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PATIENT ENGAGEMENT SURVEY REPORT

As clinical trials become more costly and patient recruitment increasingly problematic, those who conduct clinical research have turned to patient-centric initiatives to improve patient recruitment, retention and engagement.

Ken Getz, director of sponsored research and associate professor at the Tufts Center for the Study of Drug Development, Tufts University School of Medicine, has studied patient engagement issues for years.

"Where we've typically fallen short is we second guess what the patient is really looking for," Getz said in an [interview](#) for the Bridging Clinical Research & Clinical Health Care Collaborative. Instead, the industry should ask patients to describe what a clinically meaningful benefit would be, for example, or what would make it easier for them to participate in a trial.

Getz believes that there are three main things that patients want: They want to know that the clinical trial is relevant to the management of their disease and that participating will be convenient for them. And, they want to know that their participation mattered. "When we satisfy those three things, we've really achieved a superior level of engagement," Getz said.¹

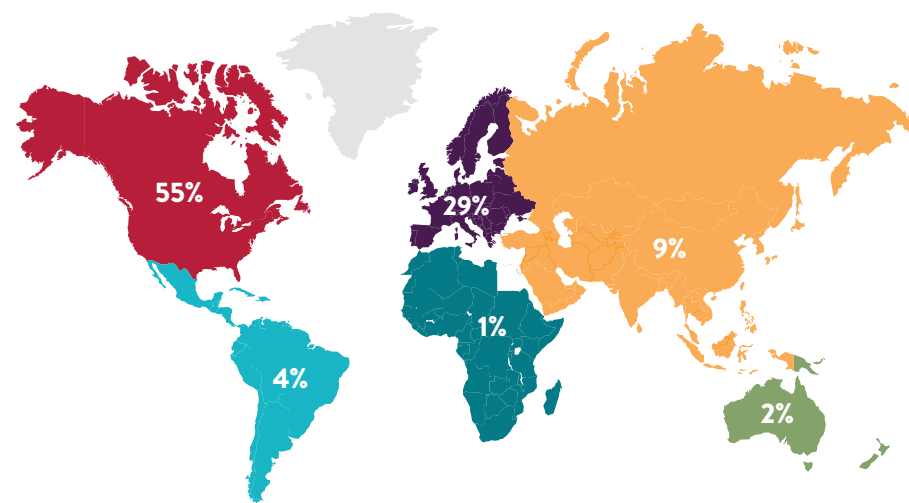
To determine how well the industry is implementing patient engagement initiatives, SCORR Marketing conducted a survey in partnership with Applied Clinical Trials.

Survey participant demographics include:

- Organization types – those who work for research sites, academic/ research institutions and hospitals, pharmaceutical and biopharmaceutical companies, and contract research organizations (CROs).
- Job functions – those in clinical operations, project management, patient recruitment, and research and development (R&D).
- Locations – more than half of respondents from North America, almost one-third in Europe; respondents from six continents.
- Company size – respondents from both smaller (1,000 employees or fewer) and larger (1,000+ employees) companies.

In this report, we provide information about:

- Whether companies have personnel or departments dedicated to patient engagement
- Company goals for patient engagement initiatives
- Tactics used to engage patients and their level of effectiveness
- Metrics used to measure patient engagement
- Challenges faced in implementation
- Predicted patient engagement trends



Technology does not necessarily lead to more effective patient engagement. The most effective tactic is personal contact.

In terms of effectiveness, the best patient engagement tactic is in-person contact (8.57 on a 10-point scale); this is among the least technologically driven tactics. While technological innovations may provide useful aids to engage patients, the industry has found that in-person contact is the most effective way to engage patients, followed by phone calls. In contrast, these industry respondents report that web portals and companion apps are among the least effective tactics.

Question	Top Answer
What is the most effective patient engagement tactic?	In-person contact
Do patient engagement tactics vary by the patient's age?	Yes
Have technological innovations provided positive ROI?	Unsure

Effectiveness of patient engagement tactics

- Two other patient engagement tactics considered quite effective were phone (7.45 on a 10-point scale) and text messaging (7.21).
- The two lowest-rated patient engagement tactics were chat/instant messaging (5.37 on a 10-point scale) and companion apps (5.38).

Technological innovations and positive ROI

- Whether mHealth wearables or companion apps provide a positive return on investment is questionable. While 21 percent of respondents said they do improve ROI, an equal number disagreed and said they do not. A plurality of respondents (43%) were unsure.
- This uncertainty over whether technological innovations provide positive ROI may be impacted by a growing belief that innovations take too long to implement. A recent Veeva/Tufts study found that "the time it takes companies to design and release clinical trial databases is having a negative impact on conducting and completing trials."¹ Because those in the industry might be skeptical of the merits of innovations when data collection leads to delays, the industry may need better data integration tools before meaningful ROI can be determined.
- Respondents from larger companies (41%) were more than twice as likely to have said technological innovations positively impact ROI than were those from smaller companies (16%).

While patient engagement has been a hot topic and initiatives to improve engagement appear to be on the rise, many companies fail to deploy even the most basic methods to engage patients.

Sixty percent of respondent companies have no person or department primarily responsible for patient engagement, and 41 percent do not solicit input from their patients.

Question	Top Answer
Do you have a dedicated patient engagement person or department?	No
How is patient input solicited?	We don't solicit input from patients
What is the metric most often used to measure patient engagement?	Retention

Person/department primarily responsible for patient engagement

- CROs are especially unlikely to have dedicated patient engagement personnel; only 13 percent of CRO respondents reported that they did. On the other hand, pharma and biopharma companies (38%) were the most inclined to have dedicated patient engagement personnel.
- Those involved in patient recruitment (53%) were the most likely to report that their companies have a person or department primarily responsible for patient engagement. Project managers (27%) and respondents in clinical operations (also 27%) were the least likely.

Solicitation of patient input

- About half of those who work at research sites (52%) or CROs (50%) say their companies do not solicit input from patients. A much smaller proportion of pharma/biopharma respondents (13%) said their companies do not seek patient input.
- Clinical operations personnel (50%) were the most likely to state that their companies do not solicit patient input. Those who work in patient recruitment (20%) were the least likely.
- Smaller companies (1,000 employees or fewer) (48%) seek patient input less often than do large companies (28%).

Metrics

- More than half of respondent companies (53%) measure patient retention. Slightly less than half (47%) measure patient adherence to the protocol. Nearly a quarter (24%) do not have any patient engagement metrics.
- CROs (83%) and research sites (78%) were especially likely to measure retention levels.
- Perhaps surprisingly, large companies (42%) are more than twice as likely to NOT use patient engagement metrics as were small companies (17%).

The budget is to blame for not implementing patient engagement initiatives, respondents said, and likely will continue to be the challenge. This may temper growth in patient engagement initiatives.

More than one-fourth of respondents (26%) said a lack of money in the budget is the most significant challenge to the implementation of patient engagement initiatives. Similarly, almost one-third (32%) said budgets will most affect the extent of their company's future patient engagement initiatives.

With so much concern about budgets, it is not surprising that a plurality (36%) of respondents said that patient engagement initiatives at their company will increase only a little over the next two years.

Question	Top Answer
What is the most significant patient engagement challenge?	Not in the study budget
What is the most important factor affecting the future?	Sufficient budget
Will patient engagement initiatives increase or decrease in the future?	Increase a little

Not in the study budget – the most significant challenge

- Those who work at research sites (44%) were especially inclined to identify a lack of budget as their most significant challenge. On the other end of the spectrum, no pharma/biopharma respondents blamed the budget.
- Project managers (45%) were the most likely job function to select a lack of earmarked money in the budget as the most significant challenge, while those in patient recruitment (15%) were the least likely.

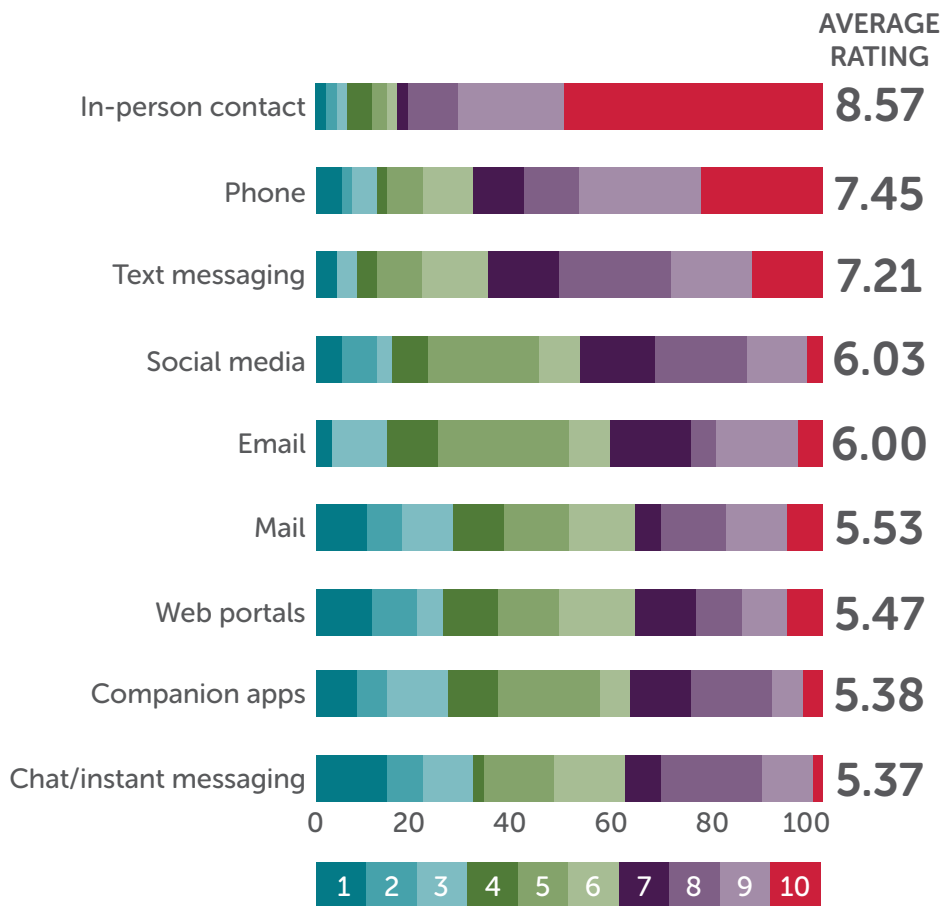
Sufficient budget – the most important future factor

- Clinical operations respondents (45%) were the most likely to choose sufficient budget as the most important factor affecting their company's future patient engagement initiatives. Project managers (18%) and those in patient recruitment (17%) were the least likely.
- North American survey participants (41%) were almost twice as likely to have said sufficient budget than were their counterparts from Europe (22%).

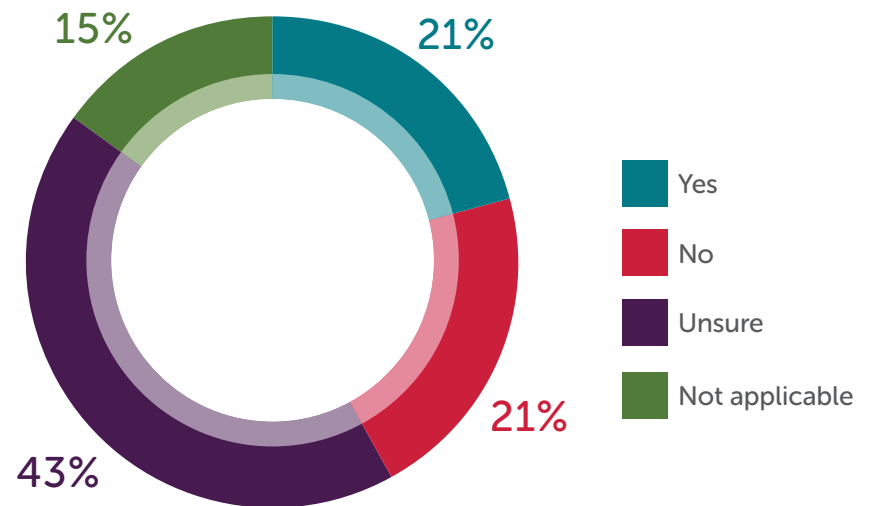
Tempered predictions

- More than one-third (36%) of respondents said that, in two years, patient engagement initiatives at their company will increase a little, while less than one-third said it would "increase a lot" (32%) or "stay the same" (29%).
- Survey participants from large companies (53%) were much more bullish about the future than were those from small companies (25%). They were more than twice as likely to say that patient engagement initiatives would increase a lot.
- Pharma/biopharma respondents were the most optimistic. Two-thirds (67%) said initiatives would increase a lot.

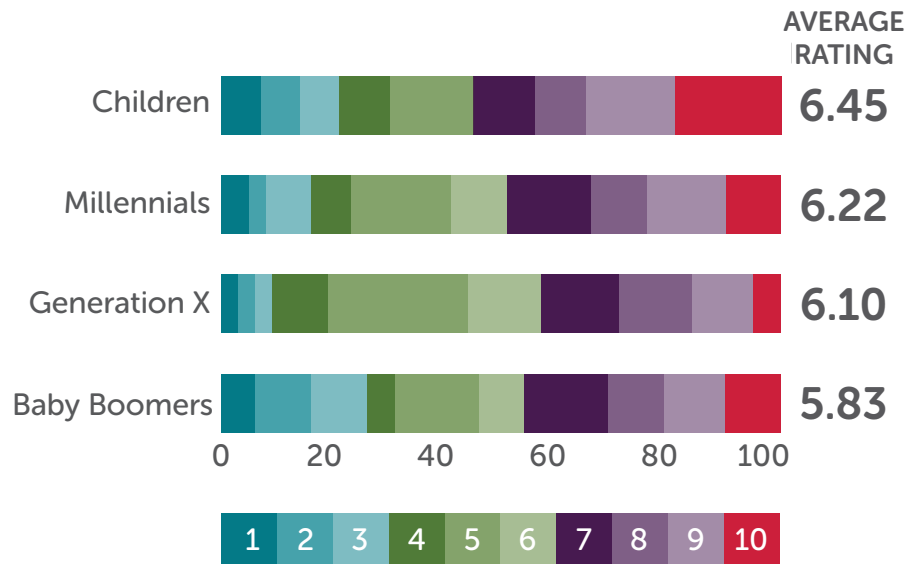
On a 1-10 scale (with 10 being the most effective), please rate the effectiveness of the following patient engagement tactics.



Has the use of technological innovations such as mHealth wearables and companion apps provided a positive ROI?



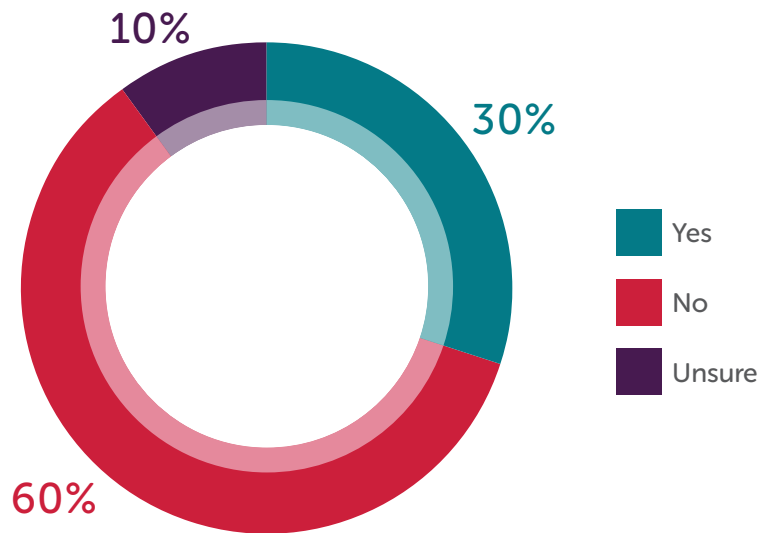
On a 1-10 scale (with 10 being the most challenging), how challenging is it to engage the following types of patients?



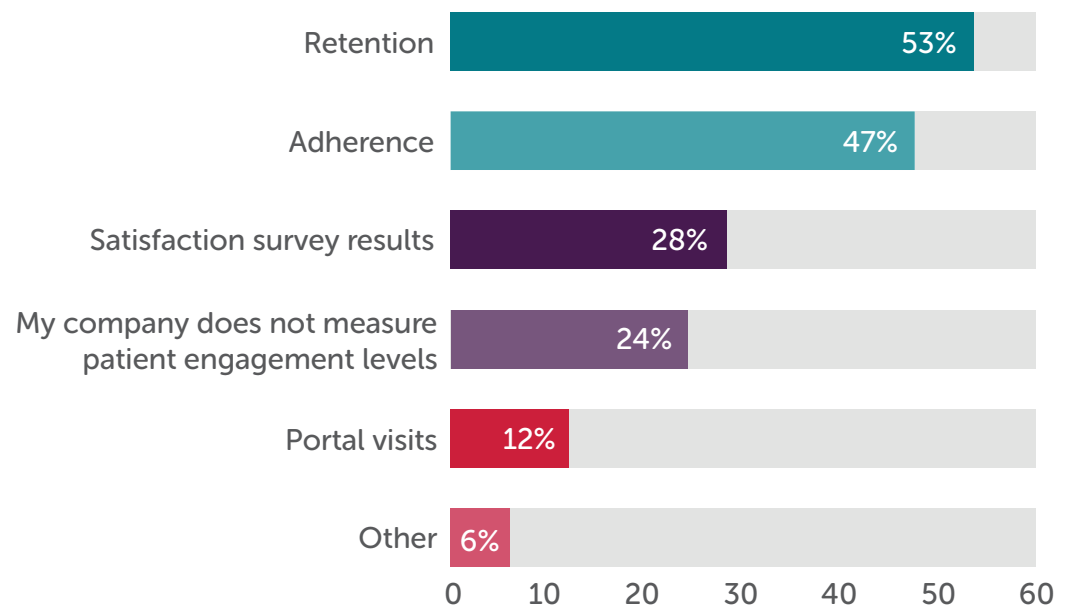
Do patient engagement tactics vary depending on the patient's age and indication?

	Age	Indication
Yes	70%	61%
No	21%	25%
Unsure	9%	14%

Is there a person or department in your company primarily responsible for patient engagement?



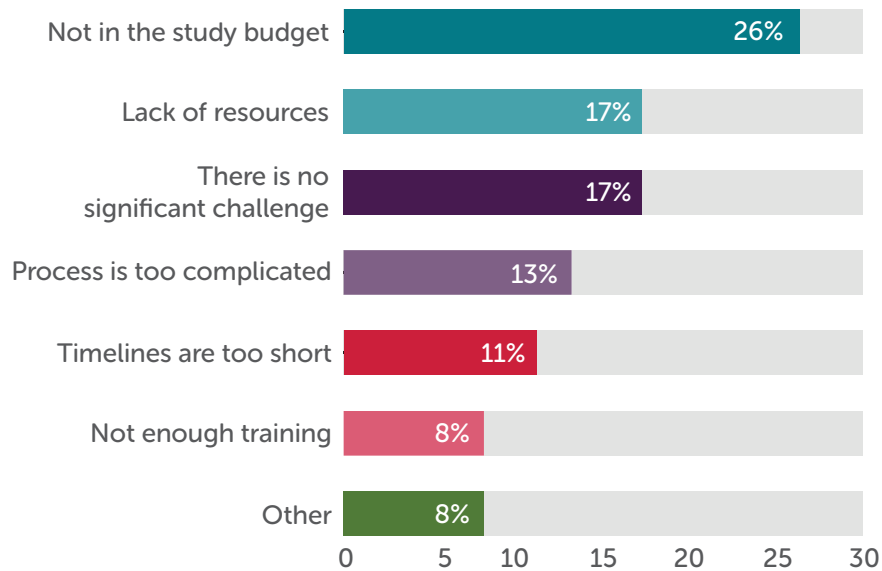
Which metrics does your company use to measure patient engagement levels? (Select all that apply.)



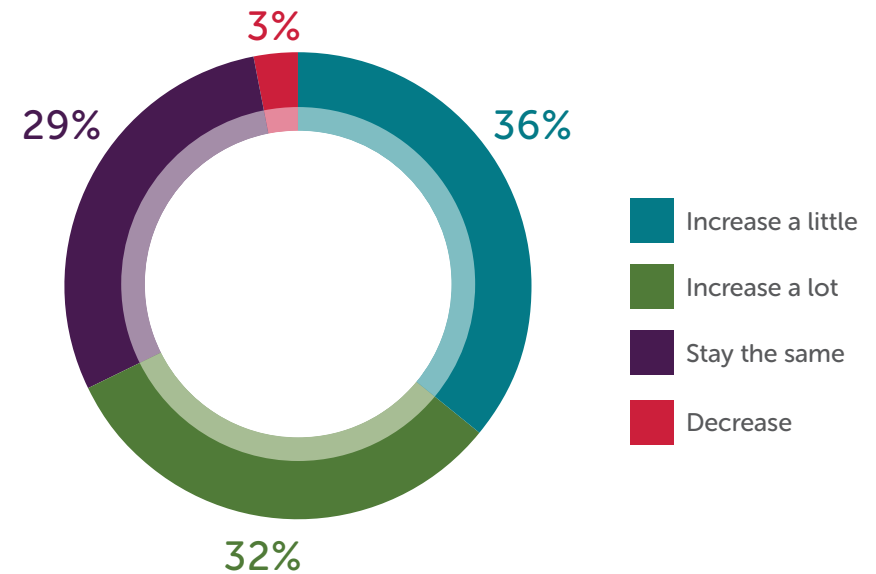
How does your company primarily solicit patient input so it can better design patient engagement initiatives?

We don't solicit input from patients	41%
Surveys	23%
Patient communities	13%
Patient advocacy groups	10%
Other	13%

What is the most significant challenge to implementing patient engagement initiatives?



In two years, patient engagement initiatives at your company will _____.



What is the most important factor that will affect the extent and nature of your company's future patient engagement initiatives?

Sufficient budget	32%
Continued technological innovation	23%
Improved product or study design	17%
Positive patient engagement metrics	15%
More patients enrolled	9%
Other	4%

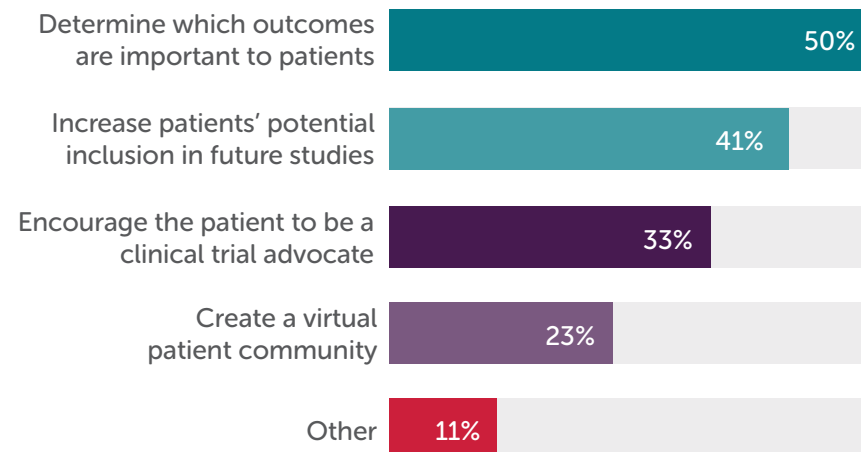
At the study design stage, which of the following patient engagement goals are most important to your company? (Select up to two goals.)

Better study/product design	40%	Identifying where more education is needed	10%
Identification of acceptable benefits and risks	38%	Medical device ease of use	7%
Preferred patient outcomes	22%	Preferred drug delivery method	3%
Patients understanding their input is valued	19%	None of the above	11%
Patient buy-in to the process	13%	Other	5%

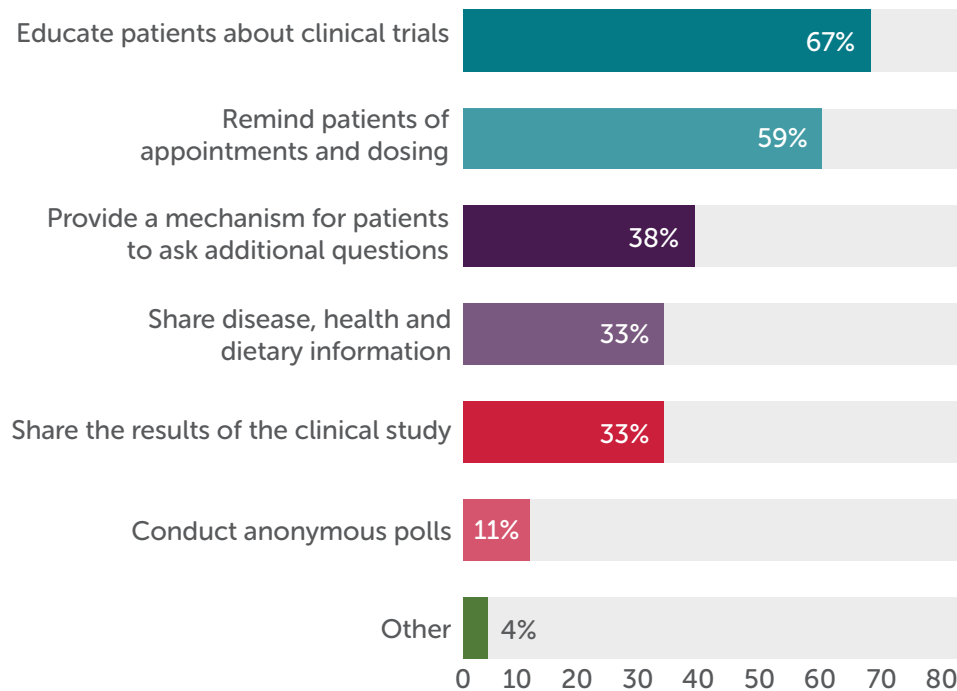
At the clinical trial stage, which of the following patient engagement goals are most important to your company? (Select up to two goals.)

Adherence to dosing and visit schedule	52%
Higher retention rate	39%
Satisfied patients	39%
Better patient experience	34%
Development of clinical trial advocates	6%
None of the above	2%
Other	2%

Which of the following are your company's most important longer-term patient engagement goals? (Select up to two goals.)

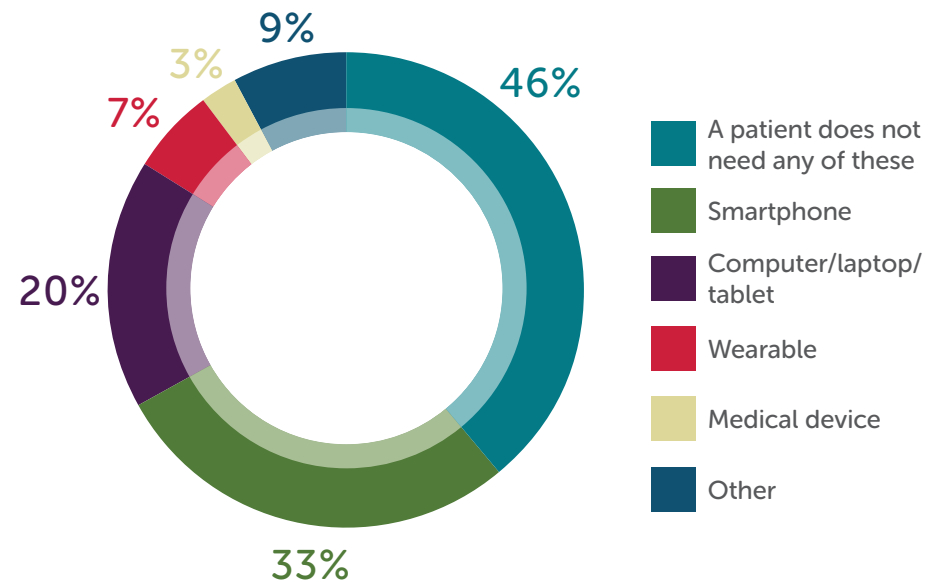


In which ways does your company engage patients to create a better patient experience? (Select all that apply.)



Note: As indicated earlier, Getz said that one of three main things that patients want is to know their participation mattered.¹ But only a third of respondents said their companies share the results of a clinical study.

Which of the following does your company require patients to have so that it can implement patient engagement initiatives? (Select all that apply.)





Technological innovations do not necessarily translate into effective patient engagement tactics.



The older the age group of patients, the easier they are to engage.



Lack of financial resources is the greatest obstacle to patient engagement initiatives.



Despite the popularity of patient-centricity and patient engagement, many companies do not actually seek feedback from patients. About two in five respondents (41%) said that their companies do not solicit patient input.



Recommendation: Companies should sufficiently fund patient engagement initiatives. They know they should be more patient-centric, and doing so could provide a positive impact on patient participation and the outcomes of clinical research.

¹ Bridging Clinical Research & Clinical Health Care Collaborative. <https://www.bridgingclinical.com/speakers/ken-getz-mba/>

² "2017 eClinical Landscape Study," Veeva/Tufts Center for Study of Drug Development, Sept. 2017.

<https://www.veeva.com/wp-content/uploads/2017/09/Industry-Survey-Reveals-Clinical-Data-Management-Delays-Slow-Trial-Completion-Press-Release.pdf>