

#	First, what does research mean to you? Tell us in 1-3 sentences.	How do you think research can be improved – from the process to the final product?	How could researchers provide value to patients/participants while collecting their data?	How could patients be better included in research?	Is there anything else you'd like to share?	Start Date Submit Date Network ID
b5f65bd17	Research means bringing people and information that matter together in order to come up with impactful and measurable solutions to identified problems.	If you're conducting healthcare research, then involve the patient who the drug or product is designed for. Who knows better what they will like or dislike in the design of that final product than the sample population who will actually be using it?	Show me data. I signed off on a consent form for you to use my data. I want to know what it's being used for! What problem am I helping to solve? What possible cure is my body helping to find?	Tell us about all of the research that is going on. Don't just leave it up to us to find it ourselves. We know that it's out there, and we know that you need more clinical trial participants, more beta testers, etc., so tell us. We're here.	Awesome survey design and layout!!	2015-09-22015-09-22a8b05281
ccb086ff6	Furthering of experience either of existing technologies, new adaptations or something totally new	Realize that we are always "in the box" and perform research from that position, thus the proposition of new ideas is not only desired, it is required	provide either progress or reports or communication among participants, even anonymous	Find out what we need and desire to make our lives more liveable	thanks!	2015-09-22015-09-22ccb71d2a7
fdcd9c0e6	Studying trends and data to achieve insights into a particular subject.	Thanks for asking. It could be improved if patients were the decision makers (we could control our health care funds, choose our own treatments, define our own desired outcomes, and award the research that helps us toward those outcomes). The legislative, cultural, institutional changes required to put patients in this position of power may or may not happen, but in the meantime, you could pretend we are.	Pretend that patients are the difference between you getting funded or not. The difference between making tenure or not, getting published or not. How would you treat them then (i.e. if patients controlled your value).	This will probably be said by many, but it bears repeating: Patients should be involved in the design of a study and the desired insights to be gleaned from research. How would you include patients in your research if patients were the ultimate judges or benefactors of your research (instead of a journal, professor, gov't agency)?	I appreciate MedX making cultural strides toward empowering patients. Keep up the good work.	2015-09-22015-09-227576bfe16
2a06cc3e4	Research means combining our knowledge and experiences to learn something new together. It means collaboration around a shared goal. It is a hopeful path through understanding from where we are to where we need to be.	The IRB process needs to be revised. Best said by Faster Cures, "Imagine a bullet train on steam engine tracks. That's the system we have for medical research. 21st century science can't thrive on 19th century infrastructure." The other critically missing piece of research is the feedback loop. I want to what new knowledge has been created, what new systems and tools are in place, whose lives are improved as a result of the contribution of my time, my experiences and expertise in the research. The value of the research is not in the published paper buried inside of some journal, but in how that knowledge is applied, modified, learned from and spread	Passive listening. So much is missed in only asking questions. I think so much more could be learned though listening than through asking.	Patients could help to develop the research agenda. Patients could be collaborators in the design of the study, identifying barriers to participation before the research has been pushed out and met with inadequate recruitment, saving everyone time and money. Engage with patients and families where they are. Research should never be an inconvenience.	Don't group everyone together. The needs of the average Joe, or someone with an acute injury vary so greatly from those of us living with chronic conditions. There shouldn't be a "best" or a "one size fits all" approach to research, but rather a toolbox of options that enable me (patient) to participate in whatever capacity is right for me.	2015-09-22015-09-225b63a91f8
b6f4f7da0	To me, research means gathering and analyzing data in an effort to make sense of an outcome.	I took a Research Methods course this summer and it opened my eyes as to just how involved and complex research can be. One of the main takeaways of the course was to really examine where the data is coming from and how it is reported. If the premise of research is updated in the reporting, research is better able to serve its purpose.	Transparency is key. Similar to how you gave a brief introduction to this survey and informed us of how answers would be used, so, too, do research participants deserve the same level of informed consent and general understanding of their purpose in the study. People generally mean well and want to help others; when research is presented in that light, I believe people will rise to the occasion if they truly believe they can be of use to the study.	Speaking from my observations of the diabetic community, of which I am a member, I notice that often there is a disconnect between the research and those it is intended to help. For example, if more people visited clinicaltrials.gov and obtained background information as to the types of subjects needed for research, they may have a better grasp of how complex clinical trials research is. We all undoubtedly want cures for diseases, but the opportunities to participate in research must be presented more clearly so those who meet the criteria are more accessible.	Research is a difficult, yet very rewarding, process. I wish you the best in your "research about research!"	2015-09-22015-09-227e639cdd0
1cfeb380d	Research is the key to answering the question, why do I hurt? It gives hope, engagement, frustration, patience, strength, and opportunity.	Research needs all players involved, especially patients! We are experts. It's time we get a shot at designing the final product.	This question is fundamentally flawed. Value comes from better research questions, not from what one group can provide another.	First, patients need to be respected for being experts too. Also, patients need to be involved in medical school in order to develop better patient/researcher communication skills.	Value should always be measured against quality of life. Healthcare should be a right, not a way to advance ones ego.	2015-09-22015-09-22b257ce13f
763be007f	Research is done to find the answer to a question. Not all research will get the right answer but even the wrong answer can provide information.	Research is a process that could benefit from collaboration , design thinking and people who can focus on the issue - not how much solving the problem will cost.	Share information with patients at set intervals- (quarterly) , don't wait till the study is finished and data is published. Ask patients what information is important for them to know - side effects, and other outcomes.	Ask patients/advocates to review research topics and funding opportunities. Ask patients what outcomes they are interested in. Ask patients what questions they want answered- what research they want done.	I wish I could read some journal articles that are behind paywalls. Would also love the opportunity to sit down with researchers and talk data - like the human genome project - looking for some genetic mutation connections that I have seen anecdotally among survivors I know.	2015-09-22015-09-221154dbd1f
d1b5233da	Research is a form of organized inquiry using scientific methods that is expected to conform to ethical standards.	Research could be improved through including patients in the process in a meaningful way, from setting the questions to finding the answers, and communicating them to users of the knowledge	If researchers see patients only as subjects or raw material they are less likely to provide value to them, and yet the research experience can be very empowering. Have seen some patients use the knowledge to improve self management	It needs to be made a condition of funding. That is very effective. Also it needs to start by including patients in medical education - looking at curriculum and collaboration from Year 1	Both the patients and researchers are going to have to learn new skills to work together. In some fields researchers are like a big extended family and patients are pariahs in, often poorly briefed.	2015-09-22015-09-22ff35ce600
3567e03d4	Research is the opportunity for access to a better life if the questions asked are of value and co-designed with patients.	We need to write in a way that is accessible to patients and not pepper the paper with jargon. We also need to ensure research is open access; it needs to not sit behind a paywall.	By giving the opportunity for patients to be on the research team as an equal partner. And if patients are part of the team, they need to be compensated appropriately	Open the door and work with us an equal partners. Allow us to determine the research questions. Provide us with the necessary training to build our skills.		2015-09-22015-09-22d688e70c4
e4f46cad1	Research means answers for rare disease. It means collaboration with patient communities. It means inquiry.	Engage patient from beginning to end in an authentic way. Give them decision making capacity & respect as collaborators. Then you are doing research that is relevant to the patient community.	Value comes from doing research that will turn around and be useful to patients. This comes from listening to patients from beginning to end. Value comes from respecting the patient perspective as and equal voice to that of the researcher and integrating it into the design.	Engagement in end-points, goals. Ultimately patients'/caregivers should be engaged in funding decisions as well.		2015-09-22015-09-2237f306dbe
4d6c122b5	In short, finding a cure. Why stuff happens to gain a better understanding of the problem.	Ensure that the pursuit of profit does not hamper research.	Give us discounts on meds, hardware whatever.	That is difficult. All patients are different. I think keeping them informed is best.	No. I look forward to this event.	2015-09-22015-09-229d6a9822c
fa7bf7982	Identifying ways to improve patient defined outcomes and ability to live well with chronic conditions.	Incorporate citizens into setting priorities, being on research teams, being on funding agencies, and evaluating research results.	Provide feedback on their findings.	Setting the research agenda and priorities, on research teams steering committees helping to design the studies, on funding agencies evaluating grant applications and research results.	For patients/citizens to be involved, the process of research needs to adjust to accommodate in terms of time frames, speed to cover expenses and compensation. Training and support for patients and orientation for researchers on the partnership.	2015-09-22015-09-2282d18d8af
112062b7f	Research is a way to look for sth new. It's the path of innovation and invention.	Open innovation- meaning the interaction with customers, suppliers, researchers, producers, etc.	Offering data boards, score cards, graphs.	Apps that link to researchers/ providers.	Not at the moment	2015-09-22015-09-2220ef40587
ecaf1bd05	Solving real life problems. Engaging all stakeholders. Answering questions.	Figuring out how to get documents to be in plain language for the end user.	Clear explanations of processes and procedures- especially in projects with multiple data collection points.	Upfront as part of the research team. Identifying questions, helping evaluate data, etc. Think PCORI expectations.	Educating patients on better ways to tell their story so that Healthcare providers get it.	2015-09-22015-09-229a574f03f
a2c6421ec	Studying treatments given to patients who have serious illness or chronic condition. Control group is essential.	Bigger numbers of people. The public can no longer be the study/control group. Stop pharma companies from funding research studies. Stop pharma from playing doc's.	Ask for permission to use data. Study data and treatments. Give patients who gave data results and summary first.	Just ask them! Ask them to participate.	No	2015-09-22015-09-22c10f98d07
eb747ef9f	A systematic investigation, involving multiple cited and reputable sources as well as multiple materials.	Depends entirely on the research being done! But, collaboration! Collaborating with others to pull from various resources, fact check each other's work, provide constructive feedback re: materials gathered before taking the research to the drawing board, so to speak. Open access to journals would significantly improve the research process as well.	Involve them: collect their data and communicate to them why and how their data is reflective of an important narrative that is missing in medicine/science/ medical education. Involve them in the process, compensate them for their time, engage them as not just the source of data, but as the valuable educators patients often are.	Allow patients to help structure the research methods and work directly with the researchers themselves, give the data a living story: panels, public speaking, projects both before and during research collection. Seek out and engage perspectives (and data) from hard-to-reach populations, such as minority groups with poorer access to health care. While research is underway, keep patients updated and engaged with researchers re: what is going on with the study at that given time.	Build trust and an honest, sincere relationship with the patient community. We want to share what we know, data included, but few will do so without some level of engagement, sincerity, and trust.	2015-09-22015-09-22ed292a5ff
53f38db7f	Hypothesis based, controlled experimentation	Transparency in the process of research	Provide that data back to patients with analysis	Ensure research participants match the demographics of the general population (race, socioeconomic status, gender, age, etc)		2015-09-22015-09-22919c3a98f
534a27f5a	Research is using logical and repeatable methods to confirm or deny a hypothesis.	If research involves human subjects, or will in the eventual course, involving those subjects or their advocates in the design of the research and the iterative process and analysis.	They could give the individual patient's data back to them in real time as its being gathered. In addition, commit to releasing cumulative, deidentified data within the a reasonable period of the study's conclusion, no more than 1 year later.	They could be brought in at the very beginning and focus grouped over the course of the research. They should be partners.		2015-09-22015-09-22f67f14c3fe
3337dfdf9f	Research is an attempt to gather information (observational, qualitative, quantitative, emotional) about the world in a systematic, preferably repeatable, way.	Although research can be extremely specific, it's important to broaden the context, to use data collected from multiple perspectives to form a more holistic view. We need fewer efforts to develop "one-size" products and more effort to come up with innovative things. And we need to figure out what really works best for a wider range of people, not just the healthier, fitter people typically allowed into studies. Research should be conducted in a way that reflects the "real what reflects the way we live."	Transparency, access, and context are essential ingredients, but the details should be shaped to fit the research and participants. One approach might be to unite participant and researcher communities in a design effort in advance of a trial so that they can co-create meaningful and practical ways to provide value.	Patients (in some cases) can be engaged in the design of studies, given access to their own data, be given opportunities to contextualize their experience by supplementing the data collection with information they judge to be relevant. This can be outside the formal data collection, but the experience of patients should be treated as meaningful, and potentially useful, even though it may be quite tangential to the formal effort.		2015-09-22015-09-2216a65f6fa
390e4d4c4	The search for products and services or approaches that can result in better health and wellbeing.		Ask representative patients to help shape the studies. Ask them what outcomes matter most to them. Tell patients at the beginning and throughout what the data are being collected and used for. And directly share the ultimate findings with all the study participants in a way that is understandable to them.	Research funded by PCORI has shown many times over, patients can be study co-investigators or partner in studies in other ways. Researchers should strive to find out from patients what their concerns are, what they think should be studied, what information gaps they need filled about care for a particular condition.	PCORI -- the Patient-Centered Outcomes Research Institute -- is living and breathing patient-centered health research. It is making it happen. People should look into its work and the studies it has funded.	2015-09-22015-09-22e3a8c443f
2b114bef1f	Studying an idea, behavior or product to see the results. Research is extensive. It is hard to define in a few sentences.	Do research in a natural environment. Involve everyday people.	Show that you value their input. Include them in all levels of the research.	Ask their opinions more.	Patients and families need the info to make informed decisions about their own health.	2015-09-22015-09-22ada4a35b3f

36ed53b6	Seeking scientific answers and a cause for the cause. Maintaining open curiosity.	Engage with patients throughout the process. You theorize answers while we live realities.	Provide transparency, info along the way. We are left in the dark until the "ask your doctor" ads with cutesy graphics.	I'm astounded that patients are not sought out. My own family is a rich research subject of genetic soup. Who's curious enough to ask? I share publicly, no researcher has ever chimed in.	I can only be the best patient you allow me to be. I maintain curiosity & tinker with my health. I need doctors & researchers to value my input and discoveries.	2015-09-2	2015-09-2	973a0a95f1
083f99909	Research is the process of developing and testing a hypothesis, and then testing to determine if the hypothesis holds.	User-research, followed by user-testing, needs to be better incorporated in research.	Something the research seems isolated from the users (patients and participants) you might be trying to serve. If users can be clear in articulating 1) why are they conducting this research, 2) what do they hope they can bring back to the users, and 3) keep the users updated throughout the process I think that would be great!	I think some of this I highlighted above. Basically, include patients from the "beginning" of your research.	We need to come up with better ways to include patients in research - particularly in the early phase, and address the perceptions / concerns about HIPAA. I keep reminding people that the "P" in HIPAA is portability "not" privacy.	2015-09-2	2015-09-2	a02003f2f2
a052a533a	Research is an investment in the development of future success.	Searching through time outside of traditional research methodologies. Include end users in the entire process	Money is always nice. Outside of compensation find ways to make the participants equal members of the research team	Just that. Include patients as part of the research team. Patients are subject matter experts		2015-09-2	2015-09-2	45c6bcb9e
88018e1e1c	Answering questions	Make it more relevant to real patients in the real world	Use plain language that it appropriate to the patients/participants and in terms that they will understand, particularly when discussing statistics and risks.	Involve them from before the beginning - ask them what they want to be researched rather than including them at later stages once key decisions and directions have been set.	Bring it on!	2015-09-2	2015-09-2	da6a2235f
acefead34	Revealing scientific and medical knowledge	Research should be done without prior interests. No commercial companies should be involve.	Close monitoring with best available drugs, tools and technologies	Via advertising on SN as well as on other platforms	We must start revolutionize the healthcare system by setting global worldwide standard for tagging various kind of medical or health data in a similar way we did when we created bubmed. Then, architects and cloud experts can design the a single huge medical/ health database that is center around each patient's data. This data includes everything we have on Our current medical health record plus the possibility to add to that pt's data his/ her genetic info, real time wearable or other home devices devices data. Such a global uniform standards will not only create a sharing between all points of healthcare providers including telemedicine , overall less costs Most importantly, a starting point for healthcare analytics in a multi dimensional way that has the potential of increasing in a revolutionary unique way our scientific and medical knowledge making predictions sending the right pt to the right test instead of mass screening and later on AI that will help providing the best care for everyone!	2015-09-2	2015-09-2	c683f1d86
e199a044	Research comes from the heart of innovation. To achieve this we need curious researchers and volunteers willing to give of themselves in the hope that something better and something revolutionary can occur to save people in the way that others could not be saved.	Research can be improved by simply thanking those that volunteer and give of themselves to make change. I've never seen researchers thank the patients/participants. There are many things that could be done to change research, but a simple thank you is the easiest. And it symbolizes so much more. It recognizes that this is a process that cannot happen without patients. That patients are fundamental to the process and should be considered partners in this endeavor. To that end, if the patients are part of the process, they are colleagues in care. At the end of the research, when the data is analyzed for the scientific ends for which they were procured, that data and information should be given back to the patient. And with that data should come a thank you. Thank you for giving of yourself to make change, to help others, to trust in science.	Researchers need to share the data they collect. They need to share it with patients and if possible and with consent with other researchers. And perhaps, after the study is published, the findings shared with those involved.	They could ask us what we want studied. They could simply ask us to participate. It is so very hard to find research trials that I can take part in when I would jump at the chance to take part.	I think many pharmaceutical companies are starting to have this discussion. It's being done without these companies really talking to each other. It seems like a race to prove who is the best company rather than true collaboration. Then there are entities like PCOR meant to include patients but not willing to hear criticism and keep collaborating with patients even when the process is difficult. So many things are not taken into account. And finally, those who are poor or without, who are minorities or underrepresented are rarely invited in - creating an even greater inequity. Reach out to more people in places you never looked before and just ask. Then respect their willingness to give and give back a simple thank you.	2015-09-2	2015-09-2	e013a856e
958bcbadae	Asking the right questions to find out what we want to know but much more what we need to know	By removing unnecessary bottlenecks of technicality and including the simplicity of commonsense processes	By early giving education and enlightenment on areas of the research as pertains to the problem being researched into.	By keeping them in the loop of early dissemination of findings	None yet	2015-09-2	2015-09-2	b413a120c
c551de09c	It's a way to scientifically validate ideas , analyze data that may bring new ideas that need further research	Open access	Allie then to provide patient centered portals with other participants	Make them more aware of studies	Great conference	2015-09-2	2015-09-2	ed4b5c83f
5e9f07d3d	The study of cause and effect to prove a hypothesis, ideally under rigorous and appropriate scientific protocols, to reach a conclusion.	In medical research, specifically, I think more educated patient input could be solicited from the beginning to end - including set up, not just "did we set it up properly?" or "do you understand what we did?" That is too late. Patients need to be involved in the process the whole time - many are well educated, well practiced adults who are capable of helping build the process of research into something that will find better answers. And involvement in forming even the beginning hypothesis could create better research outcomes.	Share data, as appropriate to the study, with the patient - or offer to share it at the end. Keep them involved in the loop. Many patients love participating in studies because of the top notch care they receive, for what they perceive as "free."	Start with the patients. Start with some patients who won't be active participants IN the study but will be on or consulting with the research team. Some patients have to many comobidities to participate in studies but could be useful patient leaders/ consultants/liasons to create better ideas & patient-researcher communication.		2015-09-2	2015-09-2	30c30b1d4
9b567365f	Exploration of what is previously unknown. Research is the process of finding answers or further related questions.	It depends on the kind of research. In my field research would be helped by better data sets (bigger, more representative, more valid). In general, involving all stakeholders and applying a holistic approach would improve methodology and probably the quality of the data.	Give them a voice. Embed the ability for a interactive process during data collection. In my experience when patients know that their opinion is valued and included, that is of most value.	Again, give them a voice at all levels of the research! In one of my studies I included former patients' voice in the treatment itself: I played videos of them discussing what it was like for them to recovery and go through the treatment for patients actively going through the treatment. Hearing this "recovery role model" was more valuable than hearing the doctor's voice.	Nope!	2015-09-2	2015-09-2	ad6fb6fb7
10964fa7e	An activity to produce generalizable knowledge.	It could be made better, faster and cheaper, especially by improving the participant experience.	By providing them with actionable information about their data	Have better access to opt-in opportunities. Better websites describing them?		2015-09-2	2015-09-2	0d0b3e40c
ef2190516	systematic observation intended to create knowledge for application	dialogical approach where the knowledges of a greater variety of perspectives creates emergent understanding.	feedback in a useful format that can be used to make meaningful change	In every way :)	oh, yes...	2015-09-2	2015-09-2	91bcb7f48f
dd559eb3	Find out things driven by curiosity that you need to know more about. It can be done in many ways and many interesting things are done by citizen science people.	Include more stakeholders, early on.	Feed the data right back, both as raw data and processed and presented in an understandable way.	Ask them what they would like to contribute and what they want to get back. Plan the inclusion carefully.	Have a great day :)	2015-09-2	2015-09-2	2c523e3ce