

Disrupting Mental Illness

Roadmap for Innovation

Solving Unmet Needs Through
Technological Innovation



Introduction

Many unicorns of Silicon Valley fit a similar profile: they offer discreet solutions for specific problems, and they "disrupt" the prevailing, often inefficient ways of doing things. Uber gave users a new way to get a ride; Airbnb, an alternative to overpriced corporate hotels; Snapchat, a better way to share photos and videos.

Where our human problems are more complex, however, these one-size-fits-all solutions have often failed to succeed. In health and wellness, the impact of disruptive innovation has been patchy, and, to many people affected by disease, disappointing.¹ There is perhaps no area within health and wellness that remains wanting for disruption more than mental health.²

Perhaps it is due in part to the nature of mental illnesses. Bipolar disorder, major depressive disorder (MDD), and schizophrenia - which are the focus of this paper - are deeply complex, dynamic diseases, and no two people experience them in the same way. Each person who lives with one of these mental illnesses undergoes a unique, unpredictable journey. What may work for one person may not work for another, and what works today may not work tomorrow.³

Perhaps it is due in part to the stigma of mental illness. Movies and television shows often grossly mischaracterize mental illness, and prevailing attitudes tend to follow these misguided representations.⁴ People living with mental illness often do not talk about their condition for (very rational) fears of repercussions at work, school, or home.⁵ Friends and family, who want to help, often don't know what to do, and they may be led to misunderstand the problem.⁶





Perhaps it is also due in part to the breakdown in communication between the technology community and the mental health community. Our research and first-hand experience has shown us that many who are developing technological solutions for mental health have limited insights into the problems they're solving for. At the same time, we in the mental health community could do a better job defining the problems that need solving in bipolar disorder, major depressive disorder (MDD), and schizophrenia.

It is no wonder that despite an increase of technological solutions available on market for mental health, there are many uncertainties.⁷

People who are living with mental illness, and the families and friends who support them, are left at a loss. For those living with mental illness, their disease can feel like a rush of flooding water, and no assemblage of medicines and other interventions can build a dam strong enough to hold back the flow. Mental illness, to some degree, feels inevitable. "Good enough" becomes good enough.

This won't do. Researchers must continue to push forward and find better medicines. Investors must engage in breakthrough technologies. And we must pursue the disruptive potential of technology, while simultaneously building an "economic case" for technological intervention.

To that end, we, as the Working Group for Disrupting Mental Health, have collaborated on this white paper. In the pages that follow, we hope to share with the technology and innovation community the top unmet needs in mental health, with particular focus on bipolar disorder, major depressive disorder (MDD), and schizophrenia. We believe that the best pathway to disruption is to define the needs of those living with mental illness so that innovators can understand the problems that need to be solved. We call this our Roadmap for Innovation.



We recognize that there are limitations to this approach. As experts in medicine rather than technology, our Roadmap may fail to identify some practical, technical, and commercial barriers to innovation and development. We also concede that we cannot wholly account for the perspective of those who live with mental illness. We have tried to include this perspective as much as possible, but we feel it would be arrogant to claim we have done so without omissions.

Notwithstanding these limitations, we hold that this Roadmap for Innovation can move our field forward and ignite new ideas. We hope this paper can be seen as the start of a conversation, and we hope it invites comment from technologists, innovators, and venture capitalists, as well as those living with mental illness and others in the mental health community.

To that end, Otsuka America Pharmaceutical, Inc. is pleased to launch this paper as sponsor of the Pitch Event at the 30th Annual Psych Congress, the U.S.'s leading independent mental health conference. This Pitch Event will bring together an exclusive group of promising technologists to showcase their new innovations to the mental health community.

We hope this paper provokes new ideas and conversations. In that spirit, we encourage readers to contact us with questions, thoughts, ideas, and suggestions. Please reach out to Eli Perez, Director, Congress & Stakeholder Management, Otsuka America Pharmaceutical, Inc., at eli.perez@otsuka-us.com.

Signed,

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Mental Illness: Myths in Media and Pop Culture

Myth: People with mental illness are violent and unpredictable

Prime-time characters with mental illness are portrayed to be more violent than other characters.⁸ Some of the most notable “bad guys” in recent cinema are depicted as having a mental illness, such as *The Dark Knight*, *American Psycho*, and *Friday the 13th*. In reality, people with mental illness are 10 times more likely to be victims of violence rather than perpetrators.⁹

Myth: No one “gets better”

Therapy is often shown as an ineffective method of treatment, and characters with mental illness are rarely seen improving and/or recovering from their illness.¹⁰ In *Monk*, a TV series, the lead character has obsessive-compulsive disorder (OCD) and is shown regularly attending therapy sessions, with little to no improvement.¹¹

Myth: Mental illness explains unique talents

In movies, mental illness is often defined by exaggerated behaviors, and these behaviors “glorify” the mental illness that is (falsely) purported to cause them.¹² For instance, *A Beautiful Mind* “portrays mentally ill characters that have amazing talents but difficulty with mundane functionality.”¹³

Myth: Depictions of mental illness have gotten better

It is becoming increasingly common for producers to hire psychologists and psychiatrists as consultants¹⁴ on set, to improve representations of mental illness and combat stigma. Problematic depictions still exist, however, with *Split* as the latest example of the horror genre’s fascination with mentally ill villains. What results is in an inaccurate and violent portrayal of dissociative identity disorder (DID).¹⁵

Mental Illness: By the Numbers

1 in 4

people globally will be affected by mental disorders at some point in their lives.¹⁶

\$317 BILLION

in annual direct and indirect costs in the U.S. in 2002.¹⁷

\$100 BILLION

annual healthcare expenditures in the U.S. in 2002.¹⁸

\$2.5 TRILLION

annual global cost in 2010.¹⁹

\$6 TRILLION

annual global cost estimated in 2030.²⁰

A Framework for Innovation: Unique Considerations for Mental Health Solutions

Given the goal of this paper – to both spur and direct technological innovation for mental health – we believe it is necessary to begin by dispelling myths and affirming realities of mental illness. To that end, we offer a Framework for Innovation that details a unique set of considerations for developers, technologists, designers, and digital strategists as they seek to “disrupt” mental illness.

“Nothing about us, without us”: Technology developers must engage with those who will be using their products. The end-user – whether a person with mental illness, a supporter, or a family member – has an extremely valuable perspective that is often neglected and overlooked in the development process. Only the technologies that build upon first-hand accounts can offer practical solutions that improve lives.

We believe the phrase “nothing about us, without us” captures the spirit of this idea. This phrase gained currency in the 1990s when it was deployed by disability activists, and it was later picked up by the United Nations International Day of Disabled Persons in 2004.²¹ As developers and innovators try to understand problems in mental health to solve, no voice is more valuable than those with lived experience.



We offer two potential solutions. The first is to engage Human Factors Engineering (HFE) testing to ensure functionality. HFE testing can confirm that the solution is not only safe and effective, but that it accounts for user interaction, environmental factors, and user interface design.²²

Second, developers should look at "community-based participatory research." This model of research has been developed by healthcare researchers to learn how to work with end-users to create successful solutions and protocols.²³ The stigma, fallacies, and misrepresentations of mental illness have come to define how many people understand these diseases. They are also a surefire way to misdirect technological innovation.

Clean tools for messy problems: To state the matter plainly, those managing mental illness should not be asked to take on further burden. It is unlikely that a technology for mental health will succeed if it makes life more complicated for the user. Potential solutions must be clean, simple, and streamlined.

Fortunately, Silicon Valley leads the way in understanding "user experience" (UX) and the needs of end-users. It would be a foolish

exercise to contend, in this era of the ubiquitous smartphone, that tech giants or startups need to be taught UX by a group of mental health professionals. Nevertheless, when we look at the bulk of digital solutions on market today for mental health, we are left to conclude that many who are creating solutions have not sufficiently considered the UX of those managing mental illness. This includes not only people with mental illnesses, but also their families, supporters, and others involved in treatment and care decisions.

In considering this unique UX, it is imperative to bear in mind that the "basic stuff" is already hard enough. Adherence to medication is low;²⁴ doctors' appointments are often missed or cancelled;²⁵ and issues with jobs, school, housing, finance, and interpersonal relationships abound.²⁶ Any technology that adds to the noise is likely to be a problem, not a solution.

New solutions, but old problems: Technological solutions for mental illness cannot assume eager consumers. Most who are managing mental illness have been doing so for years, and they have been on long, sideward journeys filled with trials, errors, steps forwards and backwards.²⁷ It would be understandable for a person with a mental illness to see a new





technological solution not as innovative, but as another ostensible solution to an old problem.

Push and pull: The tools with the greatest chance at success will not only require input and participation from the user, but they will give the user something of value in return. There should be both an immediate and a long-term benefit for engaging with the technology, where feedback can promote a safe environment and developers are adequately responding to the comments and concerns of users.²⁸

Solutions should engage with users in a way that transcends the disease itself. Solutions should be interactive and entertaining. They could gamify engagement and incentivize participation.²⁹ For those with bipolar disorder and schizophrenia, this is especially true, because motivation among these groups can be low.

If a technology is imagining that a clinician or healthcare provider will be the end-user, then two goals must be achieved: 1) efficiency and 2) seamless integration into healthcare professional workflow. Professionals yearn for technology solutions that solve problems, but they will not integrate them into their practice if they are inefficient or disrupt workflow.

Adaptable solutions: People with mental illness often have fluctuating, changing sets of needs based on their current level of cognitive functioning. This works on two levels. On one hand, people with mental illness have good days and bad days - days when they eat well, sleep well, and feel well, and then days when they eat, sleep, and feel poorly. On the other hand, mental illnesses are progressive diseases, and what may be a "baseline" today will not be a baseline tomorrow, given the irreversible nature of major setbacks. For a technology solution to intervene and prove valuable over a sustained

period, it must be able to adapt to both daily, fluctuating states of function as well as long-term evolution inherent in the progressive diseases. To put it another way, a static solution can do little for a dynamic disease.

Bridging the communications gap: It is common for weeks and even months to go by between conversations with a person with mental illness and his or her mental health provider. It is not hard to imagine how, after such a stretch of time, a person with a mental illness would struggle to give a quality answer to the question: How have you been? It is also easy to imagine how psychiatrists wish they had more information to gain a better understanding of what's going on.

Given the shortage of professional psychiatrists, as well as stigma, cost, and the fragmented organization of mental health services, this status quo is not primed for change without the intervention of technology.^{30,31}

As if this were not enough, we must also account for the supporter and the family. In questions of mental illness, the supporter often plays a pivotal role in the ongoing success of treatment and care. Unfortunately, supporters are – despite everyone's best intentions – often marginalized or excluded entirely from the communication between the person with the mental illness and the healthcare provider.³²

Privacy, security, and consent: Any successful solution must ensure that data is safely stored and transferred, and that the autonomy of the person using the solution is maintained. In retail, where security has become a hot-button issue with technology, questions of security and privacy are largely transactional. In health – and especially mental health – this isn't enough. Privacy and security must be embedded in the very design of the tool.

Equally important is the question of consent. As technological tools evolve to a place where they can collect user data to create a personalized treatment plan, the user must understand the extent of this data collection and consent to the act of it. Further, this data collection must maintain privacy and security, as discussed above. The failure of a technology to maintain privacy, security, and consent could trigger a community-wide rejection of technological solutions in the mental health space.

Innovation in both design and delivery: The good news is that there is a tremendous amount of excellent content already created and available. The bad news is that much of this content is failing to get into the hands of the people who need it most. Worse, the people who need this content often have a hard time distinguishing between what is good and what isn't. The result is confusion among users and underutilization of resources. The opportunity for technology is to incorporate evidence-based evaluations to allow people with mental illness and their supporters to identify the most useful resources. If solutions can incorporate evidence-based measures and rating scales that have been tested and validated, they will mobilize the best content and resolve an ongoing struggle for those managing mental illness.

This problem is not exclusive to content. It also exists with on-market technologies, and it extends to all end-users. On one hand, medical professionals are not using all that is at their disposal.³³ New technologies often fail to account for overburdened work schedules of medical professionals, and they add responsibilities instead of taking them away. Technology must support or reduce demands on professionals, and not require substantial time commitments. On the other hand, those with mental illness, and their supporters, are rarely familiar with the many tools and solutions that have been created for them, and market clutter has left people confused and frustrated.



Unmet Needs in Bipolar Disorder, Major Depressive Disorder (MDD), and Schizophrenia

Research shows that there are many unmet needs in bipolar disorder, major depressive disorder (MDD), and schizophrenia.³⁴ Mental illnesses are moving targets, and a therapeutic solution that works for someone today may not work tomorrow. It is no wonder that much of our professional attention remains on solving unmet needs.

It is against this persistent, ongoing challenge that we identify a set of unmet needs that, we believe, can be solved by technology in the near-term. There are needs we do not discuss below that can also be solved by technology, but these will require broad healthcare policy changes before they can come to market. We have chosen not to include this kind of deeply complex regulatory solution. If we can be excused for the cliché, we do not discuss these and instead focus on the low-hanging fruit.

Unmet Need: Adherence

For the purposes of this paper, we'll employ the World Health Organization's definition of adherence outlined in their report, "Adherence to Long-Term Therapies: Evidence for Action." Adherence is: "the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider."³⁵ In the field of psychiatry, adherence is perhaps the greatest, most persistent problem we face. If we can help people with mental illness to take their medications, engage in healthy sets of behaviors, and stick to the goals they set for themselves, then we can truly "disrupt" mental illness. This, however, is no easy task.

Questions of non-adherence are complex. For some people, non-adherence is intentional. For others, it isn't.³⁶ Yet, for everyone, adherence to both pharmacological and nonpharmacological solutions is the crux to better mental health and the key to wellness.

Given the complexity of adherence, we believe one way to address the issue is not to "solve for adherence" but to solve for the barriers to adherence. We believe there are three barriers in particular that technology could solve: mental health literacy, understanding side-effects, and maintaining a medication regime.

Mental health literacy: Those with mental illness, as well as their families and supporters, often do not understand the disease they must



manage.³⁷ It is also common for people to deny the presence of an illness, either because they misunderstand the disease or they wish to deny it.³⁸ In some cases, individuals with acute mental illness may be experiencing anosognosia, a symptom that impairs the ability to understand one's own mental health condition accurately.³⁹ In all of the above situations, non-adherence can result. If technology can help people understand the scope of mental illness and the consequences of non-adherence, it could also help them adhere to treatment plans and medication regimes. There are many exceptional materials already created to teach bipolar disorder, major depressive disorder (MDD), and schizophrenia, yet these materials go underutilized.^{40,41}

Understanding side-effects: Medications for mental illness suffer from a poor UX. People will often experience the side-effects of a medication before they experience the benefits. To no surprise, this dissuades many people from maintaining a therapy.⁴² Many of the side-effects of different medications are shared - nausea, fatigue, weight-gain - and we believe one solution to this problem would be to teach

people about what to expect, and to remind them during the initial period of side-effects that what they are experiencing is expected, and that improvements to their mental health are forthcoming.

Some side-effects can have serious and long-term effects. In this case, it is important to equip both the person with mental illness, as well as the supporters, with mechanisms for managing side effects. It is also the case that people who take medications for mental illness can tend to over-imagine side effects. A technological solution to keep people grounded, with and calibrated on, what's going on would be welcome.

Maintaining a medication regime: There are a number of medication tracking devices available on the market, from reminders and dispensers, to "smart" pill boxes.⁴³ These innovations are useful, but they don't solve the problem for many who suffer from mental illness. One major population we are trying to help is not those who declare, "I refuse to take my medication", but those who would say, "I'm not sure if I should take my medication." The risk/reward ratio of a medication loses its balance, and maintaining a

medication regime can feel less worthwhile than it really is.

These three barriers to adherence are not exhaustive. Other barriers exist. We suggest them here because we believe that they are ripe for near-term technological innovation. And we also believe that, if we can solve them, we are well on our way to disrupting mental illness.

Unmet Need: Preventing Relapse Through Early Detection

Mental illnesses can be episodic. A person can feel like everything is going well, and then – seemingly out of nowhere – the illness comes roaring back. All the progress that has been made feels lost. Weeks, months, or even years of improvement can seem for naught.⁴⁴

This is untrue on two levels. First, relapse has triggers, and symptoms will manifest even if they are undetected by the person with the disease, the family, and the supporters.⁴⁵ Second, progress is not lost. A relapse is a setback, but it doesn't erase the work that has been done.⁴⁶

Nevertheless, the medical perspective of relapse can be of little comfort to the person or people managing a relapse. What a relapse is can be less important than how it feels.

We strongly encourage the development of technologies that can help those with mental illness, as well as their families and supporters, to identify early signs and symptoms to prevent relapse. It can help us break out of the habit of treating "good enough" as "good enough."

One potential avenue for a solution would be to look at changes in the speed and rhythm of language. Semantic analysis – which concerns speech patterns, terminological usage, tone, and speed of utterances – can be used as an active monitoring tool, because language can be a proxy for overall function.⁴⁷ We believe that a

tool that analyzes language to identify a relapse would be useful for many stakeholders. Another solution could be a "treatment success tracker," so that the treatment goal of maintaining a healthy and improved quality of life is sought in place of just "getting better."

Unmet Need: Promoting Wellness

As we learn more about the brain and the central nervous system, we are coming to realize the deep interconnectivity between brain health and overall health. It has become something of a truism in the medical field that what is good for the heart is good for the brain. This holds for mental health. Habits antithetical to wellness – smoking, poor diet, lack of exercise, co-morbid substance abuse – prevail, and they hold back success.⁴⁸

We, as a field, are also beginning to understand the importance of resilience – a person's ability to adapt against adversity, trauma, tragedy, threats, or significant sources of stress, such as mental illness.⁴⁹ In building resilience, individuals are better able to react to traumatic and stressful life events in a way that maintains their overall wellness. What we know is that there is a combination of factors that contribute to building resilience, including having a strong support system, the capacity to make realistic goals, and being able to manage strong emotions.⁵⁰ What is still needed is a systematic way of measuring and assessing low, medium, and high levels of resilience – and resistance to resilience.⁵¹ New technologies could be developed to evaluate, facilitate, and even improve resilience.

We propose that technologies can help people get beyond "living ill." We believe technology can lead to recovery that is beyond managing symptoms and to a level of overall wellness. Particularly, we feel that advice and guidance on wellness from psychiatrists can

fail to guide behavioral change because of – as previously discussed – the episodic nature of communications between psychiatrist and the person with a mental illness. Psychiatrists have no option but to deliver messages in a “lump sum.” A useful tool would deliver wellness advice and guide users to make good decisions with their health.

There is a growing body of research that suggests that technology can intervene successfully. A white paper on technology and healthcare solutions identified an app providing patients with on-demand decision support and a home telehealth service as examples of promising developments.⁵²

There is an extraordinary saturation of technological wellness tools on market today.⁵³ Many have aspects that would transfer to mental health, but none have yet been designed sufficiently for mental health needs. This is a missed opportunity for technologists – and a frustrating failure for those of us in the mental health community.

Unmet Need: Education and Self-Advocacy

Deborah Kolb, a best-selling author and authority on leadership and organizational negotiation, offers a useful phrase: “Be your own

best advocate.”⁵⁴ While we do not disagree, we believe that a slight tweak is in order to pluralize the predicate: “Be your own best advocates.” For it is not only the person with a mental illness who must advocate, but also his or her family and supporters. Each party must be the best advocates they can.

As previously suggested, the field of psychiatry is lucky to have a rich, comprehensive body of literature, guidelines, algorithms, and other tools to help people be their own best advocates. Yet these tools go underutilized. Tools that can teach, inform, or act as reference can empower; and empowerment is the lifeblood of advocacy. Technology has incredible potential to intervene.

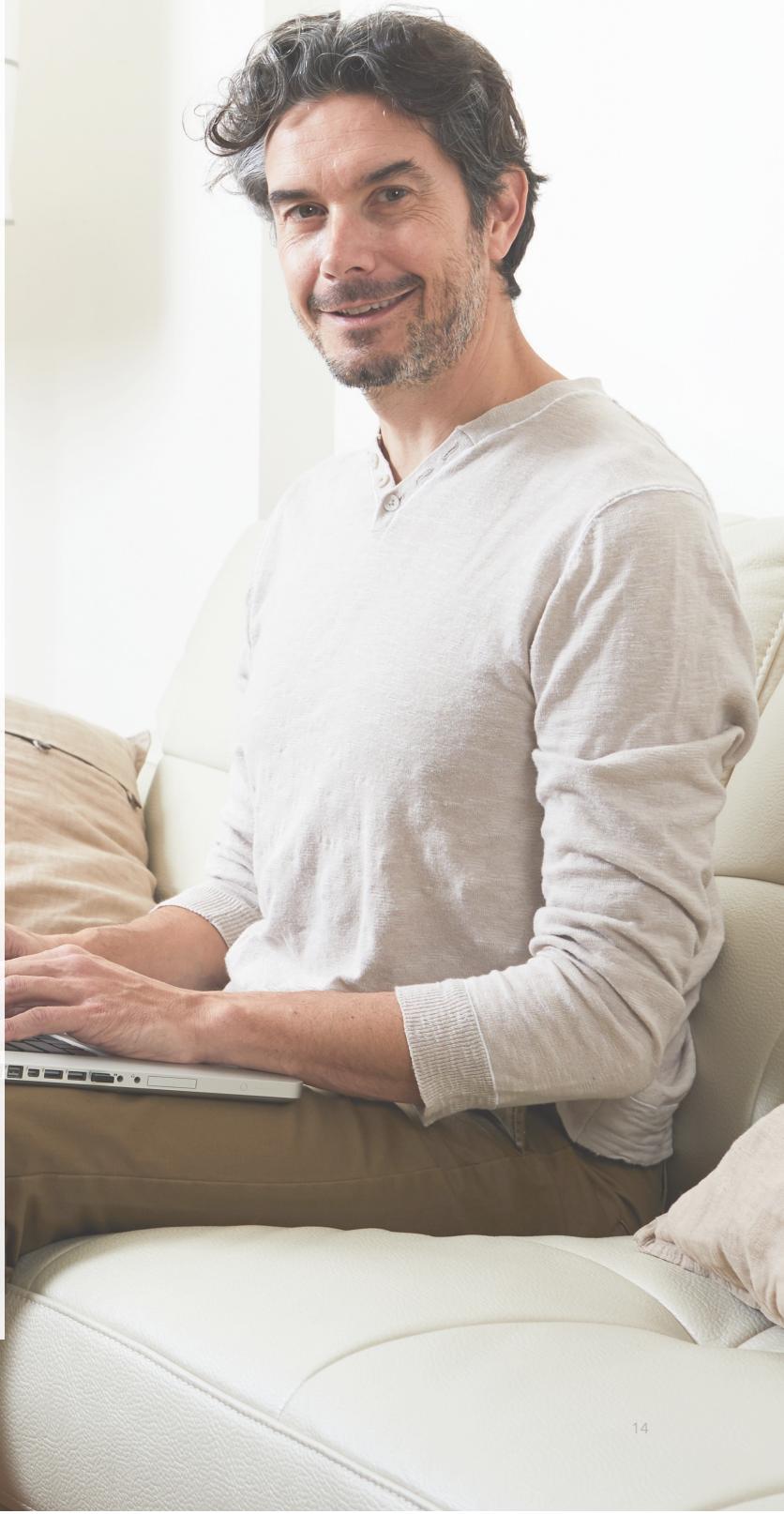
One common solution to this well-known problem is the online forum. Examples include the forums at PsychCentral and Reddit’s “depression forum.”^{55,56} We believe the online forum can be a useful tool for sharing experiences and “crowd sourcing” answers, but we also caution about the limitations. Bad advice can be given in online forums; personal experience can be presented as truth instead of anecdote; misinformation has no checks or balances. As we think about online forums, we see them as a low-ceiling solution. The better opportunity is to teach and therefore empower people to be their own best advocates.



Conclusion

The current state of technology solutions in mental health leads to two potential and antithetical interpretations. The pessimists among us could lament the lack of solutions. If mental health enjoyed a fraction of the success that we've seen in retail, transportation, or photo sharing, there'd be no need for us to write this paper. The optimist, however, could see a veritable revolution occurring, and mental health is poised for seismic disruption. To instigate this change, we need only spur and direct technological development.

For our part, we'll go with the latter interpretation. We hope you will, too.



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