Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"The Future of Biomedicine: Translating Biomedical Research into Personalized Health Care"
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The Honorable Frank Pallone, Jr. (D-NJ)

1. We know that robust data plays a critical role in advancing biomedical research and translating into new diagnostics and therapeutics – for things like COVID-19, but also chronic diseases, mental health issues, maternal health outcomes, substance use, and more. You have extensive data science experience in both public and private settings. One of the biggest challenges of data sharing is risks to patient privacy and confidentiality. We have seen unprecedented hacks and cyber-attacks on health care systems.

    a. What are our biggest vulnerabilities today, and what role do researchers play in protecting health data?

At a time when digital health solutions are becoming integral to health management, the healthcare industry faced a 755% increase in ransomware attacks in 2021[1], along with a stark increase in general cybersecurity events in their critical supply chains. All stakeholders in the healthcare ecosystem hold a responsibility to help protect our health data from unauthorized parties and ensure users trust their data will be protected through its lifecycle. Manufacturers can work with FDA and other government agencies to share best practices and ensure that there is a coordinated response to any cybersecurity incidents. Health systems and researchers must take steps to secure software that contains health data, implement strong authentication methods, and ensure access to data and systems apply least privilege concepts.

I also note that we will need to prepare for evolving cybersecurity risk as newer capabilities like quantum computing test current encryption techniques. In line with Executive Order 14028, national agencies like the Department of Defense are already preparing.[2] Over the next several

[1] SonicWall *2022 Cyber Threat Report*, released February 2022, available at https://www.sonicwall.com/2022-cyber-threat-report/

[2] Memorandum on Improving the Cybersecurity of National Security, Department of Defense, and Intelligence Community Systems, January 19, 2022, available at https://www.whitehouse.gov/briefing-room/presidential-actions/2022/01/19/memorandum-on-improving-the-cybersecurity-of-national-security-department-of-defense-and-intelligence-community-systems/

years, health-related organizations, researchers and all entities that manage sensitive data like Protected Health Information will need to consider further upgrades to their systems.

b. In your testimony, you note Congress should appropriate resources to help coordinate data sources. What resources are needed and what would those resources be used for?

As with almost any modern enterprise, public-sector or private-sector, there is an important opportunity at HHS to coordinate data resources that historically have been held in many disconnected silos within components such as FDA, CMS, NIH, ASPR, and CDC. COVID-19 revealed both the importance of this work and highlighted the challenges of synthesizing data from many disparate systems. Effective coordination of data resources involves excellent engineering (e.g., through application programming interfaces (API)), data expertise (e.g., experts in data curation, cleaning, and statistical analysis) as well as effective governance systems to ensure that access to and use of data resources is managed appropriately. Assembling various data sources and making them accessible and informative for a variety of purposes would unlock tremendous value for a broad set of stakeholders both inside and outside HHS (e.g. regulators, public health decision makers, external researchers, etc.), but this is no easy task and cannot be prioritized without necessary resources for engineering, data expertise, and governance. Appropriating resources for the explicit purpose of coordinating and curating HHS data resources can start to build the critical scientific foundation needed to embrace a commitment to the "totality of the evidence".

2. During your time at the FDA, you were instrumental in the formation and work of evidence accelerators, joining with the Reagan-Udall Foundation and the Friends of Cancer Research to improve data collection during the pandemic to help facilitate studies on potential COVID-19 treatments. These types of public-private partnerships are valuable ways to increase our understanding and utilization of new technologies and methods of study.

    a. How can we encourage greater collaboration between clinicians, researchers, and industry to help advance these efforts and facilitate further development of innovative treatments and medical technologies?

Among its many achievements, the COVID-19 Evidence Accelerator has been an effective testbed for solutions to a particularly thorny issue in clinical evidence generation: in spite of steps toward greater interoperability in health data, most healthcare data exist in segregated environments and the costs and complexity of combining these data to yield informative evidence are high. To move quickly, the Evidence Accelerator adopted a distributed model that enabled data holders and research groups to perform data analyses "close to the source" of the data, and then come together to share results and develop analytical best practices around deceptively difficult issues like the classification of disease severity for COVID-19 patients in electronic health record and claims data. Because the challenges of segregated data resources are not limited to the COVID-19 context, the Evidence Accelerator model provides important lessons to

other efforts to use real-world data, at scale, to answer questions like how a therapy or other medical technology is performing (e.g., in the post-approval or post-authorization setting). The Evidence Accelerator was managed by the Reagan-Udall Foundation, a public-private partnership that provided an appropriate forum for conversations that included academia, health technology & data companies, manufacturers, healthcare organizations and government. This is an effective model to apply more broadly beyond COVID-19.

b. What are the barriers to successful collaboration today?

This is a good question to pose, because barriers to collaboration in the development of healthcare evidence is a key challenge we will need to solve before evidence can be generated at the scale needed to support personalized health. The Evidence Accelerator demonstrated that some collaboration challenges could be overcome by bringing groups together in an environment that promoted transparency, mutual learning, and rapidly executed, iterative projects. Other challenges that need to be addressed by public and private stakeholders include the technical challenges with assembling data from different sources, high transaction costs, and the robust governance and permissioning that is needed to ensure privacy and trust.

3. It is well known that communities of color were disproportionately at risk for severe COVID-19 infection as well as COVID-19 related death. For this reason, the roll out of COVID-19 vaccine trials that equitably represented communities of color was of high importance and priority. A review of the racial diversity of the COVID-19 vaccine trials by the Kaiser Family Foundation found that both the Pfizer and Moderna vaccine trials achieved greater diversity than other previous trials although Black adults were still underrepresented.

    a. You have been heavily involved in collecting and applying demographic data during the COVID-19 pandemic. What are the biggest challenges to collecting accurate demographic data from underrepresented groups and how can we improve this accuracy moving forward?

Collecting and applying demographic data from underrepresented groups is critical for advancing healthcare of the future. Real-world data is one tool that can help us better understand these populations and meet patients where they are. For example, real-world data can help to reduce the burden of participating in clinical trials, by helping to bring clinical trials to where those individuals are, or leveraging information from the electronic health record to fill in data sets when possible.

Accurate demographic information is often missing and may need to be supplemented through other sources. For example, web-based and mobile solutions can meet people where they are in order to directly interact and securely enter information. Excellent user experience research and design can support the development of data entry interfaces that prioritize comprehension (e.g., why the information is collected) and confidence (e.g., how your data will be used). There cannot

be one-size-fits-all solutions since people have different capabilities, needs and preferences. Transparency improves confidence.

The Honorable Anna G. Eshoo (D-CA)

1. Has your organization engaged with AI-related efforts of the federal government? If so, please share any of your comments or recommendations that you believe would be useful for the Subcommittee on Health with respect to enabling biomedical innovation.

Verily has not engaged in AI-related efforts of the government. However, we believe that artificial intelligence (AI) tools hold the promise to revolutionize certain aspects of healthcare because they learn and evolve continuously. One area where AI has an important role is in the context of real-world data, where tools can be used to curate unstructured documents, such as PDF protocols or medical notes from the electronic health record. In order to realize the promise of these tools and see them safely deployed, we must develop adequate means to monitor the performance of AI-based medical tools and ensure they are producing reliable, unbiased results for all patients. We believe the federal government can play an important role in AI by providing sensible regulation in this space. That will help engender trust and provide guardrails that companies can follow.

2. Please describe any legal, policy, technical, or other protections that protects the privacy of personal information used in research conducted by your institution.

Verily maintains policies, processes, and technology that reflect requirements under certain laws and regulations, such as the Federal Policy for the Protection of Human Subjects (also called the "Common Rule"), the Food and Drug Administration (FDA) human subject protection regulations (21 CFR Parts 50 and 56), and the Health Insurance Portability and Accountability Act of 1996 (HIPAA). To meet these legal standards, Verily has implemented processes to support teams in implementing products in a compliant manner, such as using privacy enhancing de-identification processes, technology and techniques, and providing security consistent with industry standards such as the National Institute of Standards and Technology (NIST) Cybersecurity Framework.

    a. Do you believe the lack of a comprehensive privacy law reduces the desire of subjects to participate in biomedical research?

We believe that a comprehensive privacy law could be useful in creating clarity and consistency with respect to privacy for personal information generally for both industry and consumers, and that this is preferable to the current trend of individual state regulation.

    b. Do you believe federal privacy protections need to improve to protect individuals while also enabling medical research?

A comprehensive federal privacy law could facilitate responsible research if it appropriately defines the guardrails for the use, disclosure, and exchange of identifiable personal information. By facilitating research, a comprehensive federal privacy law could help promote broad policy goals reflected in other legislative efforts by Congress, such as the 21st Century Cures Act, to promote the use, disclosure, and exchange of medical data for research, personalized health care, and to promote access of medical information to individuals. Alternatively, HIPAA can be modernized to provide greater privacy protections while enabling clear pathways for medical research.

3. When Verily obtains consent from individuals to collect personal information, does that consent allow for data sharing with other Alphabet-affiliated entities?

Verily obtains informed consent from individuals to collect personal information when, for example, Verily is the sponsor of a clinical study. Verily may also obtain informed consent from individuals as part of services we are providing to another entity, such as an external clinical study sponsor, with which we have a contractual relationship. Typically, the informed consent permits Verily to use, disclose, or further share the data with third parties, such as service providers that Verily contracts with to provide study support services on behalf of Verily.

Verily may share personal information with Google when Google is a service provider acting on our behalf. For example, Verily leverages certain technology and services from Google, including cloud services, security services, data storage, website hosting and other support functions. With Google as a service provider, we enter into contractual terms with Google to protect the privacy and security of any personal information shared with Google. Google's access to data is strictly limited to the purpose of providing such services to Verily. They are required to perform the services based on our instructions and are not permitted to use the data for any other purpose. This is also true for any other service provider acting on our behalf.

Similarly, Verily may provide services to Google and other Alphabet-affiliated companies as a service provider, in which case, we will enter into appropriate contractual terms to protect the privacy and security of data that we may collect from or on behalf of an affiliate as part of those services, and make that data available to that affiliate.

4. Does Verily share personal information with other entities affiliated with Alphabet (e.g., Google, YouTube), including in aggregated, pseudonymized, anonymized, or in other ways?

    a. If so, are the receiving entities prohibited from using the data in any way? Please describe any such use limitations.

As described in question 3 above, Verily may share data with Alphabet affiliated companies through service provider relationships, which restricts the service provider's use of the data. In

some cases, that data may be de-identified, aggregated, pseudonymized, or anonymized (which we will refer to collectively as "de-identify" or "de-identified") to provide privacy protection in accordance with applicable regulatory requirements and established industry practices.

Verily may also share de-identified data with Google through collaboration agreements, such as when parties work together to support certain product development initiatives as described below. Each party's role with respect to the data is governed by the agreements. We have these types of agreements with non-Alphabet affiliated companies, as well.

b. If so, please provide a summary of what data are transferred and for what uses.

As previously described in question 2(c), Verily leverages certain technology and services from Google that require Verily to enter into a business relationship with Google, governed by contract terms that restrict Google's use of Verily's personal information. These restrictions generally prevent Google from being able to use Verily personal information in any form, i.e. aggregated, pseudonymized, anonymized, or in other ways, because Verily may have entered into other upstream business arrangements that restrict how Verily may use or disclose personal information, and these restrictions must be placed on any downstream service providers. Accordingly, when Google acts as a service provider to Verily, Verily has in place contractual terms that limit how Google is able to further use and/or disclose Verily personal information.

There may be limited instances in which Verily is sponsoring a clinical study, or Verily is providing services to a sponsor of a clinical study, in which we may use biometric monitoring technologies, such as wearables, and we may engage with Google for the use of its Fitbit device. This is an example of when Verily may use Google's device as part of a clinical trial, and Google is not providing services as a service provider, but under a collaboration agreement. Under these types of arrangements, where Verily and Google have entered into a collaboration arrangement, Verily still places contractual restrictions on Google's use of the data that are consistent with Verily's upstream agreements related to such data, and the data is either de-identified, or the partner providing the data to Verily has obtained appropriate consent for Verily's further use and/or disclosure of the data.

An example of de-identified data that Verily shares with Google in the context of a collaboration agreement includes patient diagnostic imaging used to develop machine learning software for a product intended to support medical treatment. This information is necessary to support FDA submission for the product.

Under very limited circumstances, Verily may enter into a Material Transfer Agreement (MTA) with Google for the purposes of using and exchanging de-identified data for product or software development, validation, and testing. The MTA restricts how either party may further use,

disclose, or share this information, and puts in place safeguards to protect the privacy and security of the de-identified data, including retention and disposal of the de-identified data once the intended purpose has been accomplished and/or fulfilled.

c. If the data are transformed to protect privacy (e.g., pseudonymization, anonymization), please describe the mechanisms used to protect privacy.

Verily uses various techniques to de-identify data in accordance with applicable regulatory requirements and industry standards, such as the de-identification standards set forth in the HIPAA Privacy Rule and pursuant to guidance issued by the Office for Civil Rights within HHS, "Guidance Regarding the Methods for De-Identification of Protected Health Information in Accordance with HIPAA," and other established industry guidance, such as NIST SP 800-122, "Guide to Protecting the Confidentiality of Personally Identifiable Information." To the extent the data includes residents from other countries, we apply transformation processes that comply with the rules of those applicable countries.

The Honorable G.K. Butterfield (D-NC)

1. There are over 7,000 rare diseases and the vast majority do not have an approved treatment. As you mention in your testimony, most rare diseases affect such a small number of people that a large clinical trial is often not possible. Patients are desperate for treatments and cures and have tried to self-fund trials and work with FDA and industry members to present real-world evidence in the hopes that the research and approval process will move faster.

Another common concern from rare disease groups is the need for greater coordination within FDA and the need to ensure that rare disease drug applications are being reviewed by experts in rare diseases. My friend from Florida and fellow co-chair of the Congressional Rare Disease Caucus, Mr. Bilirakis, and I introduced H.R. 1730, the STAT Act, which seeks to improve the development and approval processes for rare disease therapeutics. It does this by creating an FDA Center of Excellence for Rare Disease and a Rare Disease and Condition Advisory Committee to bring rare and ultra-rare disease experts together to focus on the unique challenges of rare disease drug development.

a. Dr. Abernethy, do you think that the FDA would benefit from a Center of Excellence for Rare Disease and do you see a benefit to ensuring a rare disease expert is included on any rare or ultra-rare drug review?

As I discussed in my testimony, while randomized clinical trials are the most powerful tool we have to generate useful evidence, they also come with significant limitations. Ultra-rare diseases may affect such a small number of patients that a sizable clinical study is not possible. We are supportive of efforts to ensure the FDA assembles relevant rare disease stakeholders to advise on these topics and also to ensure that FDA has the review resources and expertise to advise sponsors on rigorous evidence generation approaches, including the ongoing development of

evidence in the post-market setting. While a Center of Excellence approach deserves additional discussion, we also see an important opportunity for this work to be performed by existing components of FDA that focus on rare disease to ensure that scientific expertise and best practices are shared across therapeutic areas. These components include the Office of Orphan Product Development and the relevant therapeutic-area review divisions in CDER, CDRH, and CBER.

b. How can we better incorporate real-world evidence when researching and developing new rare disease drugs?

Rare diseases represent a critical area where leveraging real-world data can help us to develop safer and more effective drugs. As rare diseases affect such a small number of patients, a sizable clinical study is often not feasible. Real-world data can help us to generate historical real-world control arms in these populations, and we have already seen regulatory approvals in the leukemia space utilizing these methods. Second, we can employ real-world data to understand safety of new interventions across time. This is particularly critical for cell and gene therapies in the rare disease space where FDA expectations are for 15 years of post-approval follow up data for many of these interventions.

2. One of the major challenges the biomedical field faces is a lack of racial and ethnic diversity. This problem permeates through every part of the biomedical research industry—from the workforce to what data is collected to clinical trial design and participation.

    a. Dr. Abernethy, can you please comment on the importance of ensuring individuals from diverse racial and ethnic backgrounds are included in clinical trials to improve personalized health care?

If we are to achieve personalized healthcare of the future, it is imperative that clinical research and data gathering is fully inclusive and equitable. Information generated and used in clinical trials must represent the needs of all citizens, particularly those from racial and ethnic backgrounds that have historically been underrepresented in clinical trials.

b. An analysis of clinical trials found that just 3.8 percent were funded by the NIH or other government agencies and the rest were funded by industry or other private sources. Beyond guidelines and recommendations, is there an enforcement mechanism by which NIH and FDA can ensure that all clinical trials meet clinically appropriate diversity standards? If not, should there be?

We are supportive of policies that aim to uncover barriers to and encourage study sponsors with pursuing greater diversity and inclusion in clinical trials. We have seen several examples of this with The Cures 2.0 Act which included several provisions aimed at improving representation of diverse populations in trials, and the recently introduced H.R. 6584, the DEPICT Act which aims to build on these efforts through enhanced data reporting.

3. As noted, there have been significant accomplishments in biomedical research, precision medicine, accelerated discoveries in cancer immunotherapy and other chronic diseases coupled with state-of-the-art data science all with the goal of improving health. As we make these incredible inroads to advance science and improve health, the gaps in race and ethnic disparities persist, and in many cases continues to widen.

   Like in the case of COVID-19, across most diseases Black, Latinx, and other people of color carry the greatest burden of disease and yet remain grossly underrepresented in biomedical research. In fact, the data we currently have is limited based primarily on European cohorts (such as in the Human Genome), and therefore negatively impacts health outcomes in every area including drug development, and personalized and precision medicine.

   a. Given the overwhelming lack of diversity in biomedical research that significantly impacts generalizability and outcomes in drug discovery, precision, and personalized medicine, what priorities and policies should be in place to assure rigorous science that includes appropriate diverse representation?

It is incredibly important to highlight the need for biomedical research to account for diversity. In my hearing testimony, I identified diversity as a key factor that we must consider when building better tools to generate clinical evidence. These evidence generation tools should include new ways of conducting clinical trials, as well as new ways of generating and analyzing data outside of clinical trials. For example, access to clinical trials is likely to be a factor in the diversity of the patients participating in a given clinical study. We should therefore continue to advance the use of pragmatic clinical studies and decentralized or virtual clinical trial technologies, to make studies more efficient and to reach patients in a wider variety of settings. To complement the data we collect in a clinical trial, we must advance the robust use of real-world data.

   b. What does the "new frontier of biomedical research" look like in the context of equitable access and representation in biomedical research? Describe the process by which addressing the longstanding inequities of lack of diversity in biomedical research can have significant local and global outcomes. How can the government use policy to move the needle toward equity in this context?

The focus of my testimony was on the evidence generation tools that are needed to inform the development of personalized medicine that can benefit all patients. Better evidence – evidence that is relevant from the full diversity of patients in our society – is critical if we are to address healthcare gaps. We need this evidence to inform not only the development of groundbreaking therapies and diagnostics but also measure and optimize the factors that drive healthcare outcomes across different patients. As I mentioned in my testimony, when considering a new policy—whether related to regulatory requirements, research, or coverage and

payment—policymakers should consider whether the policy appropriately incorporates the novel evidence generation approaches such as the rigorous use of real-world data and investments in the underlying data resources needed to drive evidence generation. Agency decision makers should have the tools to apply the best available science and methodology in support of their decisions.

c. Describe biomedical research that are highlighting the differences between the use of "race" as a social construct and ancestry?

Though I can't comment on specific research, I want to underscore how critical it is for us to develop evidence generation approaches that reflect all of the relevant circumstances of a particular patient.

d. What are the implications of these distinct concepts in the new frontier" of biomedical research, and particularly in the context of the human genome, drug development, precision medicine, personalized medicine, and closing the gap in health disparities?

Personalized or precision medicine, development of new therapies and diagnostics, closing gaps in health disparities—all of these areas share a common feature, which is that they are limited by the evidence that is available to tell us whether a diagnosis or intervention actually works for, and provides value to, a given patient. In my testimony, I highlighted a number of areas where we can make progress to ensure that we have the evidence we need to provide personalized care to all patients.

e. How does data science, AI, and machine learning perpetuate racism and inequities? What will it take at the national and local level to effectively address these issues while moving this work forward to maximize the use of these tools to advance health equity?

There are legitimate concerns that the use of artificial intelligence or machine learning could cause or perpetuate biased decisionmaking. As I noted in my testimony, we must have the capability to monitor the performance of AI tools continuously to ensure they are producing reliable, unbiased results for all patients. This will require new ways of generating and analyzing data about the performance of these AI tools continuously, over time, including through the analysis of longitudinal, continuously updated datasets that incorporate data from a variety of sources, such as electronic health records.

The Honorable Michael C. Burgess, M.D. (R-TX)

1. In your testimony under the recommendations section, you mention post market monitoring of medical products. As we move towards a world that continues to utilize technology in healthcare, I believe it is important to adjust our policies to align with technological advances. What specific policies can we put into place to ensure that medical products are being evaluated properly post market?

As I noted in my testimony, policies should look for ways to incentivize - and, where appropriate, require - the development of post-market evidence generation. To do this well, policies should take into consideration the totality of the evidence and the use of more pragmatic longitudinal study designs. For example, we know that leveraging real-world evidence will be critical in the shift towards more post-approval evaluation. Policies should work to develop solutions and frameworks for synthesizing the totality of the evidence and should be clear about what must be demonstrated to satisfy requirements. Additionally, policies should work to provide guidance on how sponsors can fulfill post-market requirements using novel and light-weight study designs, while reinforcing a focus on data integrity and quality. In any policy implemented for post-market evidence, there must be a balance between enabling pragmatic and efficient study designs and upholding expectations for data quality.

2. The past two years of responding to the COVID-19 pandemic have provided much needed insight into the structure of how many of our Federal agencies operate. There have unfortunately been many things we have gotten wrong, however there have also been great successes, such as with Operation Warp Speed. With the FDA User Fee Reauthorizations quickly approaching, are there any lessons we have learned with the successes of Operation Warp Speed that could be applied to the FDA outside of a public health emergency?

There are many valuable lessons that we can and should draw from the COVID-19 pandemic experience and apply them to our continued biomedical research efforts. One theme that I highlighted in my testimony was the value derived from government agencies working together in trans-government and community coalitions to advance the science and build capabilities needed to succeed. It would benefit the biomedical community immensely if agencies continue to work together in these ways to accelerate progress and alleviate bottlenecks that impact a variety of stakeholders. Data-related issues are a key example of where we would see tremendous value in such collaboration. Agencies can begin to facilitate conversations around documentation of data quality standards so that these needs can be consistently characterized. Where appropriate, agencies can also work to coordinate access to their own data resources in order to provide better information to public health decision makers and external researchers.

The Honorable Richard Hudson (R-NC)

1. Public engagement, understanding, and meeting the public's needs is key to optimizing the impact of biomedical research in our communities. How can we best communicate

and engage with the public as to the outcomes and impact of biomedical research on their day-to-day lives? In this communication and engagement, how do we best minimize misinformation and maximize public trust? If applicable, please explain the strategies and tactics your organization or entity are utilizing to best communicate and engage with the public with regards to your biomedical research work.

Gaining and reinforcing participant trust is instrumental to achieving our novel evidence generation goals. One way we can work to do this is by collaborating with organizations that are already deeply entrenched in and trusted by communities. For example, our work with the American Heart Association on the Research Goes Red initiative is funding a study to understand how we can best educate and engage populations previously underrepresented in cardiovascular research[3]. Our efforts here will also focus on meeting the patient where they are. In the Research Goes Red study, the research will specifically address how to engage millennial women of color in heart research through online communities and social networks. The more that we can understand about participant trust and user experience, the better we can be at engaging in patient-centric evidence generation.

2. Public-private partnerships are a critical part of ensuring translational biomedical research continues to progress and achieve success. How can we better foster innovative public-private partnerships to maximize such progress and success? If applicable, please explain how your organization or entity is approaching the development and furthering of public-private partnerships.

Public-private partnerships are necessary to maximize our collective capabilities and insights and push forward the thinking in areas of greatest need. The COVID-19 Evidence Accelerator is a foundational example of how coalitions can work together to quickly advance the science and build capabilities. As mentioned above, the Evidence Accelerator demonstrated how collaboration could be encouraged by bringing groups together in an environment that promoted transparency, mutual learning, and rapidly executed, iterative projects.

3. How can stakeholders – participants, patients, researchers, and providers – best work with state and local public health departments, as well as our communities, to maximize the public health impact and outcomes of biomedical research?

As discussed above, stakeholders can work together to accelerate progress in areas where groups bring together a complementary set of capabilities, resulting in solutions where the output is greater than the sum of its parts. Organizations like the Reagan-Udall Foundation and Friends of Cancer Research can help to facilitate this work, with the COVID-19 Evidence Accelerator as an effective example of the benefit that can be derived by working together in these forums.

[3] See American Heart Association and Verily's initiative, Research Goes Red, https://www.goredforwomen.org/en/get-involved/research-goes-red