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GET THE WORD OUT

Engaging and informing everyone about treatment development is a critical step in transforming the system.



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THE PROBLEM

In order for our country to transition to high-quality evidence-based care, health research must effectively engage the public to reimagine their role in the treatment development system.

Indeed, there is already a significant movement afoot to diversify and systematically involve people in treatment development, including patients (persons with personal experience of living with a condition or illness), caregivers, and patient advocates. More and more sponsors and government agencies are meaningfully engaging the public when setting research priorities, designing clinical trial protocols, and creating more robust measures of patient experiences

While these are critical first steps, true transformation of the treatment development system, and therefore healthcare itself, will require non-conventional forms of ‘people engagement’. How can we move beyond “awareness” days, weeks, and months; educational walks and runs; and social media activism? The answer is twofold: we must not only increase the number of people who understand how the system works and why it matters in their lives, but also improve the opportunities for them to take ownership of their health.

VISION

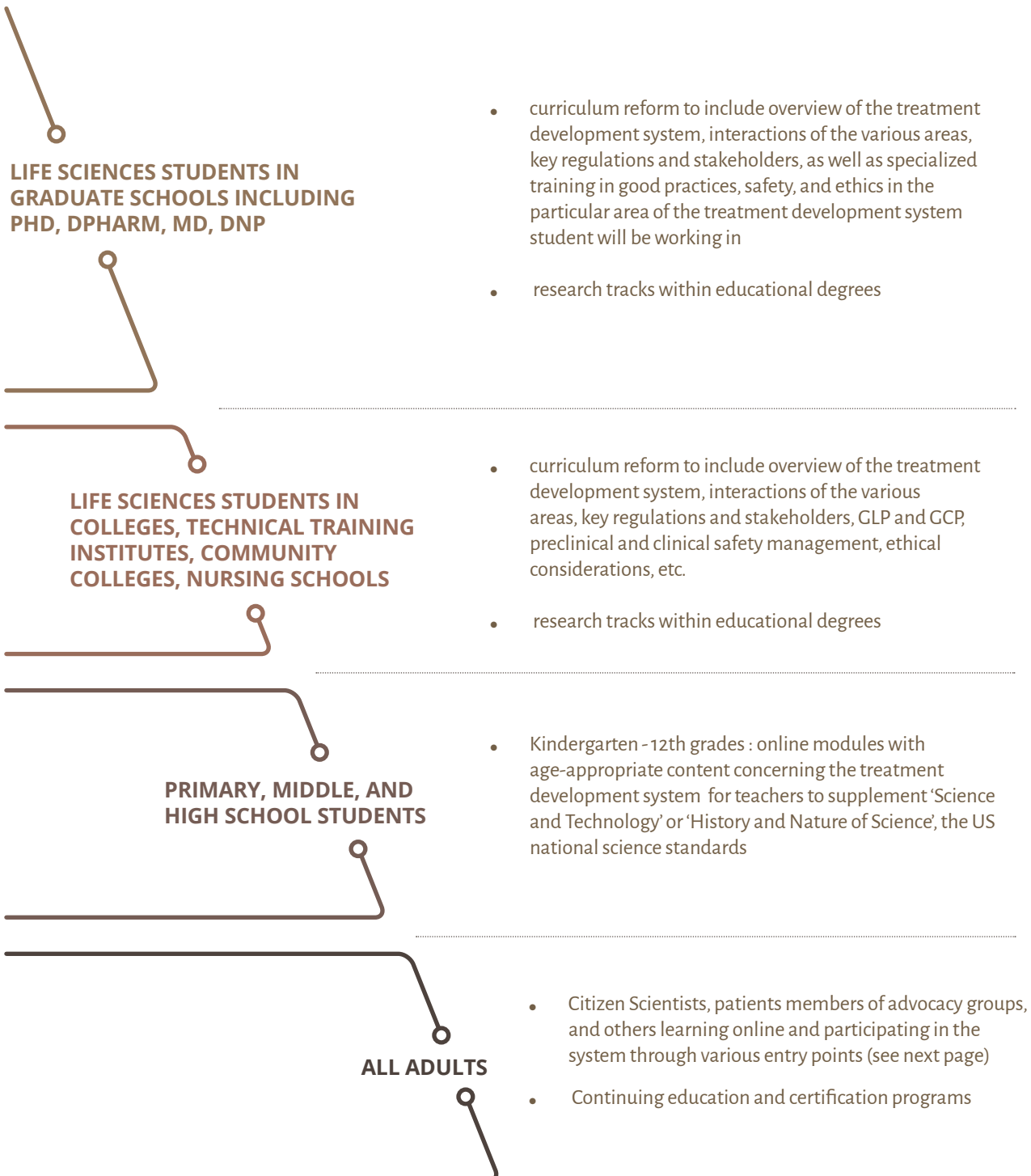
Every American should be empowered to participate in the generation, capture, and utilization of their health research data.

Everyone has a role to play in the treatment development system— whether it is by sharing health data; joining disease registries, biobanks, and clinical trials; or participating in citizen science efforts to organize and analyze biomedical papers and datasets. Yet, most of us are unaware of— or have been implicitly excluded from— the ways in which we can contribute to treatment development.

In order to be truly transformative, we must improve health research literacy. Such an intervention will require formal education for those who are still in schools, informal education for those already in the workforce, and increased opportunities for each level of the population to meaningfully participate and take ownership of their health.

NEXT STEPS

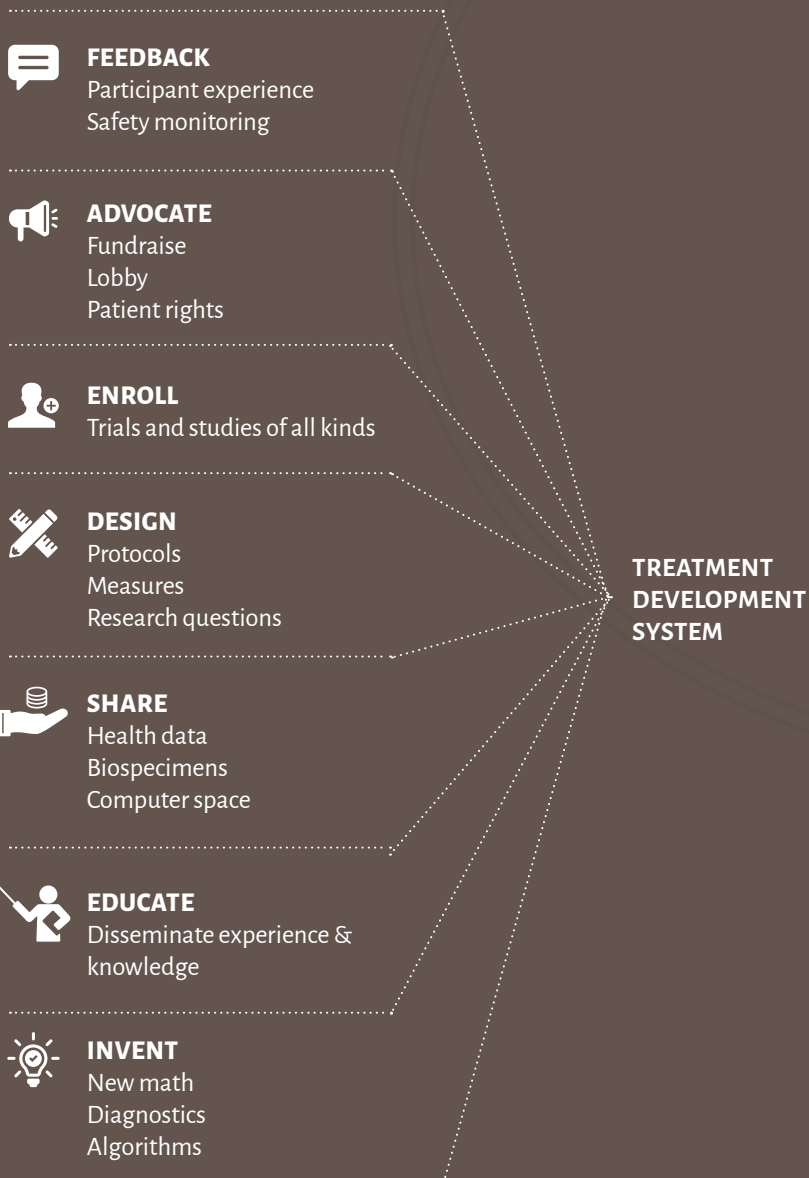
A tiered educational approach will introduce each level of the population—from school children and their families, to college and graduate students, and even future healthcare providers (diagram below)—to the current shortfalls and future promises of the treatment development system.



CONCLUSION

It is no secret that participants are the most important stakeholder in the treatment development system; without them there is no way to learn about diseases or to find treatments. And yet, for decades, the general public has simply been a passive participant, lacking a sense of inclusion or ownership in the process. People who understand the basic structure of the treatment development system are more likely to be agents of change: at worst, this increases the pool of research participants for improved treatment development, at best, this offers an opportunity to discover truly revolutionary ideas that will transform the future of healthcare.

OPPORTUNITIES TO GET INVOLVED IN THE SYSTEM




REFERENCES


- 1 NASEM. (2012). Envisioning a Transformed Clinical Trials Enterprise in the United States: Establishing an Agenda for 2020: Workshop Summary. Retrieved from <https://www.nap.edu/catalog/13345/envisioning-a-transformed-clinical-trials-enterprise-in-the-united-states>
- 2 Anderson, M. & McCleary, K. On the path to the science of patient input. *Sci Trans Med*, 8(336), 1-5.

KNOW MORE:

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