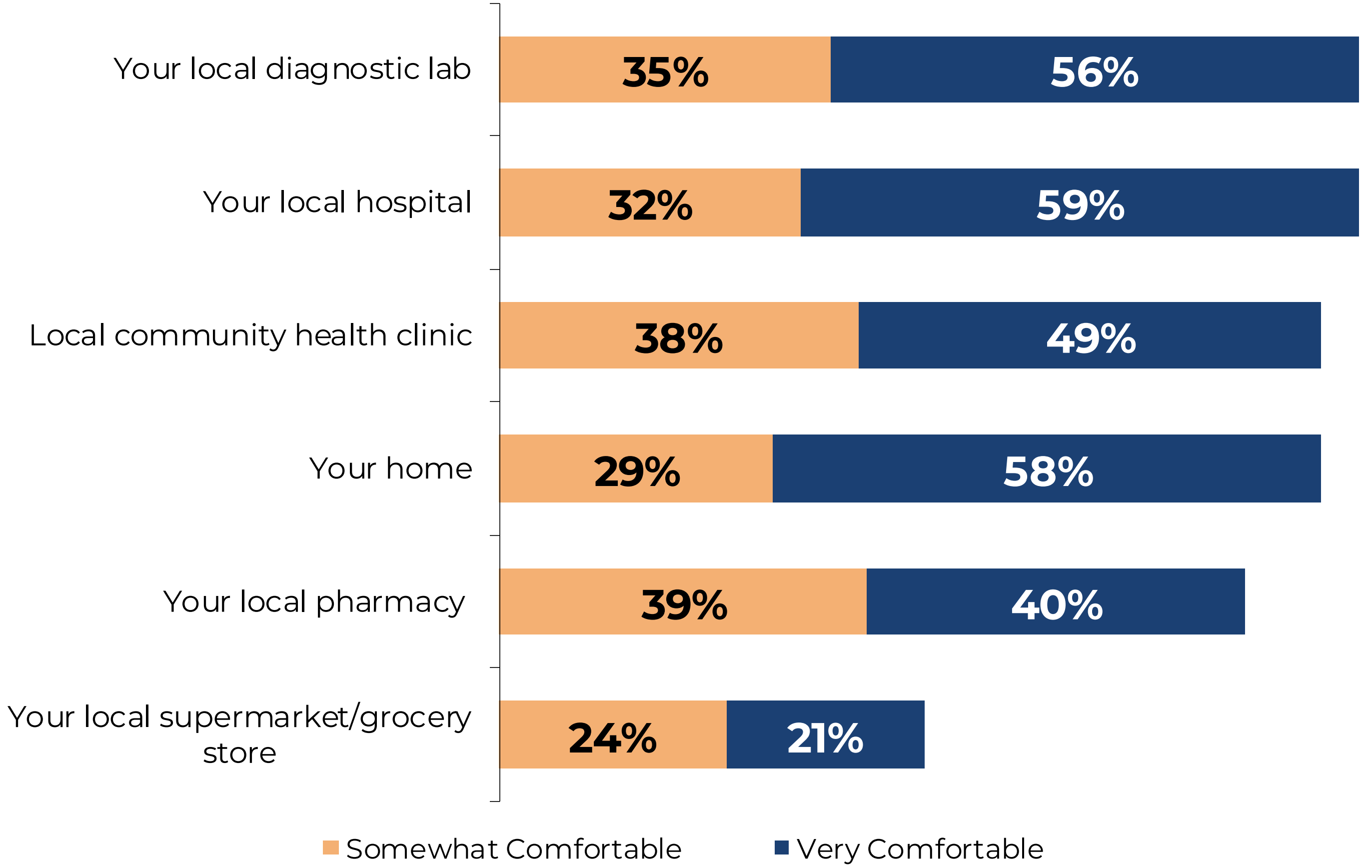
- Mobile app availability
- Information specific for caregivers
- Review and sign documents in electronic format

- Supportive services
- Information on health condition
- Availability of clinic in local community
- Some or all study visits conducted at home/office
- Satisfaction survey

Clinical Research Study Visit Setting

The local supermarket is perceived as the least comfortable setting for clinical study visits compared to other settings. Local labs, hospitals, and community health clinic settings are preferred for study visits.

If you were to participate in a clinical research study, how comfortable (if at all) would you feel participating in each of the following settings?



Black respondents were more likely to cite **'Very Comfortable' receiving care at home, the local supermarket, and the local pharmacy** compared to all other races.

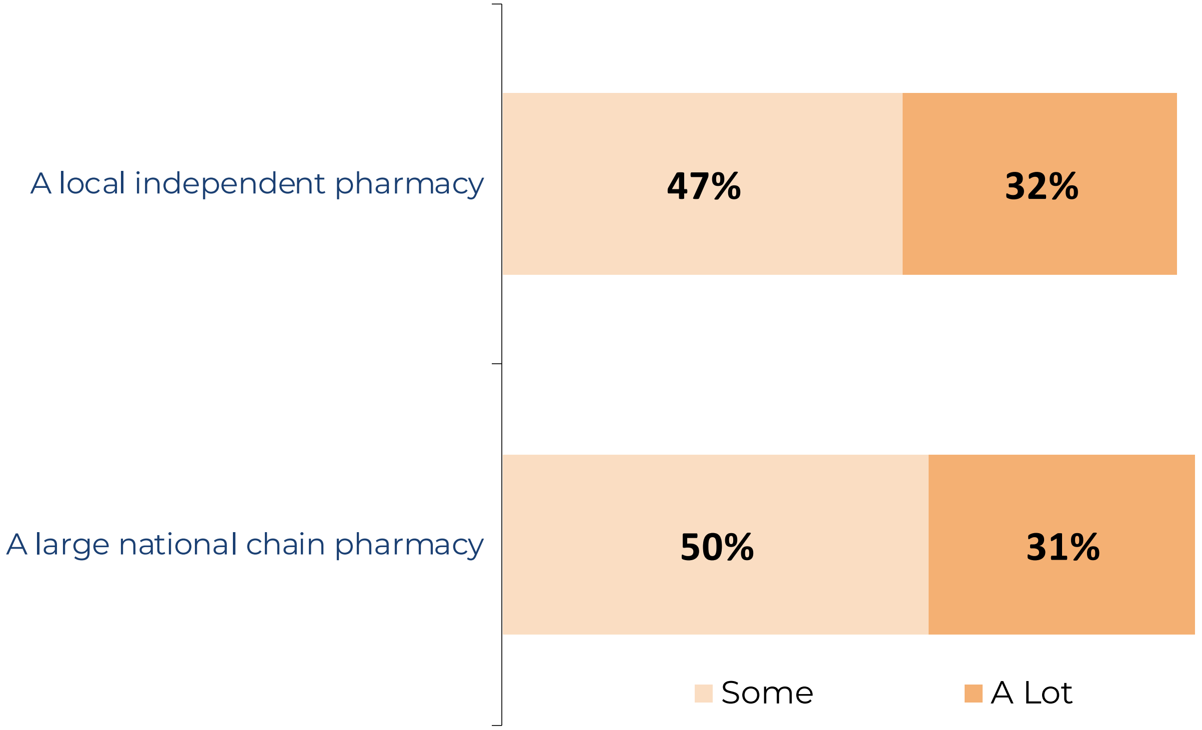
Those in **North America** were more likely to cite **'Very Comfortable' at home (68%)** compared to those in South America, Europe, and Asia-Pacific (42%, 51%, and 44%, respectively).

Sample Size = 12,017 | Base: All respondents

Trust in Pharmacy as a Clinical Research Site

There is no variation in trust between national chain and local pharmacies. However, proper staff training and privacy measures are key for increasing trust in a setting for clinical studies.

How much do you trust each of the following types of pharmacies, if at all?



Sample Size = 12,017 | Base: All respondents

What, if anything, might increase your willingness to go to a pharmacy for study visits as part of a clinical research study?

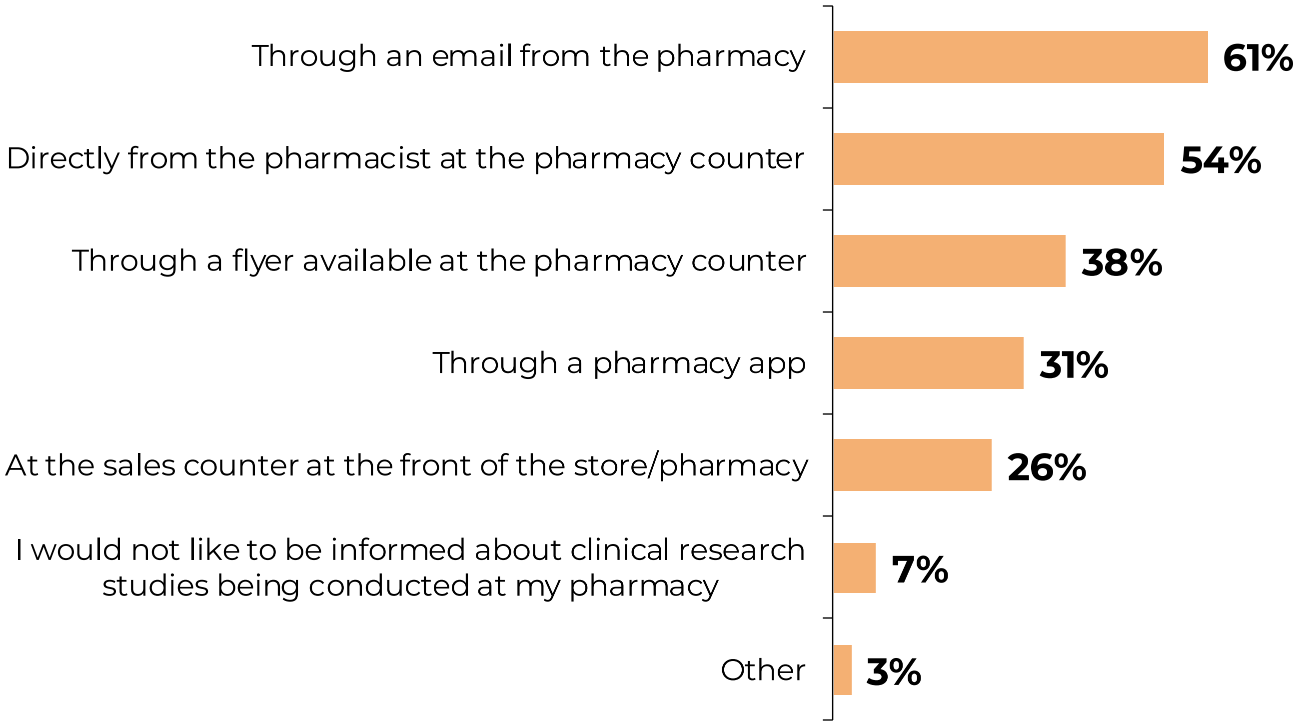
% Mentioning

- Knowing the pharmacy staff were properly trained (66%)
- Having better privacy measures in place at the pharmacy (i.e., conducting procedures in a separate room rather than using a privacy screen) (57%)
- Being provided with supporting information on the clinical research study (e.g., study guides, pamphlets) (49%)
- Being provided information on how my confidentiality would be protected (43%)
- Knowing the credentials of the pharmacy staff conducting the tests and procedures (43%)

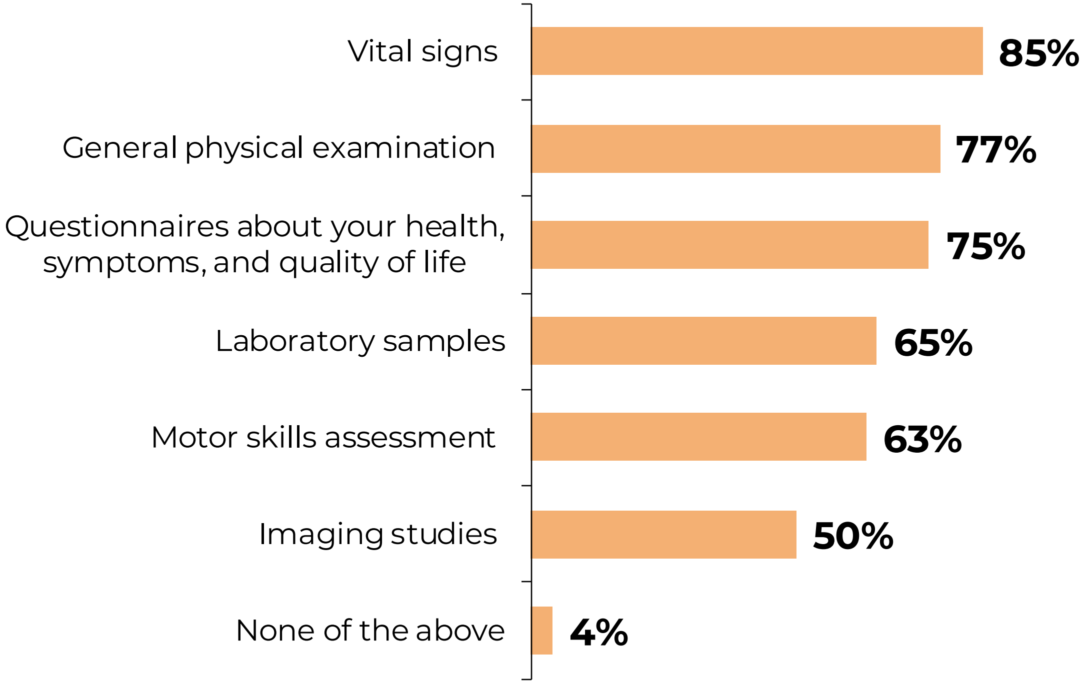
Preferred Method of Learning About Study Conducted at Pharmacy

Most would prefer to learn about a clinical research study conducted at a pharmacy via an email from the pharmacy or directly from the pharmacist at the counter. The majority would be comfortable undergoing less invasive assessments in a pharmacy setting.

How, if at all, would you like to learn about a clinical research study being conducted at your pharmacy?



What type of tests and/or assessments, if any, would you be comfortable undergoing at a pharmacy for your study visits?



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Retention Factors

Please rank the following, starting with the items that would be **most likely to keep you enrolled in a clinical research study until the end** (i.e., not drop out) and ending with the item that would be least likely to keep you enrolled?

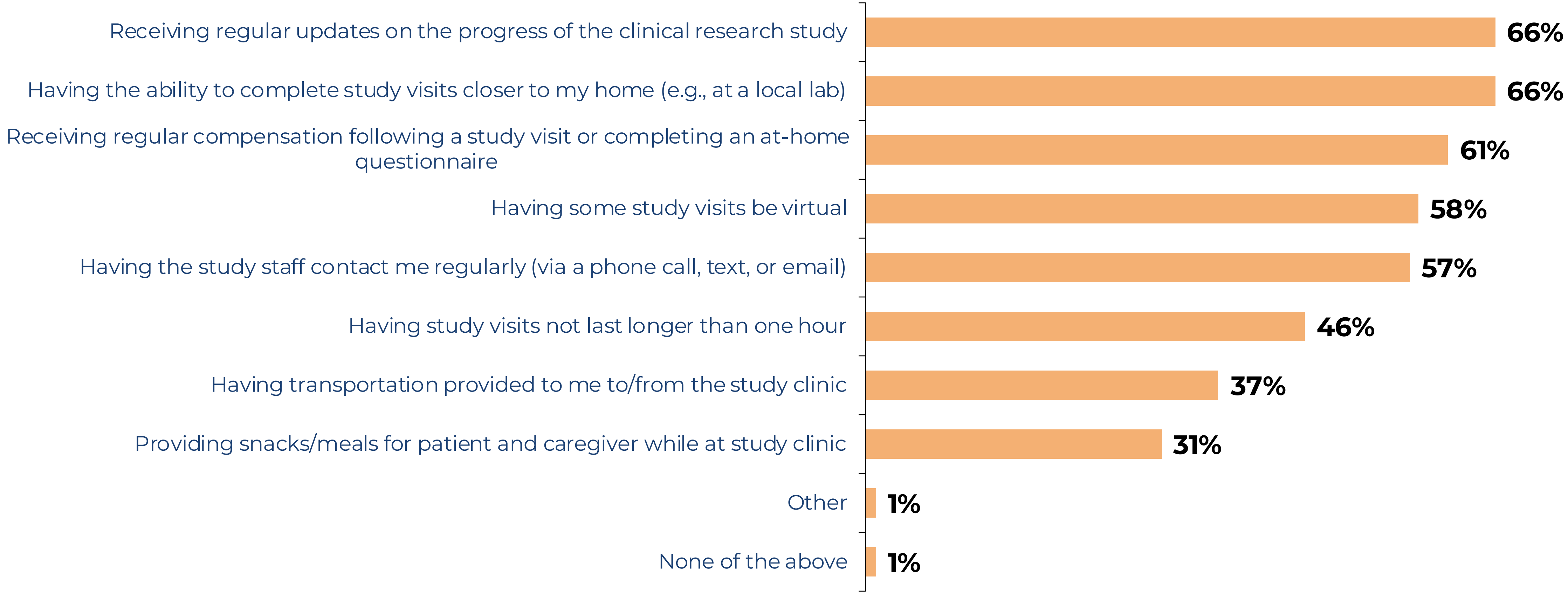
		2023 (mean score)
1	Feeling/seeing benefit from the study drug	**4.59**
2	Having the ability to complete study visits closer to my home (e.g., at a local lab)	**4.84**
3	Having study visits with flexible times	**5.02**
4	Being informed of the clinical research progress on a regular basis	**5.22**
5	Reimbursing any out-of-pocket expenses	**5.36**
6	The ability to have my study visits at home (i.e., remote study visits) rather than traveling to a study clinic	**5.58**
7	Knowing I would receive a larger amount of compensation (money) at the end of the study	**6.19**
8	Receiving small amounts of compensation (money) after every study visit	**6.28**
9	Having my study visits not last longer than one hour	**6.29**
10	Having transportation provided to me to/from the study clinic	**6.95**
11	Having childcare available	**9.70**

Sample Size = 12,017 | Base: All respondents

Long-term Retention Factors

Regular communication and updates on the study, access to local study clinics, regular compensation, and virtual options are considered the most important long-term retention factors.

Imagine a follow-up period lasting 3 to 5 years. Which of the following things are most important to keeping someone enrolled for this length of time?



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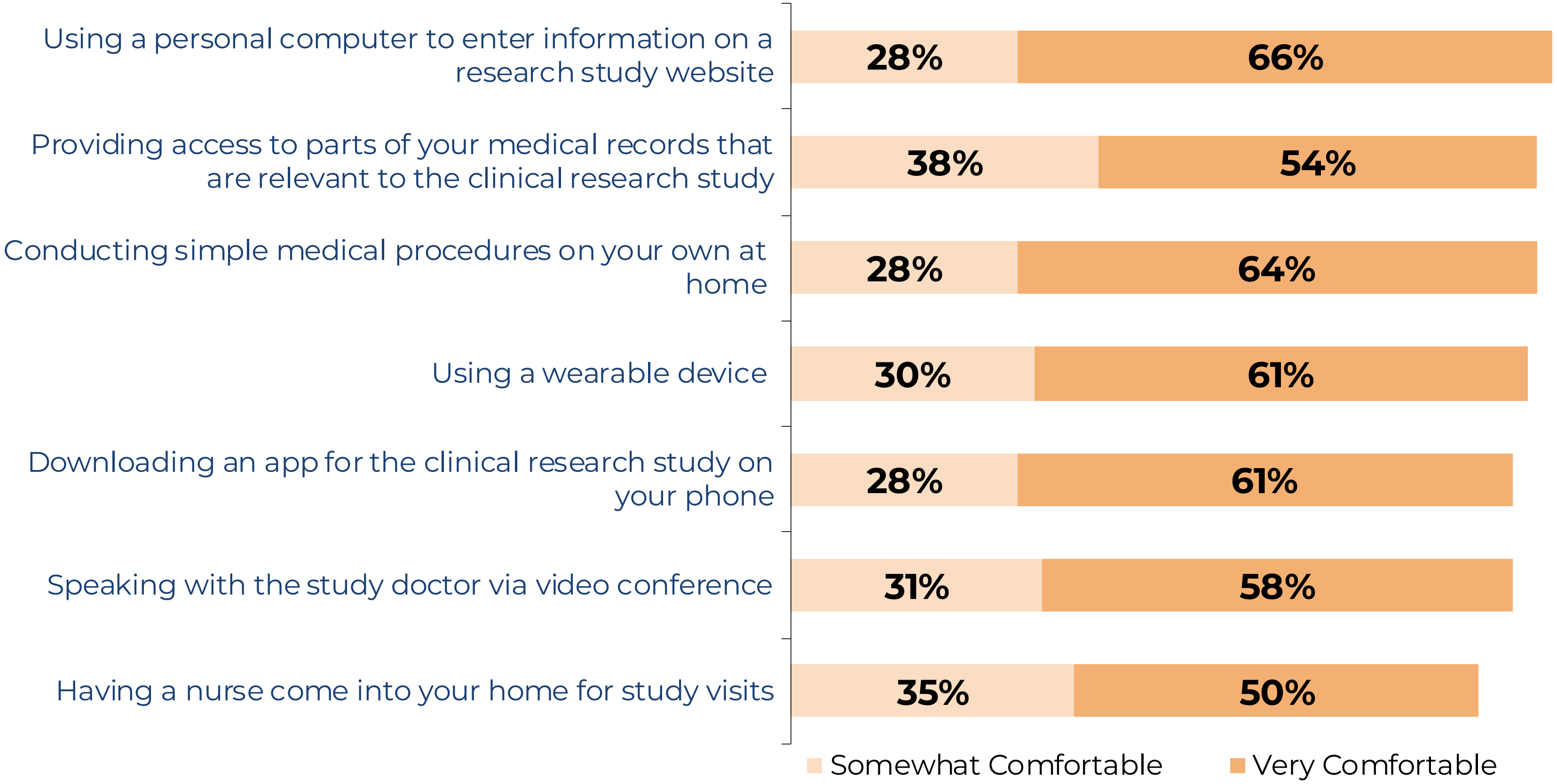
At-home and Technology Preferences

Most are comfortable providing access to parts of medical records that are relevant to the study and completing elements of the study at home.

If you were to participate in a clinical research study, how comfortable would you be with each of the following?



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Please select the reason(s) why you would **not feel comfortable**:

- I am concerned my privacy/confidentiality would not be protected (50%)
- I do not feel comfortable using this/these type(s) of technology (42%)
- I am concerned the use of technology may cost me money (e.g., data/internet usage) (24%)
- Other reasons (14%)

About This Study

The objectives of this study are to establish routine global assessments of public and patient perceptions, motivations, and experiences with clinical research in order to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in the clinical research enterprise.

Between April and June 2023, CISCRP conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CISCRP received input and support from pharmaceutical, biotechnology, and contract research organizations; investigative sites, and patients. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, Benchmark Research, and Rare Patient Voice to reach and engage respondents.

12,017
Survey Respondents

Respondent characteristics are as follows:

Gender	61% Female | 37% Male | 2% All other genders
Region	47% North America | 2% South America | 46% Europe | 4% Asia-Pacific | 1% Africa
Age	19% 18–34 years old | 18% 35–44 years old | 18% 45–54 years old | 21% 55–64 years old | 24% 65 or older
Race (top mentions)	81% White | 6% Black or African-American | 6% Asian
Ethnicity	85% Non-Hispanic | 15% Hispanic
Incidence of participation in a clinical trial	62% have never participated | 38% have participated

Note: Percentages throughout this report may not total 100 due to rounding

About CISCRP

The Center for Information and Study on Clinical Research Participation (CISCRP) is an internationally recognized non-profit organization dedicated to educating and informing the public and patients about clinical research. CISCRP works to raise awareness, enhance experiences, and strengthen communication and relationships among participants, research professionals, and the public through various services and events.

RESEARCH SERVICES

Insights guiding public and patient engagement in clinical research

- Perceptions & Insights Study
- Patient Advisory Boards
- Patient Clinical Trial Journey Workshops
- Custom Research Projects

COMMUNITY ENGAGEMENT

Educational and engaging events held in local communities to build clinical research awareness and trust

- AWARE-for-All
- Medical Heroes Appreciation 5K
- Journey to Better Health Traveling Exhibit

HEALTH COMMUNICATION SERVICES

Information in plain and easy-to-read language

- Trial Results Summaries
- Educational Brochures
- Review Panels

INTERNATIONAL EDUCATION & AWARENESS

Helpful facts and information about clinical research

- Content Licensing
- Patient Diversity Campaign
- Website Content Development

CISCRP

Thank You

CISCRP thanks the following organizations for their support of the 2023 P&I Study:

abbvie
AMGEN
AstraZeneca
Benchmark Research Raising the standard.™
Biogen
CLARINESS
Daiichi-Sankyo
EMD SERONO
greenphire®
janssen PHARMACEUTICAL COMPANIES OF Johnson&Johnson
JLC JAMES LIND CARE.
Lilly
MERCK
Otsuka
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