MATT ATKINSON:  Hello everyone and welcome to Reuters Events latest webinar, Bridging the gap: Earn patients’ trust post-pandemic to improve health outcomes.

We’re going to begin in just a moment. We’re going to give it a minute to allow as much of our audience to join in live. I can see a number of you coming in right now. So just bear with us for a second and then, we will jump right into the discussion.

Hello everyone. And, again, thank you for joining us for our latest webinar, Bridging the gap: Earn patients’ trust post-pandemic to improve health outcomes. We are going to discuss how to transform your patient engagement approach across the lifecycle by better reflecting the holistic needs, preferences and values of the patient.

I’m Matt Atkinson, a Global Project Director at Reuters Events Pharma and I have the pleasure of being your moderator today. And just before we begin, a couple of bits of housekeeping. We will be sending the recording next Monday. So please look out for that if you’d like to watch again or share with colleagues. And, again, this is an interactive webinar, so we’re going to have poll questions, we’re going to be looking for questions from you, so please engage throughout and we’ll be able to get to those points as we go through.

So as we know, the healthcare system has been going through many changes and challenges driven by COVID-19. More specifically, the pharmaceutical industry has faced various challenges in both R&D and commercial and has been rapidly developing, testing and delivering new vaccines in record time.

And while we may expect that all the efforts made will result in positive recognition for pharma and increased patient trust in the industry, we’re still witnessing the lack of trust as a core issue influencing the decisions and actions that patients take. This deep-seated mistrust, not only affects patients’ perceptions of pharma, but it also affects the healthcare decisions as evidenced by a significant portion of the population choosing not to get the COVID-19 vaccine out of mistrust.

So in today’s discussion, we’d like to take a deeper dive into some of the underlying causes of the patient trust get and hear our panelists thoughts on ways to remediate the issues that can enhance trust in patient engagement to intimately improve health outcomes.
And with that, I would like the panelists to introduce themselves. And, Sarah, if I can start with you, please.

SARAH KRUG: Good morning or good afternoon, good night, depending on the time zone that you’re in. I’m Sarah Krug. I’m a researcher by trade. I’m a patient advocate by choice. I’ve worked across sectors from cancer research and disease management at Sloan-Kettering, to varying roles at Pfizer and I now lead two organizations as Founder of the Health Collaboratory, which is a global innovation hub that’s built on the foundation of cultivating trust and human centered participatory design to amplify the voices of the patient, the care partner, the clinician in the co-design of the future of healthcare. I’m also CEO of Cancer101, which is patient advocacy organization focused on empowering patients and their families to navigate healthcare in partnership with their healthcare team.

Thank you for having me here today.

MATT ATKINSON: Melissa.

MELISSA DUPONT: Hi everyone. I’m Melissa Dupont from Sanofi. First, I wanted to just thank everyone and the panelists for taking time out of their day today. I know we’re all so very busy. I have a number of years of experience working within trial operations, been in clinical trial, multinational trials within various therapeutic areas and then, moving into patient engagement, which is my true passion. And now, we work directly with patients and individuals with different conditions and along the way, work with different kind of external and internal stakeholders.

So thank you for letting me join today.

MATT ATKINSON: And last but not least, Whitney.

WHITNEY BALDWIN: Hi, Whitney Baldwin. Good morning, good afternoon, good evening for those joining. I really appreciate you being here. Whitney Baldwin, I’m with Accenture. I’ve been with Accenture a little more than almost 10 years now. I lead what we call the Patient Experience Center of Excellence for Accenture, which is not only a North American function, but actually we engage with our colleagues in Europe as well because the issues of patients, while maybe a little bit different, there’s a lot more commonality than not.

And one thing prior to joining Accenture, I spent 20 plus years as a brand commercial guy in various roles, started in consumer packaged goods, consumer health and then into pharma for J&J and GlaxoSmithKline. And my last role at GSK was actually as the head of what we called our Brand Reputation Initiative which, frankly, was trying to take on some of the same issues that we’re seeing now. That was quite a while ago that I did that. Unfortunately, some of the same issues are happening right now. So it’s a little bit of back to the future so to speak.

In my role as Patient Experience Lead, one of the things you’ll be seeing and will be sort of a catalyst for the discussion today is a survey that we did to understand where patients view trust. Now this is a U.S. only survey, so it didn’t have a European component or other markets, but probably has some relevance there. We did this amongst 500 patients in the U.S., across multiple therapeutic areas and representative sample, gender, age, etc. And really the question, this was done in December, so this is after the vaccines had started to launch. And so, we thought that was a particularly relevant time.

And the question we asked was we define trust as it’s a firm belief in the integrity, the strength, truthfulness and competency of an organization or someone. And so, we wanted to level set on that and some of the things you’ll see, I think, not be surprising, but will be illuminating as it relates to this conversation. So looking forward to the dialogue.
MATT ATKINSON: Awesome. Thanks, Sarah, Melissa and Whitney, for joining us here today. I want to begin by launching a poll for you all to vote on. You should see it pop up on your screen in front of you now. To what extent does your organization prioritize building trust with patients, all the time, to a great extent, somewhat, very little, not at all?

And I’m going to leave that open for just a couple of minutes whilst you all get your answers in. But, Sarah, I want to come to you first off and I want to ask a question. What does trust mean as it relates to healthcare?

SARAH KRUG: Thank you for the question, Matt. So trust is one of the most important building blocks in any relationship, whether it’s trust in a friend, a partner, a colleague and even your doctor. But trust is fragile. It takes time to build. It takes seconds to break and an eternity to repair. In the 60s, about 75% of Americans had great confidence in our medical leaders. And, unfortunately, today, that percent has steeply declined to 34% and I know that we have a global audience, but in comparison to other developed countries, here in the U.S., we’re less likely to trust our doctors with about 25% expressing confidence in the health system.

We know that a lack of trust can make it less likely for a person to engage in healthy behaviors. It’s one of the best predictors of whether a patient will follow a clinician’s advice, including screenings. Trust is the cornerstone of the interactions that a patient has with the healthcare system. And when trust is tarnished, it can lead to fewer patient doctor interactions. It can lead to a lack of continuity in care, a reduction in the utilization of healthcare services.

Mistrust can lead to skepticism and a lack of confidence that the healthcare system cares about me as a patient and there’s a ripple effect in mistrust. It can lead to negative health outcomes, greatly affect medical innovation. It’s the fuel to help inequities.

So there are sense of disparities and trust across socioeconomical and racial lines and building trust among these vulnerable populations is imperative. So we have a lot of work to do as it relates to trust, specific to the healthcare space.

MATT ATKINSON: Whitney, did you have anything else to add to that?

WHITNEY BALDWIN: Yeah, I think the thing is when you put the combination of COVID and the impact across the entire healthcare system, usually things sort of tick along and you’ll see sort of hotspots, if you will, but COVID has really transformed the way people feel about their healthcare and, therefore, really looking to the healthcare ecosystem. So whether it’s doctors, whether it’s pharmacies, whether it’s pharma, the government. And the delivery to vaccines really kind of changed the frame and the way that patients both expect what they’re going to get from the healthcare system, including pharma, and we’re seeing it live right now vis-à-vis the vaccines. What Sarah talked about really is bringing this to the fore is our ability to overcome this pandemic is largely going to be driven by the fact that we need herd immunity of 75% to 80% of the population getting vaccinated.

But if you look at, as Sarah said, certain populations, including those that have been marginalized, you’re really seeing very different attitudes and that largely is a function of skepticism and trust. And so, these are the things that we’re trying to sort of unpack and this is not to say we’re going to have the answers, but as you’ll see, we did get some responses to what patients are seeing and feeling right now even in the context of the pharma’s shining example of bringing vaccines in record time, which is fantastic.
And as a person of and in the industry, I take great pride in that, however, that can also go the other way. You know, we saw a Harris Poll in the U.S. that said, versus a year ago, a significant increase in people’s positive perception, saying they’re doing a good job. And when I did the job on GSK brand reputation, we looked at that metric and it can move. It can go up, but it can also go down. That’s not the same thing as trust.

Trust is something, as Sarah said, that’s a long-term relationship building thing. So I don’t know, Melissa, do you want to build on any of that?

MELISSA DUPONT: Yeah, I fully agree. I mean even prior to COVID, it’s something that’s been really important ensuring that we’re building this trust with our patients. And, ultimately, that comes through on communication and education, really ensuring that we’re building and sharing, especially in the R&D space, information around clinical trials, decision making tools for our patients and our participants really. And, again, it’s been a long – we’re not there yet, and especially with the impact of COVID, but this isn’t something that – the issue with trust didn’t start with COVID, it was prior to that. And now, we’re seeing a little bit more of the dialogue around it and ways to address it. So I agree with you.

MATT ATKINSON: Thanks, Melissa. Alright, I am now going to share my screen and show you a quick slide. And, Whitney, I wanted to come to you with a question around this is what do patients trust – we can see, but who do patients trust most across their healthcare ecosystem? And you talked to a little about the survey and the results here.

WHITNEY BALDWIN: Yeah, so this was something that – I should be clear, this is again amongst patients in the U.S., 500 patients. And a couple of things to note here. This was something where we asked who do you trust most? Not surprisingly, healthcare provider came out the strongest here, 58%. Then pharmacy. I was actually surprised at health insurance came out a little bit better than the pharma industry.
So this is not meant to say, I think some people in pharma is like, well, don’t they understand we’re providing lifesaving medicines. The thing about trust is it’s an emotional component. And on the one hand, they may recognize that they know that these are lifesaving medicines that they rely on, but at the same time, there’s a lot of complex emotions that are going on and I think you’re seeing that in here.

It says, yes, even with the vaccines, you’re seeing this kind of thing. Does it mean it’s all bad? Not necessarily because you do see things like the Harris Poll and that says, okay, you’re doing a better job relatively speaking. But it clearly says there’s more to do here. And one interesting point is when we looked amongst subgroups in the United States for Black and African American patients, which were about 10% of the population, pharma did a little better, but only because this is a rank ordering. Their trust of healthcare providers was a lot less.

So there are dynamics again and that’s based on – I heard a good comment about this the other day from someone at Mt. Sinai Medical Center said, they have sort of an earned skepticism about what’s going on. And so, I see the line where the hospitals fall in the trust bowl. I would put hospitals under healthcare provider. It’s kind of implicit there. But it’s usually the person that they’ve gone to, so there’s personal trust there.

So this you could say it’s disheartening in the light of the vaccine delivery, but at the same time, it sort of says, this is the reality of where we are. And if you’re going to – and you’ll see in some of the other results, it’s really not just about developing the vaccines. There’s other things, other levers, that need to be understood an pulled in order to move the needle.

MATT ATKINSON: Do you think, when we’re looking at this health insurance, government, pharmaceutical industry, all at the bottom there, that they kind of indicates an overall mistrust with the system itself and that could be what’s pushing this mistrust within the industry?

WHITNEY BALDWIN: I think, Sarah, maybe you want to touch on that?

SARAH KRUG: Well, I’m sorry, whether insurance companies and pharma –

MATT ATKINSON: And the government, all three at the bottom of that poll, kind of would for me would indicate that there’s a general mistrust of the system itself and building trust in the system could be a key to unlocking trust within pharma as well.

SARAH KRUG: Absolutely. I think there are various layers to this. There are many touchpoints in healthcare that can tarnish trust. And this year, with all the initial confusion around COVID-19, there’s been growing mistrust in science and whether it can be influenced and whether both the good and the bad are truly made transparent.

And when we talk about influence, it could be the government influence and that’s the perception. Mistrust in science can threaten a patient/doctor relationship. Team based care is also at times led to a lack of connection to any one person on the team as the patient bounces around in a non-coordinated system.

We always say that every patient should have an ally on their care team that they can trust in a fragmented system and sometimes that non-clinician or a non-traditional source of information can be the best place to help build that trust, especially as we move towards this trend of episodic care, where the sacred relationship between the patient and doctor is greatly affected.

And it’s interesting that healthcare professionals came at the top of the survey because I’ve been entrenched in a health confessions research project for a couple of years, where we set out
to understand what people might conceal or lie to their doctors about. And we’ve collected over 5,000 anonymous stories of what people lie to their doctors about. And so, we know that even though doctors might be higher on the totem pole in terms of trust, we still have extensive work to do.

And then, trusted information. So regardless of sector, trust in information is a growing issue. People don’t know where to go for credible information. We live in an era of information overload and with access to the internet, there’s a lot of erroneous information out there you have to sift through. But most people don’t have the skills to distinguish what’s credible and what’s not.

And I think the COVID-19 pandemic and its ripple effect, it’s tarnished trust even more with the initial uncertainty and the conflicting information from authoritative sources. So like here in the U.S., we had the CDC and people were questioning the CDC’s motives.

And then, even now, as data continues to unfold, many are skeptical about how transparent these organizations are with their data. Unfortunately, we’re an industry where a misstep by one organization can affect trust across a particular sector. And so, we’ve been conducting a series of listening sessions, active listening sessions, I should say, with the patients to understand what they’re hearing, what they’re reading and what’s that influence on the cast of decisions that they make.

There’s also extensive skepticism as it relates to who’s monitoring the data and how it’s being monitored with Big Brother always watching. Technology is outpacing security, privacy, reliability and that can have a major impact on trust because often times there’s a lack of transparency in how information’s being collected, protected, shared. And transparency goes above and beyond tucking legal terms that no one can understand and the terms and conditions in the privacy policies.

So when I work with patients, we also have them access the terms and conditions at various interventions. On average, 90% of what they read they don’t understand. I could talk about this topic all day, as you could tell.

WHITNEY BALDWIN: Well, and I was curious, Melissa, when you saw these results, were you disheartened or what was the reaction? Do you think people in your organization would be surprised or what do you think the reaction would be?

MELISSA DUPONT: So we primarily work with patients, so we gain insights to how to build our clinical trials, really giving our patients a seat at the table. And when we talk to them around where did they get their information and when they make a decision to participate in a clinical trial or to try a drug treatment, they always say their doctor. And quite often, even if they think that they want to try something else that their doctor says, no, we don’t recommend it, they won’t try it because they really put a lot of trust in their doctor. And they also put a lot of trust in their external partnerships, like their caregivers or their family members or what they see in the community, like the patient advocacy groups.

So I’m not surprised that health providers are number one. And I think when I think about health insurance, it’s probably because they talked to somebody, they can get to somebody to ask a question. Where in the pharmaceutical industry, it’s hard to maybe get – for a patient to talk to somebody because we do have policies and privacy laws in place.

So while I would like to see it a little more evenly spread, I’m not surprised that the healthcare providers are definitely number one.
SARAH KRUG: You know, just to interject though, a sad reality is that a lot of clinicians don’t necessarily always recommend that clinical trial to care. Even though that is a trusted source, they’re also driven by incentives. So there’s a whole ripple effect there.

MELISSA DUPONT: Yeah, it is. And I agree with you, Sarah, we see it quite often where a patient will tell us that their doctors flat out told them no, we don’t recommend. You’re going to stay this course. We don’t recommend you go to a trial or we don’t want to refer you to another doctor especially with COVID, there’s limited to see a lot their patients. So they don’t really want them going outside. So we are seeing this when we talk to them to try to figure out how are they making decision and who do they trust to participate.

MATT ATKINSON: I am going to show you another slide now, so you should see it come up in front of you. And, Sarah, I’d be interested to get your thoughts on this and how is mistrust impacting healthcare?

WHITNEY BALDWIN: Yeah, maybe I’ll just do it. So this is from the survey, Sarah, so let me just jump in and then, you can comment. We asked how is this experience affected you? Now, implicitly vaccines and the whole delivery of that and the speed was part of this. I think the good news is it showed there was an increase in trust. So if you look at significantly moderately, that’s about 35%, 45% no change, but then there were others for whom the issues you cited, it actually kind of went the other way. So net, there was I’d call a modest increase in trust and while that’s good news, to me, what it said and the way I interpret it was, I think many in pharma would say, well, we develop these vaccines, we’re saving lives, we’re here, we did it in record speed, why don’t you give us credit.

And the reality was that they are giving a bit of credit, but they see it as kind of that’s your job. That’s your job to develop the medicines and, frankly, they would probably look and say, well, that’s why you’re earn so much money is because of that’s your job.

So we’re not going to give you extra credit for that and as a matter of fact, we saw sort of – it also changed their expectations to say, in terms of the R&D process, it’s like they actually said, well, that’s great, but what about my condition? Where’s the same urgency for my situation? Can’t you show that there?

So their expectations have changed dramatically and this is evidence that there’s some good news, but it can’t just be only about the medicines, there has to be other things.

So, Sarah, I don’t know if you want to add in.

SARAH KRUG: Yeah, so as Whitney mentioned, despite the fact that we’re in the midst of a debilitating pandemic that’s disrupted our lives substantially, there is widespread distrust in R&D efforts around COVID-19. And it’s 34% of Americans said that they’re likely not going to get a COVID-19 vaccine as per the study and those numbers jumped to about 49% in Blacks, even though they’re one of the hardest hit by the pandemic. The majority of Blacks do have low levels of trust in the healthcare system in general.

And as per a recent Kaiser study, 7 out of 10, Blacks said that the healthcare system treats people unfairly based on race often. And that’s a substantial increase from when that similar question was asked about 20 years ago.

There was another study that came out, I believe it was last Friday, that showed that even U.S. healthcare workers were skeptical about COVID-19 vaccines. So approximately 15% of American, front line healthcare workers have not been vaccinated for COVID-19, even though they’ve been among the first eligible to receive the treatment in those communities.

And then shifting away from all things COVID related, just as it relates to mistrust in healthcare
healthcare in general, in the LGBTQ community, for instance, a lack of trust in healthcare has led to many avoiding, delaying their care and visits to the doctor. The LGBTQ community often negotiates whether they should disclose their sexual orientation and gender identity status to their clinicians based on how safe they feel during the visit. And these patients are affected by a healthcare system that could be discriminatory, makes assumptions, lacks cultural sensitivity and mistrust makes people, patients, less likely to follow medical advice from a clinician and stick to a treatment plan.

It’s affecting the utilization of digital health, where, as I mentioned earlier, people are skeptical about how their privacy will be maintained. And then, let’s not forget about the impact on innovation and research. We know that clinical trial participants should be reflect the diversity of our population with a particular emphasis on including the type of people most affected by a particular disease, but there’s significant imbalance in representation of various ethnicities and race in research.

And then, this lack of diversity can lead to the development of innovations that haven’t translated well into real world use. And I understand that there are various efforts underway to address these issues and that’s great, recognizing that trust building, it has to be part of the strategy.

MATT ATKINSON: Melissa, have you sort of seen similar or do the results surprise you? Have you seen sort of similar growth in trust or sort of no change within Sanofi and what you’ve been – or at least over the last year?

MELISSA DUPONT: So what I think what we’ve done here is we continue to work at warp speed. We were able to complete like to help build trust, we were able to continue our clinical trials during COVID. We didn’t stop any of our clinical trials. So in a way, it forced us in the pharma to accelerate a little bit of innovation. Meaning, we found a way to get our treatments to patients. We found a way to quickly do virtual health visits that maybe we were slow to adopt earlier. We were able to ship meds directly to our patients’ homes and things like that without interruption.

So for me, I think, that the way that we’re trying to continue to build trust in our patients and in clinical trials. So I think that’s something that we’ve been trying to do prior to COVID-19.

WHITNEY BALDWIN: Just to build on Melissa’s comment, I think it’s a really important point. We did other research about patients, the impact of COVID and you saw a dramatic increase in things like telehealth and we all have seen this kind of thing. And I think what we saw was that people who had experienced telehealth or televisits, actually had a really positive view. And not for every condition, but they said, frankly, it was good or better than their prior healthcare experience.

And I think the broader picture is much of the healthcare ecosystem, including pharma and recognizing there are some restrictions, it takes a lot of work for a patient. They have to do all the work to be their own ambassador, to go towards the system, if you will. In this instance, it was a first time ever. It kind of went the other way that the entire healthcare ecosystem, pharma, provider networks, patients weren’t coming in, so they had to go towards them in much more tangible ways.

And I think that’s a fundamental shift. I mean I don’t think doctors ever thought that their patients wouldn’t be coming in. That just never occurred to them. So I think they realized they too had to do things differently. So to your point, whether it was in a clinical trial space, to evolve to more digital enablement that allowed them to do things from the home. We see a lot of that. But also, in the commercial space, it’s a real recognition that it’s not just about the doctor. It is, in fact, that having a balanced approach with a patient, as well as HCP focus, that’s become, I think, much more apparent to people.
It's not that it wasn’t there. It’s just the level of the intensity if you will.

MELISSA DUPONT: Yeah, and I just want to also recognize Sarah’s point and the importance of really making sure that we’re able to get into our patient communities, right, making sure that we can find a way to treat everyone, especially with clinical trials because we want to make sure that we’re treating the patients that are going to really – we’re studying and having them not just be in our clinical trials, but are actually going to be prescribed in the real world. So that’s really important for the health value for the outcomes and ensuring that.

And I think with, in a positive way, with the COVID-19 is we’re finding ways to expand that, to find ways to really go right into the community and we’re learning this. So I hope that we can continue to see an uptick around the communication, the education and I know we’ll talk about it in a little bit, really to help build that trust and move that needle up.

SARAH KRUG: And who would have thought that decentralized clinical trials would have blossomed the way it did.

MELISSA DUPONT: Yeah, we’ve been talking about it for years in this industry pushing it. And it took the pandemic really to amplify and accelerate it.

MATT ATKINSON: I would like to come to our second poll now and you should see these results come up in front of you again. What do you believe are the biggest barriers to earning patients’ trust, fairly high drug prices, a need for greater transparency and product development, clinical trials, lack of patient assistant and educational resources, incorporating patient perspective throughout product lifecycle and other? If you don’t see your answer there, but you’d like to contribute, please pop your answer in the chat function at the bottom of the screen. And, again, we’ll leave that open for just a moment.

I want to come again to our panelists and ask you why should pharma care about distrust?

And we can kind of comment on the audience answers in a second, but in the first instance, I’d be interested to hear why? Why should you care?

SARAH KRUG: So, I’ll chime in. So whenever silver linings, the only silver lining that came out of 2020 is that the term clinical trial became a household name. It was the first time that many had been introduced to the world of clinical trials thanks to the media. Every media outlet was talking about the innovation race to the cure. It was the first time people understood they could potentially be part of saving the world.

But things like the use of words, Operation Warp Speed, they didn’t help. So Operation Warp Speed means rapid speed, faster than the speed of light and it’s a term that originated in science fiction and actually became popular through Star Trek. And we do extensive work in the words that cause confusion amongst patients. And one of our assessments showed that the term Operation Warp Speed actually led to low confidence in the COVID-19 vaccine because no one wants to be part of anything that potentially seems rushed. A connection to science fiction isn’t reassuring.

So something as simple as a label of this operation may have influenced a person’s decision to get the COVID-19 vaccine. And there are also many patients who had ailments for - and Whitney alluded to this a minute ago, but those in the rare disease community, for instance, they questioned motivations. Every company is chasing the cure because of how many people have COVID-19 and they came up with multiple treatments in record speed. What about me and my disease? All I ever hear is an average of 17 years from bench to bedside. This led to people questioning underlying motivations.
So it’s definitely an opportunity to provide more context and information to ensure this doesn’t turn into a dark cloud over time. And there is a return on investment to trust. We’ve been working with patients over the years to conduct trust assessments, to measure how the words we use, the actions that we take, the deliverables that we launch and the interactions that we have affect trust across organizations and sectors across healthcare. So until we recognize that there’s a return on value to trust and that’s embedded into strategy, we’re not going to be able to move the needle.

MATT ATKINSON: I am going into the poll now and share these results. So 14% see unfairly high drug prices, 26% see a need for greater transparency and product development, clinical trials, lack of patient assistance and educational resources at 25% and the highest was at 29%, incorporating patient perspective throughout the product lifecycle. But we have had a number of answers coming through in the chat box and I want to read these out as well.

Patient centric healthcare rather than media centric healthcare, policy and regulations make it harder, biggest barrier is the media, including scheme mongering, fake news and politicizing healthcare. Most people still think of clinical trials as being a guinea pig and some experiment. And the perceived high prices of innovation and the rhetoric of academia and bureaucrats have complicated chain of pharmaceuticals, distributors, insurers, so their system itself. Again, the system itself. Education. And a couple of other answers sort of reiterating the ones we’ve seen and heard here.

Melissa, from an internal perspective, does that sort of align with what you would have expected?

MELISSA DUPONT: Yeah, I was curious to see, I think like what I thought was going to be more of the number on actually ended up being the top three. For me, patient perspectives is obviously number one. That’s what I do every day and we do work across the lifecycle. So we work in early, early development, making sure we talk with people and different individuals globally that might be living with a certain disease or condition to really get an understanding around their disease experience first and then, as we move into clinical trials, making sure that it’s relevant for them.

Do we have meaningful patient outcomes? Not just something that we think the FDA or EMA is going to approve, but something that’s meaningful for patients as well. And then, taking that into regular (inaudible) and commercial as well. Taking that information that we’ve learned early, early on and continue to build upon it. And it also helps in decision making and understanding real world. Like what’s a burden to participate in a clinical trial? And then, what’s the burden going to be in the real world if I have to take a medication three times a day, once a day, orally, like an injectable, things like that? You know, what’s the impact on that and symptoms and safety?

So the patient perspective is extremely important. And with that, it kind of goes into the number two answer, around patient and education and transparency. That’s key. We need to make sure that we’re partnering with our advocacy groups and our hospitals to making sure that we’re sharing enough information around clinical trials that’s easy to understand and I know that we have lay summaries that are shared after a clinical trial is over. So instead of someone trying to read a medical journal or something like that, we have a clinical set of report for our patients and our participants that’s written in some easy to understand language. So that’s an example of that.

MATT ATKINSON: And there’s a business imperative to caring about trust, isn’t there as well? It’s not just obviously the end goal is be to health outcomes. There’s no question in there,
but within that is higher rates of patient adherence and building trust and that patient perspective and strategy does lead to better business results?

MELISSA DUPONT: Sarah mentioned that earlier, sorry, I didn’t mean to jump in, but Sarah had mentioned that in the beginning how important trust is, especially to not only having adherence to someone’s medication, but to seeing their doctors regularly, to making sure they’re following up with other external resources to help them. Maybe it’s not just their doctor, maybe it’s something like a social worker or someone like that to build that circle to help a patient advocate for themselves to continue to be better. And, Whitney, I’m sorry, I jumped in.

WHITNEY BALDWIN: Yeah, I agree and I think there’s a couple of things. One is this notion of, well, pharma, we have regulations. I’ve been there a long time and, yes, there are regulations. But there are regulations in other industries. And as we saw in COVID, FDA can evolve and you just have to figure out a way to help them understand what you’re trying to do can actually have a positive outcome on patient perception and ultimately outcomes. And there’s examples where that’s happened. So I don’t fully accept this sort of, well, we’re regulated kind of thing. I think that we got to test ourselves as an industry.

And I think going to your area of clinical trials, the stats around clinical trials are pretty applauding in terms of 5% to 10% of the patients, of the eligible population, aren’t even aware. And then, when you look at the number that actually enroll and then, are part of a trial. There’s a business impact and trust is implicit in some of those numbers, as well as on the commercial side, the issue of adherence, people kind of see you, well, you just want me to stay on your medicines. And I think it’s the way we communicate and how we engage that’s really interfering with it. And I don’t think pharma, frankly, focuses to the degree that they should on those types of things and it can have a positive human outcome and business outcome.

MATT ATKINSON: Melissa, we’ve got an audience question here and I want to ask it to you because I think it relates to sort of your line of work. And it’s do not underestimate the caregiving realities of patient when it comes to trust. They deal with the situation as the giver. So how about finding a way to include this as well in clinical studies, it would help create to given this is as a catalyzing fit to improve trust? Is this something you guys try to include as their caregiver within the studies and son on?

MELISSA DUPONT: We do actually. I actually have a caregiver interview next week. I’m talking to caregivers and we are trying to find ways to incorporate that. And it’s not just in the clinical design. We’re also trying to find ways to support, how do we help support caregivers globally? Because they might be the ones that have to drive the patient to participate in a trial that’s outside maybe their standard norm.

And also, what’s the impact of the caregiver who just within a disease itself? So how does it impact how they care for their loved one, but not only that, but how is it affecting them and their own health as well? So there’s a lot of things that we’re looking into. I mean we’ve only just tapped the surface of this. It’s definitely a very important thing and it also it not only impacts the patient and their decision making, but also impacts the caregiver as well in their life.

MATT ATKINSON: I am going to share my screen again in just a second, but the question I’m going to ask and get you all to respond to is what actions can pharma take to earn patients’ trust? And again, we’re going to see some results from the Accenture survey. Those should be up in front of you now.

Lower drug prices, 83%. I’ll just read the first couple of ones at the top there. Publicly shared clinical research, data in a clear and transparent
manner, 82%; financially supported access to treatment, 78%; provided more educational resources to patient, 75%; and supported government policies protecting patients’ rights and health at 74%. I might just leave that open to our panelists and allow somebody to jump in, but what are your thoughts on those results?

WHITNEY BALDWIN: Yeah, I mean when we saw this, first of all, the lower drug prices, not surprised. That’s always going to come up. Historically, it’s come up. That’s probably not something that’s going to be hit upon, but it is a pain point. But what’s more important is if you look across the board, it’s not just about developing more medicines, although that’s certainly sort of, as I said, table stakes. If you look at this, this is both in the R&D sector, as well as the commercial sector. All these things that are there and it’s not that pharma isn’t doing them. They can point to – I look at some of the things, whether it’s patient assistance or education, there are efforts there but its, frankly, patients aren’t aware of them. And there’s not enough attention and focus on, for example, financial, as well as other types of support that are needed now, particularly in this time of COVID.

Things like sharing clinical trial transparency. We think we do it, but again, when I look at some of the portals that are about the clinical trials, frankly, I wouldn’t call them particularly patient centric. So I think this is this whole issue of there’s more than just the focus around medicines, if you will, and these are multi-pronged, multi-track types of things that pharma, I think can and should elevate and do differently and better. And if done in an appropriate way, I think patients would respond. We have other research that says things like patient services. They value them if they’re approached in the right way.

So I think some of this is you would say is expected, but some would it’s going beyond the medicine. These are trust value levers is the way I look at it.

SARAH KRUG: Yeah, and I’m happy to chime in. And many people have heard me say this often, and it’s become my motto, but transparency is the most disruptive innovation of the 21st Century. And I think we have a lot of work to do in this regard.

It’s great to see that data sharing has become an imperative for many, but we also need to take it one step further and ensure that people can understand what that data means within the context of their lives. You know, it’s up to use to translate healthcare speak. For many, healthcare is like a foreign flick and we need to provide the subtitles. There’s been a transformational shift to partner with the experts by experience, the patients, across healthcare. And as we recognize that the life expertise of the person with the disease is an invaluable resource that can help clarify a patient’s priorities, their needs, long before we embark upon discovery.

It’s important we cut out safe spaces to integrate the voice of vulnerable populations that are typically not heard, which has been a focus of our work with patients.

And then, the last thing, I think in order for the pharmaceutical industry to evolve from that perception that they’re just a drug manufacturer to that perception that they’re a healthcare company focused on health and well-being, they’re going to need to do more as it relates to investing in people’s health before, during and after their ill. Patient support services that extend in to prevention and as Melissa mentioned, caregiver support.

And I’m sure many here in the U.S. have heard, not to make light of this, but Krispy Kreme is offering free donuts to people until the end of the year if they get vaccinated. And correct me if I’m wrong, but I think it’s a donut a day. I haven’t had a Krispy Kreme since college, so I’m not
100% certain. But donuts are obviously not the healthiest option. Obesity, there are complications with COVID-19, but we won’t go there. But sadly, many patients have asked if pharma was funding that campaign.

But what if pharma did something radical and partnered with a wellness company and with each vaccine gave out a free gym membership or a gift card where you could only purchase healthy foods based on the SKUs or something that demonstrated that pharma’s concerned about people before, during and after they’re ill. And it infuriates me because I worked for a pharma for a decade. We did great work. All of you are doing phenomenal work, but it’s not reaching the average person affected by a condition. And so, there needs to be more transparency, even about all these wonderful things that you are doing because you’re not just all about the medication, but sometimes these patients don’t see that.

So it’s imperative that we shift our mindsets from how do we convince people to trust us, to how do we become more trustworthy over time?

MELISSA DUPONT: Yeah, so Sarah, I really just want to jump in on that a little bit because I really wanted to share an example of something like that, at least on the R&D side. So we had an opportunity in working with Susan G. Komen to actually go into a urban hospital with non-native English speaking patients, who were just newly diagnosed with breast cancer and we really just wanted to sit and talk with them around their new diagnosis, their feelings, if they were to participate in a clinical trial, showing them a study design, talking to them about assessments. We did all of this with a nurse interpreter, right there in a hospital at a roundtable. And they expressed huge fears around a biopsy, around a punch biopsy that was to be done right at the beginning of the study, saying that they were newly diagnosed and they had this fear about punching my skin might spread the cancer. It was a tremendous fear and it was acknowledged.

We were able to go back to the clinical team, share this and actually have it removed from the design itself and that’s why it’s so important to make sure that we’re going in, talking to our patients and figuring things out early on to understand and making sure we’re not just sitting at a roundtable with one type of patient advocates that talk every day and understand clinical trials, that we’re going to all the communities and learning. And that was something quite amazing, I think, and I just wanted to share that that those are opportunities that we can continue to try to leverage.

Obviously, this was pre-COVID, so we have to get creative on how to do that, but I would like to see that continue.

SARAH KRUG: Yeah, that’s a great example, Melissa.

WHITNEY BALDWIN: Terrific example. I mean what struck me is like, well, that’s irrational. Well, yeah, but that’s where they are. So go towards them, help them see that you get - you used the word acknowledged, that’s a fundamental word that I think is kind of skipped over. And so, I think that acknowledgement and then saying, no, we’re going to change things a little bit. That’s the type of small, yet, large change that I think can and should happen.

MELISSA DUPONT: And I just want to be careful when I see a comment come up about the irrational. I mean I don’t want to say that was irrational fear. I’m not. I haven’t been newly diagnosed with breast cancer. That’s a genuine fear from a patient population. And we were able to bring it back to our scientists and they were able to find a way to say, we don’t need this. We don’t need to collect this. This isn’t a data piece that we need. We can get it another way, to support the design, to support the clinical trial. And so, then we were able to acknowledge worry and fear and that goes into trust.
WHITNEY BALDWIN: Yeah, sorry, I should be clear. I wasn’t saying, making a judgement on them. I could see how some of the clinical folks could view it that way. So, apologies if I –

MELISSA DUPONT: And it was a aha, an education moment for sure for our clinical team because they might not of – they didn’t even think that would be a problem.

SARAH KRUG: And that’s a great way to really build that trust is account for the emotional journey that that patient goes through and the caregiver goes through as you’re also mapping that patient journey, if you will. So I love that you’re really taking that into account.

MATT ATKINSON: And it’s also about removing assumptions through a lot of this process, isn’t it? Education is the greatest example. So using plain language on when you’re speaking to a patient and removing the assumption that they’re going to know that this means that or they’re going to be – know the pharmaceutical lingo because we work in a pretty complicated system and it’s for us who work in it. And so, for those who are not part of it can be – removing the assumption to communicate is vital, I think,

MELISSA DUPONT: Yeah, and I think with some of this, we don’t really want everyone to go into Google to find those answers. I think if we can anticipate the questions upfront and give the answers in advance that are clear and easy to understand, it’ll help going down that rabbit hole of Google and that’s where when you see all of the misinformation as well.

SARAH KRUG: Yeah, and it’s not even just the pharmaceutical terms as Matt mentioned. It’s our words, assessment showed that term negative, which I think most of us understand causes confusion because a negative test can mean a bad thing to a patient, but in healthcare terms it’s actually a good thing. And so, the simple words that we’re using to convey things to patients, the way in which we’re conveying it. So we all also take in information differently. So, for instance, I’m a linguistic learner. I think I’m the only person that when I watch a Ted Talk, I watch the first minute on video and then, if there’s a script, I read the remainder because I like to take in information by reading it. Some people are visual. Some are auditory. And so, we also have to recognize and as we’re providing data, as we’re providing information, we can’t do it in a one size fits all manner. We really have to tailor it based on how people take in information and can act upon that information over time.

MELISSA DUPONT: I fully agree. That’s actually been one of my platforms in fighting spots all the time that making sure that if we’re sharing information or if a patient’s participating in something, we have to understand that everyone learns differently. So providing a visual tool over an in tool and maybe even something sit down and have like a co-team trainer. So there’s all different ways.

MATT ATKINSON: We have five minutes left. So I want to ask the audience a question now and I’m going to give you the opportunity to please answer this in the chat box. So free form, send your answers very fast. So what is one step you can take to help build trust and what is the biggest barrier to succeeding? And I want to ask the panelists to close up in these last five minutes, what is the one thing you’d like to see happen in healthcare or in pharma related to trust? And I am going to start with Sarah, please.

SARAH KRUG: I’ll go back to the statement I made earlier about transparency being the most disruptive innovation of the 21st Century. So let’s start sharing more data in a way that people can understand, so that over time, we can rebuild that trust.

MATT ATKINSON: Melissa.
MELISSA DUPONT: For me, I think we’ve all learned it’s really just about relationship building, the education and really making sure we’re going into the right patient communities. That’s going to be something that’s key and making sure that we’re meeting all of our patient’s where they’re at. We’ve proven that we can do it, so let’s try to continue that and try to keep up that momentum. That’s for me really important and I think also, like Sarah said, the transparency and I think that goes along with the education and relationship building.

WHITNEY BALDWIN: Yeah, for me, I think the key thing that I keep coming away with and a lot of the comments there is the history of pharma is science and it’s talking about some of the things and Melissa said about the science and talking to doctors is very rational. But in my experience, healthcare is largely emotional because people feel vulnerable, etc. And they’re already dealing with a condition that they don’t want to have. So instead of it being about sort of a clinical and medical orientation, can’t we make it not even patient centric, human centric? And the human centric concept goes beyond sort of the physiological needs and recognize that for patients, the way we treat them sometimes is we’re talking about their, for lack of a better word, their treatment journey and that’s sort of the focus. They look at their lives, their condition, in the context of their life journey. So how we appropriately connecting and going towards them to understand where that life journey is, where it makes sense for us to play and doing it consistently over time. This has historically been when we feel threatened as an industry versus saying, how are we going to establish a “relationship” in an appropriate way, where they want us and where they see value. That will pay dividends for us in my view as an industry. And the trust can rebuild, but it has to be done consistently and over time.

MATT ATKINSON: Interesting because the relationship between pharma and the patient, it has an intermediary in terms of that HCP. And so, I have a question here from Todd and it’s probably, we’ve got a couple more minutes left. So he says, how we can improve level of trust HCP tip for education and research coming from pharma and do you think improving this metric in the pharma HCP relationship would trickle down and positively impact patient trust with pharma? What are your thoughts? I can see some nodding heads.

MELISSA DUPONT: Yeah, so I can actually give you some good examples. I agree and I know that I’m working within the MS space that we have a consortium, kind of around this piece, making sure that we’re sharing HCP education and also, making sure that our HCPs are representative of the patient population. So I think it’s important as well to continue to educate and have that information for our HCPs and for their staff as well.

SARAH KRUG: And technically, medical education for clinicians, there’s a whole governance structure here in the U.S. to ensure that it’s fair, balanced, unbiased, it’s been peer reviewed, things of that sort. So the HCP education I’m typically less concerned about. The patient side, it’s a little bit of the Wild, Wild West. It’s not governed, but I’m working on that. So if anyone wants to join me on that effort, ping me.

WHITNEY BALDWIN: Well, I think it’s about enabling the language piece between the two of them because there’s a disconnect and there’s plenty of data around that. I think as you have cited, Sarah. So for me, it’s about we’re not just saying it’s all about the patient. Obviously, it’s got to be that how can pharma enable that dialogue in a different way, so both feel like they’re enhancing their own relationship and pharma can be a facilitator at that.

SARAH KRUG: And I think it’s important for patients to also start recognizing the expertise we all bring to the table. So pharma sits on so much science, so much data and I don’t know
any other entity that has that much – you have that bird’s eye view as it relates to everything that’s going on. And until we start to shed more light on the strengths and weaknesses we all bring to the table, we’re not going to be able to move that needle. But I think it’s imperative we put more of a spotlight on that because we all have an important role to play in improving health outcomes over time.

MELISSA DUPONT: Yeah, I agree. I do want to just highlight really quickly. I’ve been seeming some of the chats roll up. And at the end of the day, we really just need to make sure our patients, our patient advocacy groups, really have a seat at that table in some of this key decision making and as we’re spitting out tools, we didn’t just create them. We’re making sure our patients are reviewing them too and that they make sense. So I actually agree with a lot of those comments that have come up and I want to thank you for recognizing that.

MATT ATKINSON: Well, unfortunately, that is the end of our time. How time flies. Sarah, Melissa, Whitney, I really want to appreciate, thank you for your time today, especially Accenture, who have been our partner in putting this webinar together. If you want to learn a little bit more about some of the work they’re doing or learn about the results from the research, you can go to accenture.com/patientxlab or reach out to Whitney at Whitney.Baldwin@accenture.com and I’m sure if you had any more questions, you’d be able to find all our speakers on LinkedIn and feel free to connect with them. I hope you don’t mind me saying.

Look, again, thank you so much for all your time today. I hope you’ve learned a lot and until next time. Thanks.