

# Canadian Tuberculosis Standards

7<sup>th</sup> Edition

## Chapter 14: Tuberculosis Prevention and Care in First Nations, Inuit and Métis Peoples



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## CHAPTER 14

# TUBERCULOSIS PREVENTION AND CARE IN FIRST NATIONS, INUIT AND MÉTIS PEOPLES

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### KEY MESSAGES/POINTS

- In Canada, the incidence rate of TB is higher among Aboriginal people than the foreign-born and Canadian-born non-Aboriginals, but the greatest burden of disease, as measured by the number of cases, occurs in the foreign-born.
- Status Indians in Manitoba and Saskatchewan and the Inuit in Nunavut have the highest incidence rates among Aboriginals in Canada.
- In the 1980s, after decades of decline, the incidence of TB among the Inuit began to level off. However, beginning in the late 1990s and continuing until 2010, rates increased, resulting in Canada's own "U-shaped curve of concern".
- Determinants of TB infection and disease in the Aboriginal people of Canada differ with respect to comorbidities, genetic factors, transmission factors and the social determinants of health when compared to the rest of Canada.
- Social determinants of health, including lack of food security, housing, health care access, education and income are seen with higher frequency in Aboriginal groups in Canada.
- Programmatic issues in TB prevention in Aboriginal groups in Canada that can be strengthened include strong TB partnerships with communities, increased community awareness, improving adherence to TB medications and underscoring the importance of effective contact investigation.
- According to the most recent statistics released in 2012, the current rate of TB among the Canadian-born Aboriginal population is 26.4 per 100,000. Across Canada rates of new active and retreatment TB cases for the Aboriginal population were as follows: North American Indian 22.2 per 100,000 (188 cases), Inuit 198.6 per 100,000 (116 cases) and Métis 7.5 per 100,000 (26 cases).
- In 2005, FNIHB set a long-term goal to reduce TB incidence to 3.6 per 100,000 among on-reserve First Nations and Inuit regions in Canada by 2015. Results to date suggest that this goal will not be met.

- To meet these goals and achieve a substantial reduction in rates of TB among Canadian-born Aboriginal peoples it seems likely that intensified and coordinated efforts using novel approaches will be necessary.

## THE ABORIGINAL POPULATION OF CANADA

The *Constitution Act* of 1982 recognizes three major groups of Aboriginal people in Canada: First Nations (North American Indian), Métis and Inuit (see Appendix A, Glossary). Estimates from the 2006 Canadian census (data from the 2011 Census were not available at the time of publication) for the Aboriginal population were as follows: 1,172,790 people identified their ethnic origin as Aboriginal, 698,025 of these as First Nations/North American Indian, 389,780 as Métis and 50,480 as Inuit.<sup>1</sup> Of the total First Nations (FN) population, 564,870 people (81%) are registered according to the terms of the *Indian Act* of 1876 as Status Indians.<sup>2</sup> As of December 2011, these individuals are associated with over 600 bands, and 53% of registered FN individuals live on one of more than 1,000 reserves. The First Nations population resides primarily in Ontario and the western provinces.<sup>3</sup> The Inuit span four regions that constitute Inuit Nunangat (Inuit Homeland): Inuvialuit (Northwest Territories), Nunavut, Nunavik (Northern Québec) and Nunatsiavut (Labrador). The Métis are distinct from First Nations, Inuit and non-Aboriginal people and are of mixed Aboriginal and European ancestry. Little is said about the Métis in this chapter because routine surveillance data on Métis status are not systematically collected, and census-based population estimates of Métis are dependent upon self-identification.

Unique challenges exist in the prevention and control of tuberculosis (TB) in First Nations and Inuit populations. These include the wide dispersal of populations over large and remote geographic areas, jurisdictional issues in health care delivery, the imperative to deliver culturally appropriate care, and the prevalence of socioeconomic and biologic risk factors for TB, including poverty, malnutrition, poor housing, diabetes and renal disease.

## HISTORICAL AND CULTURAL ASPECTS OF TB IN FIRST NATIONS AND INUIT POPULATIONS

North and South American human remains dating from the time of pre-European contact show anatomic and radiological evidence of mycobacterial disease, and *Mycobacterium tuberculosis* complex has been identified.<sup>4</sup> However, epidemic TB in Canadian FN and Inuit populations occurred after European contact in the 19th and 20th centuries. Recent work suggests that *M. tuberculosis* was dispersed across Canada by the fur trade.<sup>5</sup> This dispersal appears to have been associated with small populations of *M. tuberculosis* infected individuals existing at a relatively stable level until ecologic, political and economic factors led to expansion in the late 19th and early 20th centuries.

Social and environmental risk factors for the epidemic spread of TB in these populations included the movement of individuals to reserves, hamlets and residential schools. In addition to crowded living conditions, which favoured transmission of infection, malnutrition both on and off reserve fostered progression of infection to disease.<sup>6-10</sup> The story of the TB epidemic in FN and Inuit populations speaks of transgenerational loss and suffering.<sup>6-10</sup> Families and communities were disrupted as children, parents and grandchildren were sent to sanatoria throughout southern Canada for long periods of time, sometimes never to return. Survival was often accompanied by a legacy of emotional, psychological and physical “scars.” Those who work in prevention and care in the 21st century must be aware of the existence of a “collective memory” of the suffering associated with the TB epidemic in these populations.

## EPIDEMIOLOGY OF TB IN ABORIGINAL POPULATIONS

The epidemiology of TB in Aboriginal populations in Canada is described in Chapter 1, Epidemiology of Tuberculosis in Canada. The following points deserve emphasis:

- In Canada, the incidence rate of TB is higher among Aboriginal people than the foreign-born and Canadian-born non-Aboriginals, but the greatest burden of disease, as measured by the number of cases, occurs in the foreign-born.<sup>11</sup>
- While the incidence rate of TB in FN and Inuit populations as a whole is higher than in Canadian-born non-Aboriginal populations, there are wide variations in rates among regions and communities.<sup>11,12</sup>
- Status Indians in Manitoba and Saskatchewan and the Inuit in Nunavut have the highest incidence rates among Aboriginals in Canada.
- TB incidence rates have remained stagnant in the FN population over the past decade.
- In the 1980s, after decades of decline, the incidence of TB among the Inuit began to level off. However, beginning in the late 1990s and continuing until 2010, rates increased, resulting in Canada’s own “U-shaped curve of concern.”<sup>13</sup>
- TB is proportionately more common among the very young in Canadian-born Aboriginal populations than in Canadian-born non-Aboriginals, in whom a greater proportion of cases is seen in older age groups.<sup>11</sup>
- In western Canada, significantly greater clustering of TB cases has been noted in Canadian-born Aboriginal groups than in non-Aboriginal groups.<sup>14</sup>
- Estimates of the prevalence of latent tuberculosis infection (LTBI) in Canadian-born Aboriginal people vary widely (0% to 50%) because of the heterogeneous nature of the study groups. See Chapter 12, Contact Follow-up and Outbreak Management in Tuberculosis Control, for further details.
- In some areas of Canada, the incidence of TB among FN persons living off-reserve, either in communities adjacent to reserves or in the core area of cities (which may function as “urban reserves”), is equal to the incidence among those living on-reserve.<sup>15</sup>

## RESPONSIBILITY FOR TB PREVENTION AND CONTROL IN FIRST NATIONS AND INUIT POPULATIONS

(From Health Canada's Strategy Against Tuberculosis for First Nations On-Reserve<sup>16</sup>)

Provinces and territories have the legislated authority for TB prevention and control within their jurisdictions. In the territories, ultimate responsibility for TB prevention and care for the entire population rests solely with the territorial governments. In contrast, within the provinces, TB prevention and care for FN and Inuit is a shared responsibility that varies by region according to each region's level of collaboration with Health Canada's First Nations and Inuit Health Branch (FNIHB) regional offices, provincial governments and FN or Inuit organizations/communities. These collaborations are influenced by the respective provincial public health legislation. For the Inuit communities within the geographic boundaries of provinces, such as in Nunavik in Northern Québec and Nunatsiavut in Labrador, the provinces are responsible for TB prevention and control. In Nunavik, Québec provides all TB services. In Nunatsiavut, the provincial government of Newfoundland and Labrador offers some services, and FNIHB provides funding to the Nunatsiavut Government to complement the provincial services provided.

## DETERMINANTS OF TB INFECTION AND DISEASE IN ABORIGINAL POPULATIONS

Determinants of infection and disease are associated with the agent (*M. tuberculosis*), the host (affected person) and the environment (social, economic, cultural and political). These factors may affect the risk of infection, disease or both. Determinants may be causally linked (risk factor) with infection and/or disease, or linked through an association (risk marker) that is not necessarily causal. Behaviours such as alcohol and drug abuse may be considered host determinants, but they also relate to the environment as it applies to health.

### AGENT

In Manitoba, central nervous system TB is associated with Aboriginal ethnicity and a particular strain, identified by restriction fragment-length polymorphism, which is prevalent in Aboriginal communities in that province.<sup>17</sup> Cytokine assays and studies of *in vivo* mouse models suggest that this strain is hypervirulent compared with other clinical isolates.<sup>18,19</sup> In Alberta there is no evidence that the Beijing/W family of strains, imported from the Western Pacific, is associated with greater transmission, clustering or penetration into the Aboriginal population of the province.<sup>20</sup>

## HOST

### Comorbidities

The following are recognized risk factors for the development of active TB disease in relation to the Canadian Aboriginal population (details regarding the risk factors mentioned below, including the risk of active TB development associated with each, are described in Chapter 6, Treatment of Latent Tuberculosis Infection).

- **HIV infection** is increasing in incidence and prevalence in Aboriginal populations<sup>21</sup> and is the strongest known risk factor for the development of disease in those with remotely or recently acquired TB infection. HIV status was reported to the Public Health Agency of Canada for 17% of Aboriginal Canadian cases in 1997, rising to 68% by 2010. The proportion of TB cases that have been HIV tested and reported has been increasing almost certainly as a result of two very explicit national advisories, the introduction of highly active antiretroviral therapy and the demonstrated feasibility of using an “opt-out” approach to HIV testing in TB patients.<sup>22</sup> In Alberta, where universal HIV testing of TB patients has been in place since 2003, HIV/TB coinfection was significantly greater in middle-aged (35-64 years) than young adult (15-34 years) patients and in Aboriginal and sub-Saharan African than Canadian-born non-Aboriginal people and immigrants to Canada from other regions combined.<sup>23</sup> On the prairies, two HIV exposure categories appear to predominate among Aboriginal peoples: injection drug use and heterosexual sex.<sup>24</sup> The connection between HIV, ulcerogenic sexually transmitted infection and TB has all the features of a syndemic, the latter defined as the convergence of two or more diseases that act synergistically to magnify the burden of disease.<sup>25</sup>
- **Diabetes mellitus** – the age-adjusted prevalence of diabetes (predominantly type 2) in First Nations populations is 3.3 times higher among males and 5.3 times higher among females than in the Canadian population as a whole.<sup>26</sup> An increasing prevalence of diabetes has been noted among the Inuit.<sup>27</sup> Overall rates of diabetes were higher in the Aboriginal population in Alberta, although increases in the incidence and prevalence appear to be lower, than in the general population.<sup>28</sup>
- **End-stage renal disease** – the age-standardized incidence of chronic renal failure among Aboriginal people is 2.5 to 4.0 times higher than the national rate, primarily because of diabetes mellitus and glomerulonephritis.<sup>29</sup>
- **Undernutrition** – occurs in subpopulations of Aboriginal populations.<sup>30-32</sup>
- **Tobacco use** – the Canadian Aboriginal population has a higher prevalence rate of recreational tobacco use than the rest of the Canadian population. According to FNIHB of Health Canada, 59% of on-reserve FN and 58% of Inuit smoke.<sup>33</sup> In 2006, 31% of Métis adults smoked daily, and 67% of Inuit >15 years smoked daily, as compared with the Canadian average of 15% for the same year.<sup>34</sup>
- **Alcohol and drug abuse** – Aboriginal youth have high rates of binge drinking and marijuana use.<sup>35-39</sup> Alcohol and drug abuse occur in both Aboriginal and non-Aboriginal populations. In the Aboriginal population, in particular, substance abuse must be understood within a socioeconomic, political and historical context in order to avoid stigmatization.



## GENETIC FACTORS

- Linkage between susceptibility to symptomatic TB disease and chromosome 2q35 loci near the NRAMP1 (natural resistance associated macrophage protein 1) gene was demonstrated in a large Alberta Aboriginal family undergoing an epidemic of tuberculosis.<sup>40</sup> Studies of Dene and Cree First Nations have shown a higher frequency of single nucleotide polymorphisms, affecting cytokine and vitamin D receptor expression, which are associated with increased risk of TB disease.<sup>41,42</sup> A recent study also suggests that Mycobacterium-induced toll-like receptor signaling and resulting downstream cytokine responses may be differentially regulated in the Dene compared with Caucasians.<sup>43</sup>

## ENVIRONMENT

### Social determinants of health, TB and Aboriginal peoples

The World Health Organization (WHO) defines social determinants of health as the conditions in which people are born, grow, live, work and age ([http://www.who.int/social\\_determinants/en/](http://www.who.int/social_determinants/en/)). Socioeconomic inequalities, high levels of population mobility and population growth give rise to unequal distribution of social determinants of TB.<sup>44</sup> These factors are seen with higher frequency in the Aboriginal groups in Canada. Some of the key social determinants of health related to TB include 1) food insecurity and malnutrition, 2) poor housing and environmental conditions and 3) financial, geographic and cultural barriers to health care access.

### Food security

- Food security, as defined by the WHO, occurs when “all people at all times have access to sufficient, safe, nutritious food to maintain a healthy and active life.”<sup>45</sup>
- Inuit in Nunavut experience a high prevalence of food-insecure households.<sup>46</sup> Compounding the problem of inadequate access to foods is the significantly higher cost of food in remote parts of Canada, where many Canadian-born Aboriginal people reside.<sup>47</sup>
- Canadian-born Aboriginal people continue to experience a nutritional transition that has occurred over the years from traditional foods obtained from the land that they inhabit to market foods imported from elsewhere. Significant loss of important nutrient intake due to the shift to market foods has increased the risk of diet-sensitive chronic diseases.<sup>48,49</sup>
- Food insecurity and decreased traditional food intake<sup>49</sup> may lead to specific nutritional deficiencies that can also increase the risk of TB, such as vitamin D deficiency.<sup>50</sup> Vitamin D deficiency, which is prevalent in First Nations and Inuit populations,<sup>51,52</sup> has been associated with increased risk of TB disease.<sup>53,54</sup> A recent study among the Dene showed that vitamin D supplementation enhanced innate immune macrophage responses to *M. tuberculosis* lipoprotein in Caucasian but not in Dene participants.<sup>43</sup>

One recent randomized clinical trial conducted in patients from across the United Kingdom with smear-positive TB did not show a significant difference in the time to sputum culture conversion among all comers who received vitamin D supplementation versus placebo; however, a significant difference was noted in the time to sputum conversion in people with the tt genotype of the *TaqI* vitamin D receptor polymorphism.<sup>55</sup> In a systematic review of all trials using nutritional supplements for patients being treated for active TB, routinely supplementing at or above recommended levels of micronutrients, including vitamin D, in active TB did not result in any significant clinical benefits.<sup>56,57</sup>

- Smoking, alcohol and drug abuse is sometimes associated with poor nutrition, which can also increase the risk of malnutrition as a consequence of deficiency of key micronutrients.

## Housing

Aboriginal communities are at high risk of living in houses that are overcrowded and in disrepair.<sup>58</sup> Higher TB incidence was shown to be associated with a higher average housing density among First Nations.<sup>59</sup> Furthermore, another study showed an association between the number of people living in a house and self-reported TB in First Nations.<sup>60</sup> In communities with new cases of infectious TB disease, an increased number of individuals will be exposed if there is overcrowding and cramped living conditions, along with poor ventilation in some cases, leading to propagation of infection and disease.

## Health care access

- Geography – the incidence of TB is higher in Canadian Aboriginal communities that are considered isolated, as defined by access to airplane, road, telephone and radio service.<sup>61</sup> Isolated communities maybe faced with delays in the transportation of patients and diagnostic specimens because of logistical challenges such as inclement weather.
- Staff – understaffing,<sup>62</sup> high staff turnover rates and limited knowledge of TB by some casual and temporary health care staff are common in many remote communities. Acute health care needs often claim the attention of overworked staff in preference to public health programs, including TB control.
- Diagnostic services, including but not limited to smear microscopy and radiologic equipment, may be limited in isolated communities.
- Cultural barriers – lack of Aboriginal health care staff results in lack of traditional knowledge integration. Language barriers often exist between health care staff and community members, limiting access to care.<sup>63</sup>

## Education/income

- A strong socioeconomic gradient is present with an increased risk of TB for people living in poverty and/or social deprivation within countries and within communities.<sup>63</sup>
- Poverty increases the risk of being exposed to all of the aforementioned TB risk factors; that is, people who experience poverty have a higher likelihood of being exposed to food insecurity, poor housing conditions and limited health care access.

- For example, First Nations individuals with an annual income <\$10,000 are less likely than others to use health services.<sup>64</sup>

Furthermore, poverty increases the risk of being exposed to many of the biological risk factors such as smoking, alcohol, drug use and malnutrition.<sup>63</sup>

### Transmission Factors

Broadly speaking there are only two ways to eliminate TB: to interrupt transmission altogether and to prevent active TB disease in those with latent TB infection. On the prairies and in the territories, where the incidence of TB in Status Indians is particularly high, three independent lines of evidence point to the importance of ongoing transmission – a high index of transmission, determined by calculating the average number of culture-positive pulmonary cases generated by a single source case,<sup>12</sup> high rates of disease in children<sup>65</sup> and a high proportion of clustered *M. tuberculosis* isolates.<sup>66,67</sup> Preliminary data from the Determinants of TB Transmission Project<sup>68</sup> (a mixed-method study of TB transmission on the prairies) found that 90% of the Canadian born “potential transmitters” (adult culture-positive pulmonary cases) were of Aboriginal origin.<sup>69</sup>

## PROGRAMMATIC ISSUES IN TB PREVENTION AND CARE IN ABORIGINAL POPULATIONS

In many provinces, FN populations are highly mobile in terms of travel between reserves and from reserve to urban areas.<sup>35</sup> **Error! Hyperlink reference not valid.** This presents challenges to contact investigation and case management, requiring communication and coordination between health jurisdictions. Partnership and collaboration with the community is important for TB prevention and care. Health care workers must be sensitive to the historical and current concerns of their patients. Information sharing and control over health resources are frequent areas of concern for Aboriginal people in the context of the implementation of TB control (and other health care) programs.<sup>70</sup> Lack of knowledge about TB is strongly associated with negative attitudes about, and a worse experience of, the disease.<sup>71</sup> A proactive TB health education program that makes use of lay community resources, such as individuals who have recovered from TB, their family members, elders and community health workers, is required in order to achieve a successful prevention and control program in Aboriginal communities. In 2012, Health Canada produced a renewed TB strategy for First Nations On-Reserve,<sup>72</sup> which aims to improve program delivery and performance measurement while establishing standardized, culturally appropriate TB prevention and care services, including community-based initiatives.

### ADHERENCE TO TB MEDICATIONS IN ABORIGINAL POPULATIONS

Adherence or nonadherence to treatment of latent and active TB is not consistently associated with age, sex or race.<sup>73</sup> Adherence is a task-specific behaviour, not a personality trait.<sup>74</sup> The terms “adherence” and “nonadherence” may only be used when the patient and provider have agreed to a care plan. Establishing this initial agreement is a critical and often overlooked step.

Various criteria that trigger closer supervision of patients with active TB disease have been suggested in the literature, on the basis of missed appointments or home visits, pill counts in the case of self-administered therapy, urine isoniazid testing or concern voiced by the health worker.<sup>73</sup> Barriers to adherence derive from a complex interaction between the health system, and personal and social factors. Suggested interventions<sup>75</sup> to remove barriers to adherence at the health system level are as follows:

- Enhanced programs of directly observed therapy and directly observed preventive therapy that bring care closer to the patient (e.g. to the home), use incentives (e.g. food) and enablers (e.g. vouchers), assist the patient to deal with competing life priorities (e.g. work, school), are holistic and provide efficient care (e.g. through development of reminder and follow-up mechanisms, simplification of protocols, reduction of referral times and rigorous tracking of migrating patients).
- Provision of “permeable” care that does not require negotiation on the part of those who lack power, voice and material means. Permeable health services are emotionally/culturally “accessible”; they work at making patients feel valued and respected, and the focus of care.
- Aboriginal community health workers, preferably from the local community/area, function as educators, advocates and cultural brokers, ensuring that staff are knowledgeable and well trained to understand and address patient needs, and are given support (e.g. protected workload).

**Interventions<sup>75</sup> shown to be effective at the personal and social levels include the following:**

- Incorporate indigenous beliefs about causation and cure into the program, including traditional healing practices, as guided by patient wishes. Ensure that the key language concepts that are used are developed in partnership with Aboriginal people.
- Use creative multimedia methods to bring life to the educational process.
- Effective education conveys cognitive messages but also affective messages of empathy, openness, concern and respect. The messenger is the message.
- TB therapy will not be successful if it competes with addictions. Use harm-reduction methods.
- Use techniques from other health models (e.g. identify sponsors/mentors). Engage family and community groups for patient support. Utilize verbal or written “contracts” if appropriate.

Cases of nonadherence to TB care frequently highlight potential conflicts between personal and collective rights. In the context of Canadian indigenous communities, an open discussion of these issues is encouraged in order to determine solutions that are culturally and legally sensitive and appropriate.<sup>75</sup>

## THE IMPORTANCE OF EFFECTIVE CONTACT INVESTIGATION IN ABORIGINAL COMMUNITIES

Successful contact investigation is extremely important in Aboriginal communities, not only because of the burden of active TB disease but also the remote location of many communities, limited access to health care and chronic under-housing, all of which can facilitate transmission.<sup>76</sup> General contact investigation guidelines<sup>4-6</sup> (see also Chapter 12, Contact Follow-up and Outbreak Management in Tuberculosis Control) may be of limited use as they are not specific to the unique social structure and environment of Aboriginal communities.<sup>77-79</sup> There are other inherent challenges to conducting effective contact investigation in some settings, including language and cultural barriers, as well as the social stigma associated with TB. Inadequate contact investigation leads to missed opportunities to identify secondary active cases and ensure that infected contacts are identified and treated.<sup>80</sup>

Because of the limitations of routine contact investigation and the negative consequences of inadequate contact investigation, new approaches are under investigation and, in some cases, in use to establish effective TB control in those people and communities at greatest risk. A recent publication detailed some of these newer methodologies, including social network analysis (SNA), geographic information systems (GIS) and genomics, in the context of TB contact investigation in low-prevalence countries.<sup>81</sup> How these approaches could be implemented in Aboriginal communities requires investigation. SNA methods, alone and in combination with conventional and molecular epidemiology, have been used to examine TB clusters and outbreaks both retrospectively and prospectively in both Aboriginal and non-Aboriginal settings.<sup>82-85</sup> Network methods have also clearly documented that locations are key to contact investigation. With respect to Aboriginal TB control, network analysis has helped an understanding of outbreak boundaries, locations of transmission and the risk of TB in contacts in remote communities in Manitoba.<sup>85</sup> GIS techniques are used to visualize data involving distance and location.<sup>86</sup> These techniques have been used to examine the distribution of TB cases, risk factors for acquiring disease and the relationship of TB to the surrounding environment.<sup>87-89</sup> In a recent outbreak investigation involving TB in Aboriginal people, genomic (bacterial genetics) data from the clustered *M. tuberculosis* organisms were used to identify transmission events and confirm multiple simultaneous outbreaks within the community.<sup>89</sup> This investigation integrated clinical data, SNA and genomics to better characterize an outbreak that had significantly affected community members. It also confirmed that social factors played a larger role in the outbreak than organism virulence.

According to the most recent statistics released in 2012,<sup>90</sup> the current rate of TB among the Canadian-born Aboriginal population is 26.4 per 100,000. Across Canada rates of new active and retreatment TB cases for the Aboriginal population were as follows: North American Indian 22.2 per 100,000 (188 cases), Inuit 198.6 per 100,000 (116 cases) and Métis 7.5 per 100,000 (26 cases). In 2005, FNIHB set a long-term goal to reduce TB incidence to 3.6 per 100,000 among on-reserve First Nations and Inuit regions in Canada by 2015.<sup>16</sup> Results to date suggest that this goal will not be met (see Chapter 1, Epidemiology of Tuberculosis in Canada). To meet these goals and achieve a substantial reduction in rates of TB among Canadian-born Aboriginal peoples it seems likely that intensified and coordinated efforts using novel approaches will be necessary.

■ ■ ■

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