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Progress, challenges, and the role of public engagement to improve tick-borne disease literacy

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Vector-borne diseases have increased worldwide, facilitated by globalization and variations in climate. Tick and tick-borne disease researchers, veterinarians, medical practitioners, and public health specialists are working to share their expertise on tick ecology, disease transmission, diagnostics, and treatment in order to control tick-borne epidemics and potential pandemics. This review will be a brief overview of the current status of tick-borne diseases, challenges on the scientific and public fronts, and the role of public engagement in improving citizen education within the context of ticks and tick-borne disease research.

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Introduction

Humans live in a globally connected world, where activities in one part of the world may have impacts on other distantly connected part. Fluctuations in climate have been correlated with changes in vector biology and increased vector-borne diseases at local and global scales [1–3,4••]. Although tick-borne diseases (TBD) may not be as dramatically impacted by sudden short-term changes in temperature as mosquito-borne diseases, warmer winters have been correlated with invasion and establishment of certain tick vector species into northern latitudes [3,4••,5].

Scientists, medical and veterinary practitioners, and public health specialists strive to understand vector biology and disease dynamics, design better diagnostic tools, and develop better treatments for vector-borne diseases on behalf of the public. TBD experts therefore have a responsibility to disseminate their findings and recommendations to the public in a clear, concise manner that can be readily understood. This review provides an overview of the current status of research on ticks and TBD, challenges facing TBD experts, and the importance of active, bidirectional engagement with the public.

Ticks

Ticks are obligate bloodfeeding arachnids in the order Acari [6]. Fossil evidence from Baltic amber suggest ticks have been parasitizing vertebrates since the Cretaceous (ca 99 MYA) [7,8]. Although known for their role as vectors of pathogens, ticks themselves are considered noxious pests whose bites can be cause irritations, anemia, localized or systemic allergic reactions (including meat allergies), as well as more serious issues such as tick paralysis [9–11].

At the time of this writing, there are 722 described species of hard ticks (Ixodidae) and 208 species of soft ticks (Argasidae) [6]. Approximately 5% of known Ixodidae and 2% of Argasidae are known vectors of zoonotic diseases [12]. Since at least 38% of all tick species are known to bite humans (though not necessarily the intended hosts), it is likely that new TBD will continue to be identified [12,13••]. As human populations grow, broader encroachment and fragmentation of wild habitats may increase contact with pathogen-laden ticks [14].

Global tick-borne diseases

TBD incidence is increasing at an alarming rate, signaling the need for a more proactive stance to prevent outbreaks of pandemic proportions [15]. While *Borrelia burgdorferi* (the causal agent of Lyme borreliosis) is by far the most prevalent tick-borne pathogen in the temperate countries of the world, other emerging or newly discovered tick-borne pathogens (many of which are potentially fatal) are also being described annually [4••,16–18]. Worldwide there are two TBD of pandemic or epidemic scale recognized by the World Health Organization (Crimean-Congo Hemorrhagic Fever and Tularemia [http://www.who.int/emergencies/diseases/en/]). Rocky Mountain Spotted Fever, an emergent TBD that is spreading throughout the Americas, can be transmitted by multiple tick species [19•]. Factors contributing to increased TBD incidence include habitat fragmentation, global travel, importation of animals, changing environmental conditions, and shifts in host populations in response to light pollution, habitat removal or encroachment, or altered migration behaviors of reservoir hosts) [4••,14,20–24].

While some countries have dedicated significant scientific, political, and/or monetary resources toward TBD research, other countries lack the facilities or funds for monitoring and combatting TBD, or do not consider TBD as top priorities for public health, particularly when they are being impacted by other vector-borne diseases [25]. Nevertheless, the impacts of TBD in poorer countries can exacerbate already-existing socioeconomic inequalities [25,26]. In a globally connected world, public health concerns in one country are no longer isolated and the 'every country for itself' attitude of the past no longer holds true. Global exports, exotic pet trade, and human travel have all contributed to introduction of novel vector species and their pathogens into nonnative areas [23,24,27]. Excluding global human traffic and trade, many migrating wild species (such as birds) travel between tropical and arctic biorealms and have been implicated as vehicles for invading tick species as far north as the arctic circle [28•,29–31].

Ticks and tick-borne disease in USA

Although 40 of 84 described species of ticks in the contiguous United States are known to bite humans, eight species are responsible for the majority of TBD [13••,32,33]. These few species represent multiple taxa, yet the common characteristics that make them such effective vectors is the generality of host preference and the behavior of actively seeking out hosts. In contrast, many species of ticks are nidicolous, preferring to remain within the nest or burrows of their hosts for the entirety of their lifecycles [34]. However, if their preferred host is no longer available, some nidicolous species will readily seek non-typical hosts [35,36]. This can result in sudden outbreaks of diseases when an unsuspecting human comes in contact with a hungry tick (e.g. tickborne relapsing fever transmitted by the soft tick *Ornithodoros hermsii* feeding on rodents and humans co-inhabiting cabins) [35].

Between 2004 and 2016, reported cases of TBD have more than doubled [37]. Lyme disease (LD) (principally caused by *Borrelia burgdorferi sensu stricto* in the United States) accounted for 402,502 of the 642,602 total reported vector-borne (62.6%), and 82% of all reported TBD cases [18]. It is estimated that 300,000 cases of LD are diagnosed each year, although only 10% of these cases are actually reported to the Centers for Disease Control (CDC) [18]. LD was first described in the early 1970s, manifesting first as a juvenile form of arthritis in Lyme Connecticut, but until the incidence rates rose significantly, it was not a priority for public health [38,39]. Eventually, LD did garner enough national attention to inspire a Senate bill that increased federal funds for improving tick-borne disease-related activities (research, treatment, prevention, and education). In December of 2016, President Obama signed the *21st Century Cures Act*, which included authorization of the Department of Health and Human Services to support TBD research and create a multidisciplinary 'Tick-borne Disease Working Group'. Although national effort toward TBD control can be slow, there is at least hope that support is now available for research.

Challenges on the scientific front

Vector biologists can play a key role in providing insight into environmental management to prevent tick infestation or disease transmission. Improving communication between vector researchers and other TBD-related fields would greatly improve disease surveillance. Some diagnostic facilities have an expert who can identify vector species using morphological and/or molecular characteristics (e.g. New York State Veterinary Diagnostic Laboratory).

There is a need for fast, affordable, and reliable multiplex diagnostic tools, and many new options are on the horizon. Whole genome sequencing technology has made it possible to identify novel tick-borne pathogens as they are encountered (such as *Borrelia mayonii*, Heartland and Bourbon viruses) [37]. While these diagnostic tools are promising, many are proprietary, making it difficult for those doing field vector surveillance to find a standardized diagnostic approach without sending off materials to a commercial laboratory.

Challenges on the public front

When TBD specialists do not effectively communicate with the public, the public may not be aware of the research progress being made. As medical, veterinary, and scientific professions develop and test methods for combatting new or emerging tick-borne pathogens, the public is ultimately the intended beneficiary. Yet many TBD experts will refrain from public engagement, particularly when they feel an issue is politicized and that the intended audience does not want to listen.

Tick bite prevention education is not easy and may require repetition, persistence, and patience. In response to changes in climate and the eventual spread of LD, the Canadian government launched an aggressive campaign of tick and reservoir host surveillance, assessment of public TBD literacy, and public education in 2014 [3,40–42,43•]. Over time they have observed that, despite overall increase in general awareness of LD, less than half the population was utilizing tick prevention strategies [44]. Humans can be slow to change health behavior, but communications on TBD risk need to be persistent about the importance of preventative measures for eventual change [44].

TBD-literacy

The most effective strategies for tick bite prevention (and TBD transmission) are avoidance of high-risk areas, preventative approaches such as showers and tick checks, and proper application or usage of acaricides and/or

repellents. It is important to ensure that these strategies are clear to maximize the likelihood that the public will follow these strategies correctly and consistently.

One hurdle that a successful TBD prevention and management program needs to overcome is the level of TBD awareness of the average patient. Patients may not know how to prevent tick bites or identify symptoms beyond the not-always-present erythema migrans, the classic LD expanding annular rash (bullseye) [38]. Patients may hold misconceptions about TBD, often acquired through online browsing, social media, or television sources. Local or regional efforts to improve public education on tick bite prevention are sometimes available in more populated or well-funded areas, but these approaches often fail to effectively reach disadvantaged people, areas in which technology-based dissemination is not an option, or very rural or wilderness areas.

Publicly available sources of TBD information

Passive dissemination of TBD knowledge has its role in providing information regarding the outcomes of data analysis and recommendations for high-risk areas. The Centers for Disease Control maintains several informative pages on their website ranging from recommendations on communicating risk, reporting recent TBD-related findings, as well as suggested approaches to communicating TBD risk for medical professionals [10] (https://www.cdc.gov/ticks/; https://www.cdc.gov/ncezid/; https://www.cdc.gov/niosh/topics/tick-borne/resources.html). The CDC site represents a wealth of information, but much of it is geared toward disseminating information to scientists, practitioners, or public health experts, or on best practices when communicating to the public. Although some pages are intended for the public, they can sometimes be difficult to navigate. Nevertheless, the information presented is usually up-to-date and cites information based on current or recently completed studies published in peer-reviewed journals.

Another publicly available, but not readily discoverable resource is available from the US Army. The Disease Epidemiology Division US Army Zoonotic Disease Report for 2015 was released by the Army Public Health Center in 2017 (http://phc.amedd.army.mil/Periodical%20Library/ZDR_CY2015_v2.pdf). These data reflect the One Health approach in that the data collected here include all zoonotic incidents from active-duty military personnel, incidents from non-active duty beneficiaries, the location of acquisition of zoonotic diseases, veterinary disease summaries on DoD-associated animals, and wildlife and vector surveillance results.

Several universities maintain TBD educational resource (e.g. University of Rhode Island's http://www.tickencounter.org). These sites balance information, levity, and effective visual aids to engage the nonscientist. Some universities have developed apps, collect citizen-based data state- or nationwide (including photos of ticks), and present tick risk predictions relevant to season, tick species, and present regional TBD diseases. Tick-encounters.org uses compelling (and sometimes entertaining) multimedia presentations that appeal to the public sector ranging from computer graphics, mobile applications, resources on tick pathogen testing, and several educational how-to videos on pesticide application, tick checks, and tick removal.

Dispelling misconceptions through engagement

Community engagement has been shown to be highly effective in providing citizens the opportunity to ask questions, voice concerns, and dispel fears about mosquito control strategies implemented by the World Mosquito Program (formerly Eliminate Dengue [45•]). Similarly, TBD active engagement at the local or regional scales may encourage citizens to learn how to protect themselves, but also to dispel certain misconceptions about risk, symptom recognition, and prevention. For instance, TBD may be perceived as a disease of more rural environments, but in fact, people in urban areas may also be at risk if at least one vector and one zoonotic reservoir host are present [11,46]. Even though urban areas are mostly managed, many species of wildlife can adjust to and thrive in manmade habitats (parks, trails, gardens, attics, backyards, etc.) [11].

While it is assumed that people who engage in 'outdoor activities' are at risk, what constitutes 'outdoor activity' may not necessarily be as obvious as hunting, biking, or camping. Gardeners, pet owners, farmers, scouts, hunters, foresters, as well as citizens utilizing common greenspaces (e.g. parks) may be potentially exposed to tick habitats [44,47••,48–50]. Those who provide support such as environmental health specialists or wilderness providers also need to be trained in being tick-vigilant [48,51].

"One Health Initiative"

Globalization has connected the world in remarkable ways, but has also accelerated the spread of vector-borne diseases [37]. Each new or re-emerging infectious disease highlights the need for rapid disease prevention and control. This requires multidisciplinary communication between veterinary and medical health care workers, wildlife biologists, ecologists, anthropologists, and others. 'One Health' reflects the realization that emerging zoonotic diseases occur at the interfaces of animal–human–ecosystem [13••].

Although veterinary and medical professionals have largely pioneered much of the effort, 'One Health Initiative' was intended to foster communication across multiple disciplines [52]. The value of One Health-based multidisciplinary communication between physicians and

veterinarians is evident in the example of a fatal disease outbreak is the Rocky Mountain Spotted Fever (RMSF) case in Mississippi [13••,53]. Two dogs misdiagnosed with ehrlichiosis died of RMSF, followed thereafter by their owner. Subsequently, there was an investigation and successful treatment of the remaining two dogs for RMSF. The surviving dogs had been infested with *Rhipicephalus sanguineus* (the brown dog tick), previously not considered a vector of RMSF [53]. This case identified *R. sanguineus* as a competent vector of RMSF and indicated that dogs can serve as sentinels for RMSF. Furthermore, if a dog is suspected of being infected with RMSF, both veterinary and medical professionals should report this to the appropriate medical authority (e.g. state public health agencies or the CDC) [53].

Human health is integrally tied to the health of domestic and wild animals. The importance of cross-communication between veterinary and medical professionals is evident, particularly in respect to zoonoses[13••,52,54]. Pet owners may have an increased risk of tick bites [47••]. Dogs can acquire ectoparasites when multiple dogs are in contact, or if the dogs are boarded in a kennel, and then bring the ticks home with them [55]. Similarly, cats that hunt outdoors may encounter wildlife (e.g. groundhogs, squirrels, chipmunks) and become exposed to zoonotic diseases [56–59]. More generally, humans and domesticated animals are at higher risk of acquiring tick-borne pathogens from reservoir hosts when living in close proximity to or in contact with wildlife [47••,57,60,61].

Passive tick surveillance

Passive tick surveillance usually involves submissions by non-acarologists to experts at regional, state, or national level institutions. This requires doctors, veterinarians, or other citizens to submit tick samples for identification and/or testing for pathogens. The advantage to this approach is that it can cover a wide geographic range, providing a finer-scale resolution of the tick/TBD load [41,43•,62,63]. The main caveat is that associated data may be incomplete, the samples can be damaged during removal (losing important morphological characteristics), and there is an intrinsic host-association bias for ticks found on humans or domestic animals [64]. It is also time-consuming and effort-intensive to catalog and curate the database generated from the samples and the metadata [65,66]. Nevertheless, these data represent a measure of the risk of bites because the ticks are usually extracted from or associated with host tissue. Passive surveillance data can be complementary to active surveillance data, and can also be used to tailor experimental designs for downstream host-association studies using trapped, hunted, or road-killed animals, or combined with CO_2 or host volatile-modified trapping from nests or burrows [40,67–69].

Because animals may represent sentinels for zoonotic diseases, indirect mining of electronic pet health records can be useful alternative for identifying increased risk of TBD through records of tick infestations [70]. This approach did not require intensive surveillance or molecular diagnostics and could serve as a cost-effective complement to an already existing tick surveillance program to identify pockets of tick activity that might be missed by passive surveillance alone. Collectively, tick from companion animals could be used to create a real-time map of TBD risk (e.g. http://www.capcvet.org).

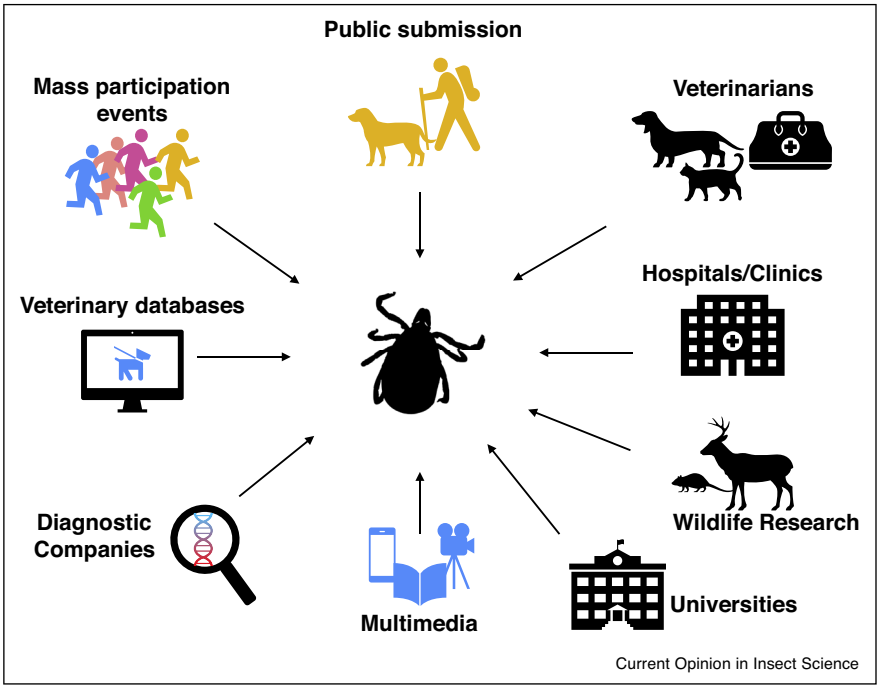
Novel public engagement approaches

Multi-disciplinary approaches to TBD education through citizen engagement can cultivate exciting, creative, and sometimes unusual methods (Figure 1). The Dutch National Institute for Public Health and the Environment (RIVM) has used a multimedia strategy (website, media, video game, leaflets) to target adults and children for TBD education [71,72]. Alone, these approaches have not been shown to significantly improve tick bite prevention, but together they work as complementary strategies to reinforce good preventative practices. Additionally, RIVM launched a website and an affiliated app (https://www.tekenradar.nl/) that allows citizens to record data associated with when they were bitten (age, photo of the tick, the bite, whether they have had Lyme disease before, whether or not they develop a bulls-eye rash) [73]. While citizens are responsible for initial symptom diagnosis and reporting, ticks can also be submitted for identification and testing by trained professionals [73]. Public submissions of tick photos for identification have also been used in Canada and in the USA [74].

Another nontraditional public engagement approach is the use of mass participation events (e.g. marathons) to engage a large group of people converging at a single location in contributing to a tick risk study [75••]. Mass participation events are great opportunities for large-scale citizen contributions in a localized area [75••]. In many ways, it has the advantages of a 'bioblitz', a group event in which scientists and citizens meet at a particular location for a brief period of time to capture and identify as many species in an area to estimate local biodiversity (https://www.inaturalist.org/pages/bioblitz+guide). However, the mass participation tick collection takes advantage of an already existing event to collect data and to educate the participants about tick checks and TBD.

Citizen science approach can be useful for fine-scale active tick surveillance [76]. Each citizen enrolled in the study monitored a small plot (e.g. their backyard) and provided repeated measures of tick load from multiple sources such as pets, gardens, or flags (using a white towel or cloth on vegetation) [76]. This fine-scale approach concurs with the finding by the CDC, which found that for residential properties, determining absolute numbers of infected ticks would provide a better estimate of risk, particularly if the degree of human use of

Figure 1



Sources of ticks from surveillance. Tick surveillance provides useful information that can be used to identify risk of tick bites and TBD traditional sources. Information can be from more traditional sources such as veterinary or medical hospitals or clinics, universities, or wildlife biologists. Other sources of ticks, host-association, or pathogen data may include tick testing companies, electronic veterinary record databases, mass participation events, or various public-based contributions (physical or photographic submissions, citizen scientists, etc).

the property is also taken into account [77]. This becomes a much more tenable undertaking once citizens are involved in the data collection process. In another study, Seifert *et al.* (2016) partnered with rural high school teachers to teach high school students about science, TBD, and tick surveillance [78•]. This model could be extended toward other community-based groups such as elementary schools, school nurses, parent–teacher organizations, or clubs to train children and their parents about how to prevent tick bites.

Suggestions for public engagement

One of the ways we can encourage TBD literacy is to cultivate more active community involvement in tick surveillance and provide control strategies that are easy to follow. There are many potential approaches that can be explored or implemented. Multiple social medial platforms, citizen science, groups, and formal science communication (scicomm) training of TBD experts collectively may expand the reach and efficacy of outreach education.

Approaches to improve TBD literacy need to go beyond the deficit model of public engagement (i.e. unidirectional dissemination of information). It is important to assess public familiarity with tick bite prevention, resistance to pesticide use, likelihood of compliance, recognition of TBD symptoms, and necessity of consulting a physician or veterinarian. The public should also be directed to scientists who specialize in identifying ticks.

Social media can be highly effective at disseminating information rapidly, but requires careful planning and proper timing for maximum impact. The platform chosen for outreach needs to match the audience — different platforms appeal to different demographics [79,80]. Social media may also provide data on local or regional tick abundance and seasonality or report invasive tick species (https://twitter.com/Contagion_Live/status/979056024119373826). However, strategic forethought and marketing expertise is advisable to avoid potential unwanted outcomes (e.g. ticks on poppy seed muffins, https://twitter.com/CDCgov/status/993523011281145858).

Citizen science can be used to facilitate public submission of data and allow interested citizens to be more actively involved in a scientific process that may benefit them. Citizen science-based projects allow scientists to increase the amount of data collected or handled that would otherwise be difficult to achieve. It is important, however, to ensure a bidirectional conversation between the public and researchers, providing regular updates on the progress of studies in which they are participating.

Formal training of TBD specialists in science communication is not normally part of graduate or postgraduate career experience, but perhaps it should be. TBD specialists need to be able to disseminate their data beyond the academic and professional spheres to journalists, policy makers, stakeholders, industry, but without the use of jargon [81•]. Developing positive bidirectional lines of communication between TBD experts and the media provides journalists with news on scientific progress and insight into what tick species is a vector of which disease, and gives scientists the opportunity to reach a large audience. TBD experts in turn need to listen and adjust management recommendations while taking into consideration the cultural, socio-economical, and physical limitations of citizens.

Best models for engagement may be dependent on the target audience. An effective engagement approach would be to firstly keep the message simple and jargon-free, secondly have easy-to-understand protocols, and lastly use visual aids. While there is definitely an appeal to incorporate next-gen technology (e.g. augmented, virtual, or mixed reality), the emphasis should be on the message and not on the 'glitz'.

Conclusion

TBD researchers, practitioners, and experts have the advantage over many other members of the scientific community. The public loves to hate ticks and is therefore much more likely to engage in conversation about ticks, TBD, and ways to prevent tick bites. This makes public engagement that much easier, but taken a step further, public involvement can provide insight into activities and/or studies in which the average citizen can feel personally empowered as contributors to the scientific process.

Although there may be the perception amongst scientists that the public does not trust scientific research, this is a misconception and in fact the opposite is true [82]. Scientists are becoming acutely aware of the importance of effective science communication and this applies to TBD experts as well. It is the responsibility of those studying vector biology, vector-borne diseases, and public health to teach the public how to protect themselves, prevent or minimize vector-borne disease transmission, recognize symptoms that require immediate attention, and to record information that will facilitate correct diagnosis and treatment. Transitioning from simply providing information to actively engaging communities will ultimately improve our vector-borne disease education efforts.

The United States is a very large country, so while there are many great local or regional efforts, there is still a need for unifying TBD education efforts and integration of resources. Efforts at state or regional levels vary — in some states, dedicated staff members spend a great deal of effort on vector control and on public outreach, while in others, the burden falls on academic institutions or public health departments. Perhaps with the passing of the 21st Century Cures Act and the CDC report on vector-borne disease on the rise, support for improved TBD public education is just on the horizon [37,83••].

Conflict of interest statement

Nothing declared.

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