# Interventions au niveau de la population

Au niveau de la population, les interventions traitent les facteurs et les pratiques en matière de stigmatisation en ciblant des normes sociales et la politique publique. Les interventions à ce niveau recoupent des systèmes multiples et peuvent avoir une influence profonde sur la stigmatisation au sein et au-delà du système de santé.

#### Modifier les normes sociales

Les campagnes au niveau de la population contestent les stéréotypes et les préjugés en ayant recours à des modèles d'éducation et de contact similaires aux interventions au niveau individuel et interpersonnel. En règle générale, les activités d'évaluation ont mis l'accent sur les campagnes médiatiques ciblant la stigmatisation liée à la santé mentale, y compris Time to Change (en Angleterre) et Beyond Blue (en Australie). Selon des données probantes provenant de revues narratives menées dans le domaine de la santé mentale, les campagnes médiatiques au niveau de la population qui visent à influer sur la stigmatisation ont, à court terme, des répercussions positives de faibles à modérées. 193, 234 Outre les initiatives locales, l'initiative Time to Change a ciblé la population générale par l'entremise des médias de masse nationaux et de l'activité de marketing social, en mettant l'accent sur l'éducation, la réduction des préjugés et l'évolution du comportement.<sup>234</sup> Une amélioration au niveau des connaissances, des attitudes et des comportements

prémédités autodéclarés au niveau de la population a été notée, en plus d'une réduction dans la discrimination déclarée par les utilisateurs de services de santé mentale. 193, 234, 235 En Australie, dans le cadre de l'initiative Beyond Blue, on a eu recours notamment à des activités médiatiques au niveau de la population afin de cibler les connaissances, les croyances et les compétences du public en matière de santé mentale. 193 La campagne a été associée à des changements positifs à l'égard des attitudes publiques autodéclarées. 193

La stigmatisation subit également l'influence de ses représentations dans les médias, lesquels peuvent exercer une influence sur les facteurs de stigmatisation comme la peur et les attitudes préjudiciables.<sup>236</sup> En santé mentale, les interventions de lutte contre la stigmatisation dans les médias comprennent : une surveillance de la couverture médiatique à la suite d'initiatives de lutte contre la stigmatisation à l'échelle nationale ou locale et la publication de lignes directrices sur l'établissement de rapports en matière de santé mentale, ainsi que de l'enseignement à l'intention des journalistes et des étudiants en journalisme. L'efficacité de telles interventions a fait l'objet de peu d'études, et les conclusions sont mitigées, mais les approches les plus prometteuses comprennent des interventions en matière d'éducation axées sur les contacts ainsi que l'élaboration et la communication de lignes directrices par des institutions les plus influentes.236

# Réflexions d'un groupe de discussion sur la façon d'aborder la stigmatisation

Les participants ont discuté d'interventions qui favorisaient l'autonomisation par les arts. Par exemple, des documentaires comme « Take Me to the Prom » [Amène-moi au bal], présente de manière détaillée les expériences de personnes LGBTQ2+ assistant au bal des finissants de leur école secondaire plusieurs décennies après avoir terminé leurs études secondaires.<sup>237</sup> Les interventions axées sur les arts peuvent améliorer la représentation dans les médias et ont le potentiel de faire évoluer les normes sociales.

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#### Des droits et des protections pour tous les Canadiens

Les lois et les politiques peuvent prévenir un comportement discriminatoire et fournir une protection contre celui-ci, tout en informant que la stigmatisation et les préjugés sont inacceptables. <sup>183, 238</sup> Au Canada, la réglementation comprend la *Loi canadienne sur les droits de la personne* et la *Charte canadienne des droits et libertés*. Les interventions politiques au niveau de la population qui ciblent les facteurs et les pratiques en matière de stigmatisation sont celles qui ont le plus grand potentiel d'avoir des répercussions généralisées, ce qui est particulièrement manifeste dans la recherche portant sur la relation entre les politiques et les inégalités en matière de santé. <sup>105, 238, 239</sup>

Au Canada, la recherche approfondie soulevant les associations existant entre la fréquentation des pensionnats indiens chez les Autochtones et un vaste éventail d'inégalités en matière de santé mentale et physique chez d'anciens élèves des pensionnats et ses générations subséquentes constitue un exemple puissant.<sup>240</sup> Les pensionnats indiens ont tenté d'éradiquer la langue, les pratiques et les croyances culturelles des enfants autochtones, sans oublier que de nombreux enfants ont également été victimes de violence physique, sexuelle ou émotionnelle.<sup>240</sup> Les pensionnats indiens ont été liés à de mauvais résultats de santé physique, notamment des taux plus élevés de maladies chroniques et infectieuses, ainsi que des cas de détresse mentale, de dépression, de consommation de substances, de stress et de comportements suicidaires.<sup>240</sup>

La majorité des autres recherches effectuées au niveau de la population et s'orientant sur le lien existant entre les politiques stigmatisantes et les résultats de santé de la population provient des États-Unis. Les lois Jim Crow — c'est-à-dire des lois d'État et locales qui, jusqu'en 1964, avaient légalisé la ségrégation raciale — ont été associées à des inégalités en matière de santé liées au cancer du sein, à la mortalité infantile et à la mortalité prématurée chez les Afro-Américains. 241-243 Dans un autre exemple, l'adoption de lois étatiques autorisant le déni de services aux couples de même sexe a été associée à une augmentation dans la proportion d'adultes appartenant à une minorité sexuelle déclarant de la détresse mentale.<sup>244</sup> Inversement, les lois qui accordent des droits égaux sont liées à une amélioration du bien-être. Dans une étude longitudinale portant sur les femmes lesbiennes et bisexuelles à Chicago, les mesures législatives sur l'union civile ont été associées à des niveaux de conscience liés à la stigmatisation, à la discrimination perçue et aux symptômes de dépression plus faibles.245



#### CITATION D'UN GROUPE DE DISCUSSION

« Il faut aller au-delà des systèmes existants. [Nous avons] besoin de sensibilisation et... d'un message clair de la société [...] Les personnes qui sont non-minoritaires doivent être influencées par la réalité – le prochain combat, c'est celui-là qu'il faut absolument traiter. »

"It is necessary to go beyond existing systems. [We] need awareness and... [a] strong social message... Other non-minority people must be influenced by reality – the next battle is the one that must be dealt with."

Peu de recherches évaluent l'impact des initiatives politiques au niveau de la population liée à la stigmatisation sur les inégalités en matière de santé dans le contexte canadien. Cependant, des lois actuelles, comme la criminalisation de la non-divulgation du VIH et la consommation personnelle de droques, ont été signalées comme jouant un rôle dans le renforcement de la stigmatisation.246-250 La discrimination a également été codifiée dans des lois, comme la Loi sur les Indiens, qui a été établie il y a près de 150 ans, et qui continue à régir et à limiter de grandes sphères de la vie pour les membres des Premières Nations, dont la terre, l'identité, l'autonomie et l'activité économique. 21, 251-253 Cela se répercute parallèlement dans les ressources insuffisantes qui sont attribuées à l'éducation, au logement et aux services de santé et sociaux pour les Premières Nations.21, 114

Un exemple de la façon dont les données probantes ont éclairé de nouvelles politiques afin de réduire la stigmatisation est survenu récemment. En décembre 2018, le Canada a été le premier pays à s'inscrire à la campagne mondiale U=U (Indétectable = Non transmissible). Cette campagne est fondée sur des données probantes qui illustrent que lorsqu'une personne est traitée efficacement pour le VIH et qu'elle maintient une charge virale indétectable, elle ne pose véritablement aucun risque de transmission sexuelle. La stigmatisation demeure l'un des plus grands obstacles qui empêchent des Canadiens d'avoir accès à des services de prévention, de dépistage, de traitement et de soutien en matière de VIH, et cette transformation a des répercussions importantes sur la réduction de la stigmatisation liée au VIH. En guise de réponse, Justice Canada a annoncé qu'il publierait une nouvelle directive liée aux poursuites pénales relatives à la non-divulgation du VIH, d'après les éléments de preuve scientifique examinés par l'Agence de la santé publique du Canada.<sup>254</sup>

# Principes pour orienter les interventions de lutte contre la stigmatisation

Malgré qu'il y a de plus en plus de recherches qui sont effectuées sur l'intervention de lutte contre la stigmatisation, il est toujours difficile de savoir « ce qui fonctionne » et dans quel contexte, pour traiter la stigmatisation et la discrimination. Il s'agit d'une difficulté courante dans le domaine de la recherche en intervention. Le temps ou les ressources sont souvent inadéquats pour concevoir, mettre en œuvre et évaluer de façon rigoureuse les interventions (voir la zone de texte). Ce processus est encore plus complexe en ce qui a trait aux interventions au niveau de la population. Cela a donné lieu à une répartition inégale de la recherche à travers les niveaux ainsi qu'à une incompatibilité entre le focus de recherche (au niveau individuel ou interpersonnel) et les niveaux où le plus grand impact est possible (au niveau institutionnel ou de la population).

Une meilleure compréhension de ce qui fonctionne demande également que l'on tienne compte des multiples voix et modes de savoir. Même si la responsabilité du changement incombe aux décideurs et aux dirigeants du système, ce sont les collectivités qui possèdent de longs antécédents de résistance et de leadership quant à la lutte contre la stigmatisation et la discrimination. Le fondement de nos efforts pour traiter la stigmatisation et la discrimination provient de la collectivité, notamment des personnes possédant une expérience vécue et des organismes communautaires. Les collectivités qui sont victimes de stigmatisation se sont appuyées les unes les autres afin de renforcer la solidarité et de contester les facteurs et les pratiques stigmatisants, de façon à atténuer les répercussions des expériences découlant de la stigmatisation chez les individus, les familles et les collectivités. 21, 255, 256

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# Élargir notre vision des données probantes

Le colonialisme et le racisme ont exercé une influence sur les systèmes de connaissances que nous valorisons et ne valorisons pas en tant que société. Cela a donné lieu à la domination des connaissances biomédicales occidentales et à la dévalorisation des systèmes de connaissances ou des « modes de savoir » autochtones.21 Il est important que nos efforts collectifs soient éclairés par les modes de savoir autochtones, de même que par les connaissances expérientielles des personnes ayant une expérience vécue de la stigmatisation. Aux fins du présent rapport, ces connaissances proviennent de chercheurs autochtones et de chercheurs racialisés, ainsi que de nos groupes de discussion.

Le Cadre d'action constitue un point de départ qui permet de cerner les interventions prometteuses en fonction de nos connaissances actuelles. Nos efforts en vue de concevoir, d'adapter, de mettre en œuvre et d'évaluer des interventions de lutte contre la stigmatisation peuvent permettre de créer un changement significatif, tout en faisant progresser ce domaine. Plusieurs principes ont été relevés dans le cadre de l'examen des données probantes qui, parallèlement aux grands principes en matière de santé publique, peuvent offrir des conseils utiles pour éclairer la marche à suivre pour les prochaines étapes.

# Principes fondamentaux pour la conception d'interventions de lutte contre la stigmatisation

- Elles sont motivées par la collaboration entre les dirigeants du système de santé et les personnes ayant une expérience vécue de la stigmatisation.
- 2. Elles sont conçues en s'appuyant sur les données probantes de la recherche, les différents modes de savoir et les connaissances expérientielles.
- 3. Elles sont à niveaux multiples, et accorde une attention particulière aux initiatives à plusieurs niveaux qui sont centrées sur les interventions au niveau institutionnel ou de la population pour traiter la stigmatisation et la discrimination systémiques dans les systèmes de santé.
- Elles sont orientées par des principes comme l'adaptation aux réalités culturelles, et les soins tenant compte des traumatismes et de la violence.
- Elles tiennent compte de l'intersectionnalité, y compris l'attention aux forces, aux ressources et à la solidarité au sein des communautés qui sont victimes de stigmatisation.
- 6. Elles sont fondées sur les principes de la recherche en intervention et de la science de la mise en œuvre, afin de faire avancer les connaissances dans le domaine.

# response of settor engagement envers l'amélioration

service axé sur la personne d'abord axé sur les traumatismes simple langage axé sur la personne d'abord fondé sur les besoins de grande qualité equitable efficace information accessible axé sur la prévention axé sur la prévention axé sur la prévention

civ Ces idées sont tirées de deux groupes de discussion. On a demandé aux participants à quoi ressemblerait, selon eux, un système de santé exempt de stigmatisation.

# La voie à suivre

Tandis que la stigmatisation est façonnée et maintenue en place par des forces socioéconomiques supérieures, notamment par des politiques et des pratiques historiques, le système de santé peut être un secteur de premier plan puissant pour soutenir le changement au Canada. Si nous faisons appel à notre pleine capacité à tous les niveaux à l'échelle du secteur de la santé, nous pouvons influencer le changement à plus grande échelle.

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Les personnes qui travaillent dans le domaine de la santé s'emploient à aider les autres à mener une vie saine et à obtenir des soins de qualité lorsqu'ils sont malades; par conséquent, le fait de critiquer notre système de santé et d'examiner nos préjugés personnels se veut difficile tant au niveau émotionnel que cognitif. Cependant, pour que nous puissions aller de l'avant, il est important que nous reconnaissions les politiques et les pratiques inacceptables qui perpétuent la dynamique de pouvoir et qui privent de ressources ceux qui pourraient en avoir le plus besoin.

Pour instaurer un service de santé plus inclusif, nous devons faire preuve d'un leadership courageux et d'un engagement soutenu pour modifier le statu quo par l'intermédiaire d'actions multiples, et ce, à plusieurs niveaux. Il faut une approche plus proactive pour traiter les obstacles communs et distincts auxquels sont confrontées les personnes stigmatisées alors qu'elles tentent d'accéder aux ressources en santé.

Chacun d'entre nous a un rôle à jouer pour y parvenir.







SYSTÈME DE SANTÉ, il nous incombe de veiller à ce que les politiques en matière de santé protègent et appuient les personnes victimes de stigmatisation; nous devons également démanteler les politiques qui discriminent ces personnes et les empêchent d'obtenir des services de santé.

En qualité de **LEADERS DU** 

Nous pouvons assurer que les services rendus à tous nos patients et nos clients soient d'une grande qualité et qu'ils soient livrés dans des environnements sécuritaires, respectueux et accueillants. Cela exige que nous mettions en place une gamme de mesures complémentaires, dont les suivantes :

- des politiques et des pratiques en matière de sécurité culturelle qui outillent les membres du personnel afin de leur permettre d'offrir des programmes et des services sensibles et appropriés;
- des approches axées sur les traumatismes et la violence qui visent à assurer que les professionnels de la santé ont recours à un langage non stigmatisant et qu'ils comprennent que les traumatismes posent un risque et compromettent un état de santé optimal;
- soutenir et financer la collaboration et la mobilisation significative des gens qui ont une expérience vécue de la stigmatisation dans l'élaboration des politiques et des programmes en santé.

Les établissements d'enseignement en santé et les associations professionnelles de la santé doivent travailler avec des partenaires, dont des personnes victimes de stigmatisation, pour orienter la transformation des pratiques, des programmes et des compétences professionnelles des fournisseurs de soins de santé de façon à veiller à ce que la stigmatisation cesse d'être perpétuée dans notre système de santé.

Il est important que nous **mesurions et** surveillions les progrès découlant des mesures que nous mettons en place. Il

s'agit d'un élément qui est essentiel à la transformation institutionnelle et nécessaire si nous voulons faire une différence. Nous pouvons systématiquement stratifier nos données selon les groupes qui sont les plus susceptibles d'être victimes de stigmatisation et procéder à une réflexion critique sur les résultats. La surveillance et l'établissement de cibles et d'objectifs réguliers pour l'amélioration au niveau de l'institution, du personnel et des patients peuvent mener à une meilleure qualité de soins et à de meilleurs résultats de santé durables.



En qualité de CHERCHEURS, comprendre les iniquités en matière de santé constitue un objectif important de notre travail. Pour ce faire, nous devons

traiter les lacunes fondamentales et inacceptables dans nos données nationales - nous ne disposons d'aucune donnée désagrégée de qualité sur l'état de santé de populations diverses ou sur leurs expériences en matière de stigmatisation. Par exemple, nous ne sommes pas en mesure d'établir de rapports uniformes sur l'espérance de vie des personnes qui s'identifient comme étant LGBTQ2+, des personnes marginalement logées, des personnes qui consomment des substances et d'autres populations diverses. Nous devons également faciliter la recherche collaborative à l'échelle des sciences de la santé, des sciences sociales et des sciences comportementales qui nous aident à examiner les répercussions de stigmates multiples. Il est important d'accorder la priorité au renforcement de la recherche en

intervention et sur la mise en œuvre pour que nous puissions déterminer ce qui fonctionne pour les personnes qui sont victimes de stigmatisation liée à des problèmes de santé et à des identités sociales.



En tant qu'INDIVIDUS, nous devons intégrer nos visions du monde et nos histoires personnelles dans le cadre de notre travail. Nous avons des préjugés

et nous sommes vulnérables à l'utilisation d'un langage stigmatisant.

Que pouvez-vous faire pour dissiper vos préjugés?

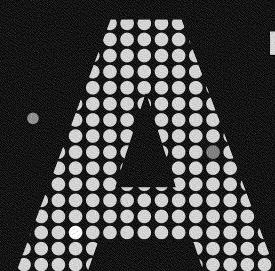
- 1. Travaillez sur vos processus de réflexion et contestez vos filtres. Cessez d'utiliser un langage déshumanisant. On peut désapprendre les préjugés. Reconnaissez et contestez les stéréotypes ou les mythes négatifs dans les médias, et surveillez vos propres pensées.
- 2. Amenez cette sensibilisation au sein de votre organisation. Examinez d'un œil critique votre culture organisationnelle et apportez des modifications à toutes les politiques discriminatoires et pratiques d'exclusion. Mettez en œuvre le Cadre d'action décrit dans le présent rapport au sein de votre organisation.
- 3. Engagez-vous dans le processus de l'apprentissage continu. La reconnaissance, la compréhension et la contestation de vos propres préjugés et de la stigmatisation systémique constituent l'engagement de toute une vie. Continuez à vous remettre en question, vous et votre organisation, et cherchez des façons de vous améliorer.

Au Canada, les valeurs que sont le respect, la diversité et l'inclusivité sont profondément ancrées. Cela nous permet de continuer à renforcer ces fondements et à promouvoir la santé optimale pour tous.

Mettre fin à la stigmatisation et bâtir un système de santé inclusif est un héritage important que nous pouvons léguer à nos générations futures.

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# ANNEXE A

Tableau de bord de l'administratrice en chef de la santé publique au Canada sur l'état de santé de la population

# Aperçu du tableau de bord

Le tableau de bord utilise un ensemble diversifié d'indicateurs de santé pour donner un aperçu de la santé générale des Canadiens. Les indicateurs sont regroupés en trois grandes catégories: l'état de santé général (tableau A), les facteurs qui influent sur la santé (tableau B) et les résultats de santé (tableau C). Le tableau de bord fait l'objet d'un examen annuel pour veiller à ce que les derniers résultats des indicateurs soient inclus. Les résultats de la version précédente du tableau de bord sont utilisés dans les cas où aucune mise à jour n'est disponible. 257 Les résultats de l'indicateur par sexe sont fournis dans la mesure où ceux-ci sont disponibles. Les résultats de l'analyse des tendances de haut niveau rendent compte des tendances des données positives (« meilleure »),

négatives (« pire ») ou neutres (« similaire ») au fil du temps. Dans certains cas, une conclusion relative à une tendance peut ne pas être possible (« S.O. ») en raison des limites des données ou des limites méthodologiques. Les résultats d'analyses comparatives internationales comparent le Canada relativement à des pays à revenus élevés similaires, par exemple en tenant compte de la moyenne des pays membres de l'Organisation de coopération et de développement économiques (OCDE). Les résultats possibles sont « meilleurs » ou « pires » que les données de références et « S.O. » dans l'éventualité où aucun indicateur international comparable n'a été soulevé.

#### TABLEAU A: État de santé général

Sujet  Espérance de vie à la naissance	Indicateur	Résultat	Résultat par sexe		Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
	Espérance de vie générale en années	82	F 84	M 80	2015-2017	Statistique de l'état civil	Meilleure	Similaire
Espérance de vie ajustée en fonction de la santé (EVAS) à la naissance	EVAS générale en année	70	F 71	M 69	2010-2012	Sources multiples <sup>ii</sup>	Meilleure	Meilleure <sup>iii</sup>
Santé perçue	% de la population âgée de 12 ans et plus qui s'estime être en « très bonne » ou « excellente » santé	61	F 60	M 61	2018	Enquête sur la santé dans les collectivités canadiennes	Similaire	Meilleure <sup>iv,v</sup>
Santé mentale perçue	% de la population âgée de 12 ans et plus qui s'estime être en « très bonne » ou « excellente » santé mentale	69	F 66	M 71	2018	Enquête sur la santé dans les collectivités canadiennes	Pire	S.O.

Organisation de coopération et de développement économiques, Panorama de la santé 2017.

Statistique Canada, Base canadienne de données sur l'état civil, les naissances et les décès et estimations de la population; Enquête sur la santé dans les collectivités canadiennes; Enquête nationale sur la santé de la population, volet Établissements de soins de santé; Enquête sur les établissements de soins pour bénéficiaires internes; Enquête canadienne sur les mesures de la santé; Recensement de la population.

iii Organisation mondiale de la Santé, Statistiques sanitaires mondiales 2018.

Organisation de coopération et de développement économiques, Panorama de la société 2016.

v En comparaison à la plupart des autres pays, le Canada avait un ensemble différent de catégories de questions et réponses à l'enquête, créant une influence positive pour cette estimation.

#### TABLEAU B: Facteurs qui influent sur la santé

Sujet	Indicateur	Résultat	Résultat par sexe	Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Facteurs socia	ux						
Appartenance à la communauté	% de la population âgée de 12 ans et plus qui déclare un sentiment d'appar- tenance « plutôt fort » ou « très fort » à la communauté locale	68	F M 70 67	2018	Enquête sur la santé dans les collectivités canadiennes	Similaire	S.O.
Pauvreté (seuil officiel de la pauvreté au Canada)	% de la population vivant sous le seuil officiel de la pauvreté au Canada, selon la Mesure du panier de consommation	10	F M9	2017	Enquête sur le revenu canadienne	Meilleure	S.O.
Pauvreté chez les enfants (seuil officiel de la pauvreté au Canada)	% d'enfants vivant sous le seuil officiel de la pauvreté au Canada, selon la Mesure du panier de consommation	9	F M9	2017	Enquête sur le revenu canadienne	Meilleure	S.O.
Éducation	% de la population âgée de 25 ans et plus ne détenant pas de certificat, de diplôme ou de grade	13	F M 13 14	2018	Enquête sur la population active	Meilleure	Meilleure <sup>vi</sup>
Besoins impérieux en matière de logement	% de ménages ayant des besoins impérieux en matière de logement <sup>vii</sup>	13	S.O.	2016	Recensement	Similaire	S.O.
Insécurité alimentaire	% de ménages qui vivent dans l'insécurité alimen- taire (de modérée à grave) <sup>vii</sup>	8	F M 10 7	2018	Enquête sur la santé dans les collectivités canadiennes	Similaire	S.O.

vi Organisation de coopération et de développement économiques, Regards sur l'éducation 2018.

Vii Un ménage ayant des besoins impérieux en matière de logement est un ménage dont le logement est considéré inadéquat, inabordable ou d'une taille non convenable, et dont le niveau de revenu est insuffisant pour permettre de payer les frais de logement d'un logement approprié et adéquat dans sa communauté.

viii Insécurité alimentaire modérée : signes que la qualité et/ou la quantité des aliments consommés est compromise; insécurité alimentaire grave : signes de réduction de l'apport alimentaire et de perturbation des habitudes alimentaires.

Sujet	Indicateur	Résultat	Résultat par sexe	Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Consommation de substances							
Tabagisme	% de la population âgée de 15 ans et plus qui déclare fumer quotidiennement ou occasionnellement à l'heure actuelle (cigarettes seulement)	15	F M 13 17	2017	Enquête canadienne sur le tabac, l'alcool et les drogues	Similaire	Better <sup>i</sup>
Cannabis	% de la population âgée de 15 ans et plus qui déclare consommer quotidiennement, ou presque, du cannabis au cours des trois derniers mois	3	F M4	2017	Enquête canadienne sur le tabac, l'alcool et les drogues	Similaireix	Pire <sup>x</sup>
Alcool	% de la population âgée de 12 ans et plus qui déclare avoir une consom- mation abusive d'alcool <sup>a</sup>	19	F M 15 24	2018	Enquête sur la santé dans les collectivités canadiennes	Similaire	Similaire <sup>i</sup>
Opioïdes	Taux de décès apparemment liés à la consommation d'opioïdes pour 100 000 habitants	12	S.O.	2018	Surveillance concernant les opioïdes	Pire	S.O.
	Taux d'hospitalisations attribuables à une surdose liée à la consommation d'opioïdes pour 100 000 habitants	17	F M 15 18	2017	Base de données sur la morbidité hospitalière	Pire	S.O.

ix Nombre limité de points de données disponibles – interpréter avec prudence.

x Organisation mondiale de la Santé, usage du cannabis au cours de la vie.

xi Par consommation abusive d'alcool, on entend les hommes qui ont déclaré avoir bu cinq verres d'alcool ou plus, ou les femmes ayant déclaré avoir bu quatre verres d'alcool ou plus, en une même occasion, au moins une fois par mois au cours de la dernière année.

Sujet	Indicateur	Résultat	Résultat par sexe	Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Facteurs de ris	sque relatifs aux enf	ants et au	comporten	ient			
Intimidation	% de jeunes de la 6° à la 10° année qui ont été victimes d'intimidation plus d'une fois ou deux au cours des deux derniers mois	28	F M 29 27	2018	Comportements de santé des jeunes d'âge scolaire	Similaire	Similairexii
Activité physique	% d'enfants et de jeunes (âgés de 5 à 17 ans) qui accumulent en moyenne au moins 60 minutes d'activité physique modérée à vigou- reuse par jour	39	F M 26 52	2016-2017	Enquête canadienne sur les mesures de la santé	Similaire	S.O.
Comportement sédentaire	% des enfants et des jeunes (âgés de 5 à 17 ans) qui déclarent suivre les recommandations pour contrer la sédentaritéxiii	54	S.O.	2016-2017	Enquête canadienne sur les mesures de la santé	S.O.	S.O.
Surpoids et obésité	% de la population âgée de 5 à 17 ans considérée comme faisant de l'embonpoint selon la définition de l'OMS	18	F M 21 16	2016-2017	Enquête canadienne sur les mesures de la santé	Similaire	Similaire <sup>i,xiv</sup>
	% de la population âgée de 5 à 17 ans considérée comme étant obèses selon la définition de l'OMS	11	F M 9 12	2016-2017	Enquête canadienne sur les mesures de la santé	Similaire	Similaire <sup>i, xiv</sup>
Violence faite aux enfants	% de la population âgée de 15 ans et plus ayant subi l'un ou l'autre des trois types de violence faite aux enfants <sup>xv</sup> avant l'âge de 1 5 ans	34	F M 32 37	2014	Enquête sociale générale	S.O.	S.O.

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XIII Recommandations en matière de comportement sédentaire : passer deux heures ou moins par jour à regarder la télévision ou à utiliser un ordinateur pendant les heures de loisir.

L'incidence combinée des enfants qui font de l'embonpoint et sont obèses est utilisée comme indicateur. ΧİV

Les types de maltraitance des enfants comprennent de la violence physique et/ou sexuelle ainsi que le fait d'être témoin de violence commise par un parent ou un tuteur à l'endroit d'un autre adulte.

Sujet	Indicateur Résultat Résultat par sex			Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale	
Facteurs de p	protection durant la p	etite enfan	ce					
Instrument de mesure du déve- loppement de la petite enfance	% d'enfants vulnérables dans l'un des cinq domaines de développement <sup>xvi</sup> avant d'entamer la 1 <sup>re</sup> année	26	F 20	M 34	Données regrou- pées de différentes années	Offord Centre for Child Studies, Université McMaster	S.O.	S.O.
Vaccination	% de la population de 2 ans ayant reçu le vaccin contre la rougeole	90	F 92	M 89	2017	Enquête sur la couverture vaccinale nationale des enfants	Similaire	Pire <sup>xvii</sup>
	% de la population de 2 ans ayant reçu les quatre doses recomman- dées du vaccin contre la diphtérie, la coqueluche et le tétanos	76	F 78	M 74	2017	Enquête sur la couverture vaccinale nationale des enfants	Similaire	Pire <sup>xvii</sup>
	% de la population de 2 ans ayant reçu le vaccin contre la polio	91	F 91	M 90	2017	Enquête sur la couverture vaccinale nationale des enfants	Similaire	S.O.
	% de la population de 2 ans ayant reçu le vaccin contre la varicelle	83	F 84	M 82	2017	Enquête sur la couverture vaccinale nationale des enfants	Similaire <sup>xviii</sup>	S.O.

xvi Les cinq domaines de développement comprennent la santé physique et le bien-être; les compétences sociales; la maturité affective; le développement cognitif et langagier; et les habiletés de communication et les connaissances générales.

xvii Organisation de coopération et de développement économiques, base de données de l'OCDE sur la famille.

xviii Interpréter avec prudence en ce qui a trait à la qualité des données.

Sujet	Indicateur	Résultat	Résultat par sexe	Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Facteurs de la	santé de la mère et	du nourris	son				
Faible poids à la naissance	Poids à la naissance inférieur à 2 500 grammes (% de naissances vivantes)	7	F M 7 6	2017	Statistique de l'état civil	Similaire	Similaire <sup>i</sup>
Allaitement	% de la population des femmes âgées de 15 à 55 ans qui ont donné nais- sance à un enfant au cours des cinq dernières années et qui déclarent l'avoir allaité exclusivement pendant au moins 6 mois, sans autre liquide, eau ou aliment solide	37	S.O.	2018	Enquête sur la santé dans les collectivités canadiennes	Similaire	Similaire

#### TABLEAU C: Résultats en santé

Sujet	Indicateur	Résultat	Résul par se		Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Maladies chro	niques et blessures							
Cancer	Taux d'incidence de tous les nouveaux cas de cancer dia- gnostiqués, pour 100 000 habitants (tous âges)	516	F 496	M 548	2017	Registre canadien du cancer	N/A	Similaire <sup>i</sup>
	Taux d'incidence de tous les nouveaux cas de cancer colorectal diagnostiqués, pour 100 000 habitants (tous âges)	66	F 55	M 80	2017	Registre canadien du cancer	Similar	S.O.
Maladie cardio- vasculaire	Taux d'incidence de tous les nouveaux cas de cardiopathie ischémique dia- gnostiqués, pour 100 000 habitants (20 ans et plus)	599	F 489	M 716	2016	Indicateurs des maladies chroniques au Canada	Meilleure	Betteri
Diabète	Taux d'incidence de tous les nouveaux cas de diabète dia- gnostiqués, pour 100 000 habitants (1 an et plus)	604	F 668	M 541	2016	Indicateurs des maladies chroniques au Canada	Meilleure	Similaire
Troubles de l'humeur	% de la population âgée de 12 ans et plus ayant déclaré avoir reçu un dia- gnostic de trouble de l'humeur d'un professionnel de la santéxix	9	F 11	M 7	2018	Enquête sur la santé dans les collectivités canadiennes	Pire	S.O.

xix Les troubles de l'humeur comprennent la dépression, le trouble bipolaire, la manie ou la dysthymie.

Sujet	Indicateur	Résultat	Résultat par sexe		Année des données les plus récentes	Source des données	Tendance au fil du temps (jusqu'à 15 ans)	Référence internationale
Maladies chro	niques et blessures							
Démence (y compris la maladie d'Alzheimer)	Taux de nouveaux cas de démence diagnostiqués, y compris la maladie d'Alzheimer, pour 100 000 habitants (65 ans et plus)	1351	F 1489	M 1193	2016	Indicateurs des maladies chroniques au Canada	Meilleure	Similaire <sup>i</sup>
Suicide	Taux de mortalité par suicide pour 100 000 habitants	11	F 6	M 17	2017	Base de données sur la mortalité	Similaire	Similaire
Blessures accidentelles	Taux d'hospitalisations attribuables à des blessures accidentelles pour 100 000 habitants (normalisé selon l'âge)	599	F 550	M 636	2017-2018	Indicateurs de santé de l'Ins- titut canadien d'information sur la santé	Meilleure	S.O.
Maladies trans	smissibles							
Tuberculose	Taux d'incidence de cas de tuber- culose active pour 100 000 habitants	5	F 4	M 6	2017	Système canadien de déclaration des cas de tuberculose	Similaire	Meilleure <sup>xx</sup>
Hépatite C	Taux de cas d'hépatite C pour 100 000 habitants	32	F 24	M 39	2017	Surveillance des maladies à déclaration obligatoire	Similaire	Meilleure <sup>xxi</sup>
VIH	Taux d'incidence de diagnostics de VIH pour 100 000 habitants	7	F 3	M 10	2017	Surveillance des maladies à déclaration obligatoire	Similaire	S.O.

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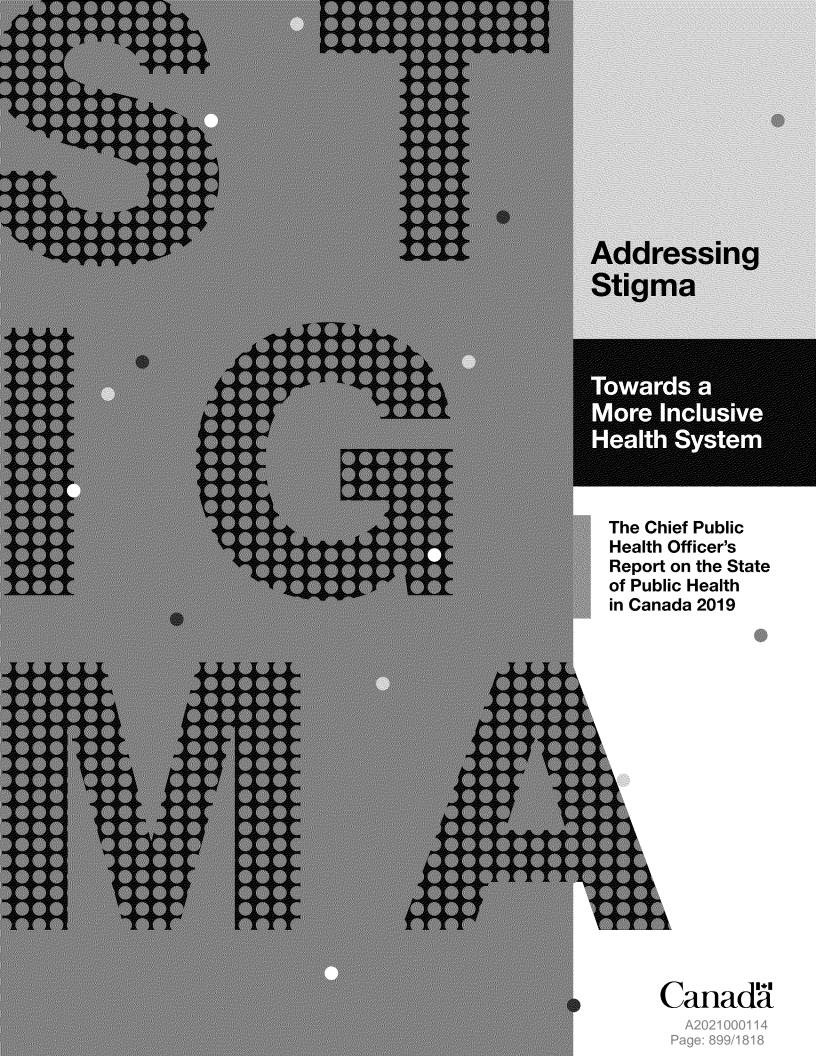
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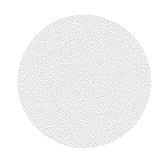
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# Message from the Chief Public Health Officer of Canada

By and large, we are a healthy nation. We can be proud of Canada's health and social systems that contribute to this status. From this position of strength, we have an even greater opportunity to lead the world in health status and to ensure all Canadians can achieve optimal health. This year, my annual report provides a snapshot of key public health trends and shines a light on one of the drivers of health inequities: stigma.

I am pleased to report on some important positive health trends this year like the lower incidence of certain chronic and other non-infectious diseases. Some social factors that lead to good health in Canada are also improving; more people are achieving post-secondary education, and poverty rates, especially childhood poverty, are decreasing.

I do continue to be concerned about worrying trends. With the dramatic rise in global measles cases this year, the risk of importation and domestic spread has increased. If we do not improve our vaccine coverage, we may lose our hard-earned measles elimination status. Sexually transmitted infections such as syphilis are also making a comeback with the additional challenge of

antibiotic-resistant bacteria causing gonorrhoea. Youth vaping rates are increasing and we do not fully understand the related harms, from potential impacts on the respiratory system to the incidence of youth cigarette smoking. The opioid crisis continues, and claimed more than 12 deaths per day in 2018. The harms may have been much greater if a range of preventive, harm reduction, and treatment measures had not been implemented.

All of these trends are reversible. We know what to do but need to re-engineer how we implement proven public health measures in today's context. This includes getting trusted, evidence-based information to Canadians in the age of misinformation and disinformation.

Although public health policies and programs should benefit all, persistent health inequities prevent many from being able to achieve their full potential. Often these differences can only be explained by how people are treated. That is why I focused this annual report on stigma and health.

Stigma affects us all. We are all vulnerable to the slow and insidious practice of dehumanizing others and we are all responsible for recognizing and stopping it.

This is what we know. Stigma is associated with poorer physical and mental health outcomes. Stigma and discrimination towards persons with health conditions, such as mental illness, substance use disorders, and HIV, cannot be understood or treated separately from stigma related to other characteristics such as race, gender, sexual orientation, age, and income.

These many forms of stigma, that intersect in complex ways, are very much present in our health system, driving those most in need from getting effective care and accessing services. It means that we, as health system leaders and practitioners, are contributing to negative health outcomes.

This report offers a way forward.

We can build on our Canadian multicultural and inclusive way of life, while at the same time openly recognize and name racism, homophobia, transphobia, and other stigmas related to social identities. We can stop using dehumanizing language, examine our own assumptions, and implement policies and education programs, while also measuring our progress towards stigma elimination across the health system. By understanding the common drivers, practices, and experiences of multiple stigmas, we may find more collaborative and effective interventions.

It is hard to face our vulnerabilities as individuals and organizations who set out to care for others but fall short on providing the safe, effective, and compassionate health system that puts people first. However, with a dose of humility and a deepened connection to people who experience stigma, we can deconstruct the "us versus them" narrative and develop the most inclusive health system in the world.

#### Dr. Theresa Tam

Chief Public Health Officer of Canada

We would like to respectfully acknowledge that the land on which we developed this report is in traditional First Nations, Inuit, and Métis territory, and we acknowledge their diverse histories and cultures. We strive for respectful partnerships with Indigenous peoples as we search for collective healing and true reconciliation.

We would also like to acknowledge the territories in which we conducted discussion groups that contributed to this report:

- We acknowledge that the discussion group in Ottawa took place on the traditional unceded territory of the Algonquin people.
- We acknowledge that the discussion group in Toronto took place on the traditional territory of the Wendat, the
- Anishnaabeg, Haudenosaunee, Métis, and the Mississaugas of the New Credit First Nation.
- We acknowledge that the discussion group in Montréal took place on the traditional unceded territory of the Mohawk people.
- We acknowledge that the discussion group in Vancouver took place on the traditional unceded territory of the Coast Salish peoples, including the territories of the Musqueam, Squamish, Stó:lō, and Tsleil-Waututh Nations.



"Greater attention needs to be paid to stigma as a social determinant of population health."



# **About this** Report

Every year, the Chief Public Health Officer writes a report on the state of public health in Canada. These reports raise the profile of public health issues and stimulate dialogue. They can also lead to action in improving and protecting the health of Canadians.

This year's report first provides a summary of the overall health of Canadians, including how different populations experience poorer health. The rest of the report focuses on stigma, one of the reasons for these differences.

#### **Health of Canadians**

Chapter One draws on indicators from the Chief Public Health Officer's Health Status Dashboard (Appendix A), as well as other national data on the health of Canadians. Some health inequalities are highlighted by the use of key examples. The dashboard provides a breakdown of national indicators by sex where possible. In the past year, some new data have been released and indicator values have been updated. In other areas, the indicator values from last year remain the same.

# Stigma and Health

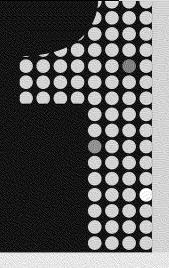
Chapter Two presents a stigma and health model that highlights the pathways from stigma to poor health outcomes and how different stigmas intersect. This new model illustrates how stigma drivers and practices, including those in the health system, can lead to health inequities. Chapter Three presents an action framework with a range of evidence-based actions that can be implemented simultaneously to reduce stigma across the health system. These sections examine a range of healthrelated stigmas as well as stigmas associated with social identities.

The information presented in the stigma chapters was synthesized from an evidence review conducted in social and health science databases.

When synthetizing the evidence, systematic reviews were prioritized and complemented by primary studies. The strongest evidence found through the review was prioritized. Where available, Canadian research has been highlighted. Emerging and promising practices were identified through the evidence review, environmental scan, and stakeholder engagement.

Throughout the stigma chapters, quotes have been included to reflect the lived experiences of stigma and broader input on solutions for developing an inclusive health system. These quotes were gathered during five discussion groups and eight interviews with a range of people with expertise in stigma across Canada. Participants included health professionals, representatives from community-based organizations, service providers, policymakers, researchers, individuals with lived and living experience, and others working to improve the health of their communities. The areas of focus included stigma experienced by First Nations, Inuit, and Métis peoples, African, Caribbean, and Black Canadians, seniors, and LGBTQ2+ people, and across health issues such as mental illness, substance use, tuberculosis, HIV, and obesity.

More information about the themes from the discussion groups and interviews can be found in the What We Heard report.



# CHAPTER 1

# **Describing the Health of Canadians**

# Introduction

Canadians are among the healthiest people in the world. In general, we live long lives in good health. Nevertheless, there are some concerning public health trends and health inequities.

The content of this chapter is based on indicator data derived from the Chief Public Health Officer's Health Status Dashboard (Appendix A), as well as other national data sources and scientific literature exploring the health of Canadians. Dashboard changes compared to the previous version that was published as part of the Chief Public Health Officer's Report on the State of Public Health in Canada 2018: Preventing Problematic Substance Use in Youth, include indicator value updates and breakdowns per sex, where available. In the event that no new indicator results were available, last year's published results are used. It is important to note, however, that national-level data can mask the health status of some groups in Canada. This chapter offers some examples of these persistent health inequities.

# **Health Trend Highlights**

# Life Expectancy is Changing

In 2017, life expectancy at birth for women was 84 years, while for men it was 80 years.<sup>2</sup> Life expectancy is affected by both the number of deaths in a population, as well as the age at which those deaths occur.

For years, life expectancy at birth has steadily increased in Canada for both sexes, but recent data suggest this may be starting to change. From 2016 to 2017, for the first time in four decades, there was no year-to-year increase in life expectancy at birth for either males or females.2

Despite this, some encouraging trends in life expectancy have been observed. Over the course of the previous three decades, male life expectancy at birth has increasingly approached the life expectancy of females, so the gap between the sexes has decreased.<sup>2</sup> Life expectancy at birth has been positively influenced by fewer deaths or later deaths related to cancer or circulatory diseases from 2016 to 2017.2

Life expectancy is changing across age groups. Older people benefitted from improved mortality rates in 2017, meaning that they are dying at a slower rate than in 2016. However, gains in life expectancy at birth, due to these improved mortality rates for older Canadians, are being largely offset by increased mortality rates among younger adults. This is especially true for males (Figure 1).2

Respective life expectancy data is based on reference period 2015–2017.

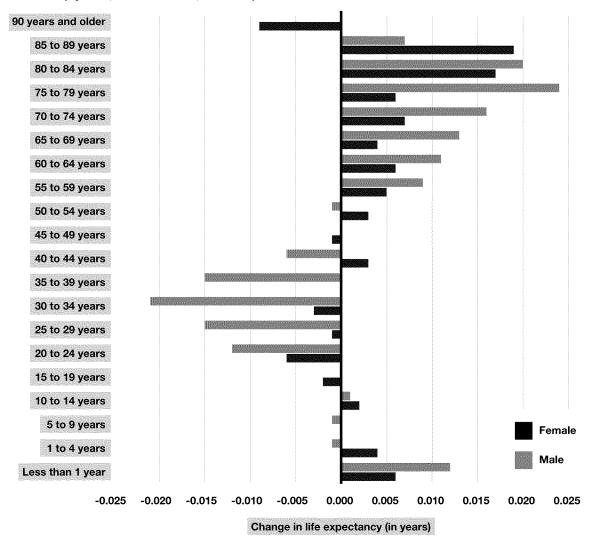
#### **Health Inequalities and Inequities in Context**

Health inequalities reflect differences in health outcomes. When these differences are related to unfair conditions, they are called health inequities. When reporting on populations that experience a disproportionate burden of poor health outcomes, it is critical to understand the context of these data.

For instance, First Nations, Inuit, and Métis peoples have had to overcome stigmatizing and catastrophic experiences throughout history, such as colonization, the loss of traditional lands and political institutions, and attempts at cultural assimilation. Poor health outcomes related to substance use and mental health are examples of the lasting impacts of intergenerational trauma (i.e., passing on the negative effects from one generation to the next) that have influenced the health of Indigenous peoples in Canada.

Unique contexts also exist for other populations, which need to be contextualized within historical, political, social, and economic conditions. Not all of these situations may be referred to in this chapter due to data and space limitations. To further explore differences in health outcomes, please refer to the report <a href="Key Health">Key Health</a> Inequalities in Canada.

FIGURE 1: Contribution of Age-specific Mortality Rates to the Change in Life Expectancy at Birth (by Sex, 2016 to 2017, Canada)



Source: Statistics Canada. Changes in life expectancy by selected causes of death, 2017.

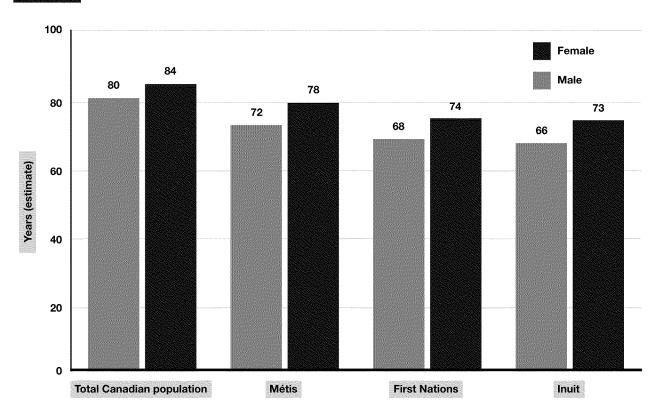
The increase in deaths in young adults has been primarily attributed to the increase in opioid-related overdose deaths, particularly among young and middle-aged men. Opioid-related deaths have had a serious impact on life expectancy for both sexes, but more so for males in British Columbia and Alberta, contributing to decreases in life expectancy in both provinces from 2016 to 2017.<sup>2</sup>

When examining different groups in Canada, life expectancy is consistently lower among First Nations, Inuit, and Métis peoples. Other differences in life expectancies are consistent with what is known on the social determinants of health, like those living with lower income have a lower life expectancy than

the general population. There are also populations for which we have very limited data. For example, life expectancy data for some populations, like other racial groups or LGBTQ2+ people, is not known.<sup>3</sup>

As seen in Figure 2, with respect to Indigenous peoples, Inuit were estimated to have a shorter life expectancy at birth, up to 14 years shorter for males, and up to 11 years shorter for females, compared to the overall Canadian population.<sup>4</sup> It is important to see these data in context; the lasting legacy of colonization and intergenerational trauma have led to systemic health inequities for First Nations, Inuit, and Métis peoples.<sup>5</sup>

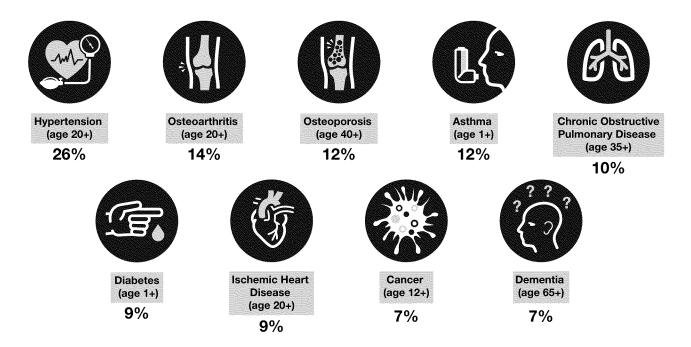
#### FIGURE 2: Life Expectancy at Birth by Indigenous Identity and Sex (Canada, 2009–2011)



Source: Pan-Canadian Health Inequalities Data Tool, 2017 Edition.

#### FIGURE 3: Prevalence Rates of Common Chronic Conditions

The prevalence rates of the most common chronic conditions are:



Note that although mood disorders are among the most common chronic conditions, they are described separately in a subsequent section.

Source: Public Health Agency of Canada. Canadian Chronic Disease Indicators, Quick Stats, 2018 Edition.

### Chronic Diseases Continue to be the Major Disease Burden

Chronic disease continues to be the biggest cause of disease burden in Canada. Close to half of Canadian adults over the age of 20 years report that they are living with at least one of ten common chronic diseases or conditions (Figure 3).<sup>7</sup>

On a positive note, recent data suggest declining incidence<sup>iv</sup> rates for a number of chronic diseases in Canada (Figure 4).<sup>7</sup> A report analyzing national data over the period of 1999 to 2012 from the Canadian Chronic Disease Surveillance System (CCDSS)

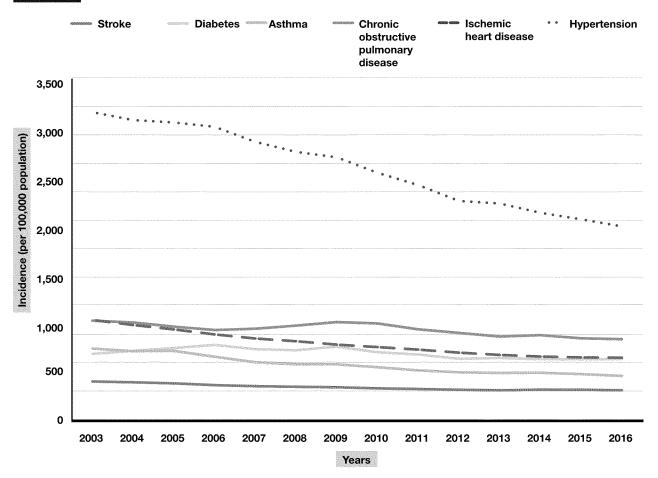
identified decreasing overall incidence trends for diagnosed asthma, chronic obstructive pulmonary disease, hypertension, ischemic heart disease, and stroke. More recent data from CCDSS reiterates the continuation of these trends between 2003 and 2016 for all described chronic diseases and points to a declining incidence rate for diabetes starting in 2006. The observed decrease in chronic disease incidence rates may be influenced by factors such as varying strategies used to diagnose, manage, and report chronic diseases across the country. Further investigations are needed to fully understand these observations.

ii The term "prevalence" is used when referring to the number of people living with an existing medical condition in a given time period.

iii Many chronic conditions are influenced by modifiable risk factors which were not addressed in this report. Please refer to the CPHO 2018 annual report.

iv The term "incidence" is used when referring to the number of people newly diagnosed with a medical condition in a given year.

#### FIGURE 4: Age-standardized Chronic Disease Incidence Estimates (2003–2016, Canada)



Source: Canadian Chronic Disease Surveillance System data files (as of August 2019).7

Canadian data also suggest a possible decline in the incidence rates of newly diagnosed cases of dementia, including Alzheimer's disease (Appendix A).<sup>9, 10</sup> A recent Lancet commission examined lifestyle factors which might influence an individual's risk of developing dementia. Evidence shows that healthy living and higher education levels may contribute to preventing or delaying dementia.<sup>11</sup> While the incidence rate may be decreasing in Canada, the burden of Alzheimer's disease and dementia is expected to continue to increase, due to factors such as a growing and aging population,

and possibly improved survival. Accordingly, between 2005 and 2016, the age-standardized prevalence rate of dementia increased by 12%.

There are health inequalities across chronic diseases. For example, South Asian as well as African, Caribbean, and Black Canadian adults are more than twice as likely to live with diabetes than White adults.<sup>3</sup> Evidence suggests that dementia rates are rising more rapidly among First Nations populations compared to the general Canadian population, including earlier disease onset.<sup>10, 12</sup>

### Poor Mental Health Continues to Impact Canadians

The good news is that 69% of Canadians aged 12 years and older reported their mental health status as very good or excellent in 2018. At the same time, the percentage of Canadians aged 12 years and older who indicated that they have been diagnosed by a health professional as having a mood disorder, such as depression, bipolar disorder, mania, or dysthymia (i.e., persistent depressive disorder) was 9% in 2018. 13

Mental health varies considerably among Canadians, with some sub-populations being much more likely to report low self-rated mental health. For example, for the period of 2010 to 2013, adults who identified as bisexual were close to three times more likely, and adults who identified as gay or lesbian, were approximately twice more likely, to report low self-rated mental health than adults who identified as heterosexual. These higher rates could be linked to internalized stress related to gender expectations and experienced discrimination.<sup>3</sup>

In Canada, suicide rates remained stable from 2000 to 2017. On average, 11 Canadians die by suicide every day. 14 In 2017, the suicide rate among males was three times higher than the rate among females. Suicide rates were highest among middleaged males. 14 Some Indigenous communities are disproportionally affected. Areas with a relatively high Inuit population had a 6.5 times higher suicide rate than areas with a low concentration of Indigenous peoples.3 Suicide rates in areas primarily inhabited by First Nations and Métis peoples were also significantly higher (four and three times, respectively) than in areas with a non-Indigenous peoples majority.3 The impacts of intergenerational trauma can ultimately manifest in poor mental health and practices that may place individuals at risk for suicide. However, it is important to note that not all Indigenous communities experience high suicide rates. For example, over 60% of First Nations bands had a suicide rate of zero. 15 Protective factors can

include opportunities to speak and learn one's traditional language, cultural identity, and connection to the land. <sup>16, 17</sup>

#### Substance Use

Substance use and its related harms remain a concerning public health issue and a national priority. Street drugs contaminated with highly toxic fentanyl and fentanyl analogues continue to drive the current epidemic of opioid related deaths. <sup>18</sup> In addition, reducing or preventing alcohol-related harm is a persistent challenge, alongside addressing emerging concerns such as tobacco use and nicotine vaping among youth.

#### High Rates of Opioid-related Deaths Continue

Nationally, more than 12 apparent opioid-related deaths occurred on average every day in 2018.18 ln early 2019, 82% of accidental opioid-related deaths involved fentanyl or fentanyl analogues. 19 Regional variations continue to be observed and some provinces and territories (British Columbia and Alberta, in particular) have been impacted more than others. Data for 2018 show that overall, men accounted for three quarters of accidental apparent opioid-related deaths in Canada. 18 Likewise, in 2018, young and middle-aged adults accounted for the most accidental apparent opioid-related deaths overall, with 27% of deaths reported among those aged 30 to 39 years, followed by 22% in those aged 40 to 49 years, 21% aged 50 to 59 years, and 20% aged 20 to 29 years. 18 Although complete national information on opioid-related harms in Indigenous peoples is lacking, available data suggest higher opioid use and associated harms, including higher rates of hospitalization, accidents, and death in some but not all Indigenous communities, compared to the general Canadian population.<sup>20</sup> In this context, it is important to note that First Nations, Inuit, and Métis peoples have experienced intergenerational trauma, abuse and systemic racism, which directly or indirectly contribute to elevated levels of substance use rates.21,22

#### Vaping Increases Among Youth

Vaping is the inhaling of a vapour created by an electronic cigarette (e-cigarette) or other vaping device. In 2017, the use of e-cigarettes as a cessation aid in the past two years was reported by 32% of current or former smokers.<sup>23</sup> Among the 3% of Canadians aged 15 years and older who used a vaping product in the past 30 days in 2017, 65% were current smokers, 20% were former smokers, and 15% reported having never smoked cigarettes.<sup>23</sup>

The increased use of vaping products by youth represents an emerging and serious health trend. Vaping can increase the risk of nicotine addiction and could alter brain development in youth.24 The long-term effect of exposure to a range of harmful chemicals such as formaldehyde, acrolein, metals, and other contaminants through vaping remains unknown. Emerging evidence points to increased risk of respiratory disease in vaping device users, highlighting the need for further studies.<sup>25, 26</sup> In 2017, approximately 15% of Canadians aged 15 years and older had ever tried a vaping product, with the greatest likelihood among youth aged 15 to 19 years (23%) and young adults aged 20 to 24 years (29%).23 A recent meta-analysis indicates that adolescents and young adults who had ever used e-cigarettes had close to four times higher odds of initiating cigarette smoking than those who had never used e-cigarettes.<sup>27</sup> Accordingly, from 2017 to 2018, the percentage of Canadian youth aged 16 to 19 years who reported vaping in the last month increased substantially by 74%.<sup>28</sup> More research is required to better understand the association between vaping and smoking behaviour in Canada, and the related health impacts.

#### Cannabis Use Rises in Adults 25+

In 2017, the prevalence of past-year cannabis use was 15%, a 3% increase compared to 2015.<sup>23</sup> Frequent cannabis use did not change between 2015 and 2017, with approximately 3% of Canadians aged 15 years and older reporting daily or almost daily cannabis use in the previous three months. It is important to note that most of the available data on cannabis consumption pre-dates cannabis legalization in Canada in 2018.<sup>29</sup> Consequently, cannabis use reporting was strengthened with

the implementation of the *Cannabis Stats Hub* in 2018, which now monitors cannabis use every three months.<sup>30</sup>

Cannabis use varies by age. In 2017, past-year use of cannabis was highest among youth aged 15 to 19 years (19%) and young adults aged 20 to 24 years (33%) compared to adults aged 25 years and older (13%). Compared to 2017, past-year cannabis use among adults aged 25 years and older increased from 10% in 2015, though there were no changes reported for other age groups. National and regional studies identified differences in cannabis use by race in youth, with Indigenous youth being the most likely group reporting lifetime and recent cannabis use. National and recent cannabis use.

By the end of 2018, the cannabis sources accessed by users largely depended on their reasons for using it. Eighty-six percent of medical users with documentation acquired cannabis from legally authorized retailers or licensed online producers, in contrast to 26% of non-medical users.<sup>33</sup> Forty-two percent of non-medical users declared obtaining cannabis from illegal sources and 54% from friends or family.<sup>33</sup>

One important contributor for harms related to cannabis use is the increased risk of motor vehicle collisions when driving under the influence of cannabis.<sup>34</sup> Among cannabis users with a valid driver's licence, 14% admitted to driving within two hours of using cannabis. This practice was nearly twice as common in males compared to females.<sup>35</sup>

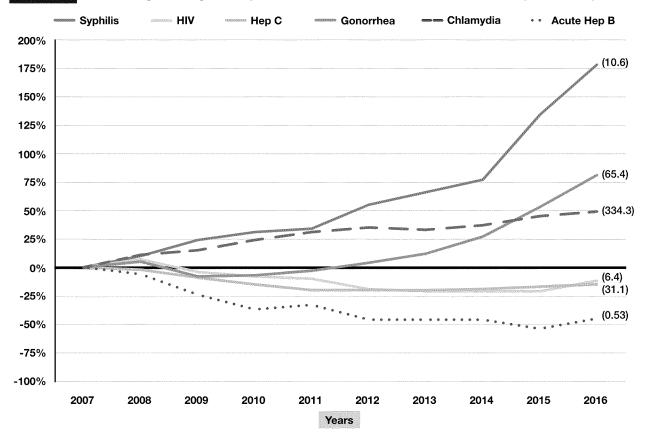
#### Heavy Drinking Rates Remain Harmfully High

Alcohol continues to be the most used psychoactive substance amongst adults and youth. In 2017, 78% of the population over 15 years of age reported drinking alcohol in the last year.<sup>23</sup> In 2017, past-year alcohol use among youth aged 15 to 19 years was 57%.<sup>23</sup> These figures were all unchanged from 2015.

Heavy drinking rates remained stable from 2017 to 2018, with 19% of Canadians aged 12 years and older reporting heavy drinking in 2018. Heavy drinking means having five or more standard drinks for men or four or more standard drinks for women, on one occasion, at least once a month in the past year. 36

14

#### FIGURE 5: Percentage Change in Reported Rates of Selected STBBI in Canada (2007–2016)



The percentages on the left represent the percent change relative to the reference year of 2007. The values in brackets represent the 2016 infection rates per 100,000 population.

Source: Adapted from Accelerating our Response: Government of Canada Five-year Action Plan on Sexually Transmitted and Blood-borne Infections.<sup>38</sup>

The rate of alcohol-related hospitalizations has increased faster for women than for men. More than 25,000 women had alcohol-related hospitalizations, representing a 3% increase from 2015–16 to 2016–17. In contrast, the increase for men was 0.6%. T

#### Sexually Transmitted and Bloodborne Infections are on the Rise

Concerning increases for some sexually transmitted and blood-borne infections (STBBI) have been observed in Canada. From 2007 to 2016, the reported rates for chlamydia, gonorrhea, and syphilis increased by 49%, 81% and 178%, respectively (Figure 5).<sup>38</sup> Moreover, six cases of congenital syphilis were reported in Canada in 2015, reversing the previous downward trend observed from 2011 to 2014.<sup>39</sup> This result is disquieting as it coincides with a rise in syphilis cases in women of childbearing age. There are numerous factors that may contribute to some extent to the

observed trends, other than a true rise in incidence. such as improved diagnostic tools, contact tracing, and case detection.40

While the number of newly diagnosed HIV infections remained relatively stable in Canada, 14% of people living with HIV were estimated to be unaware of their status in 2016.41 Similarly, as of 2016, national Hepatitis C infection rates remained stable over the course of previous years.42 An estimated 44% of Canadians living with Hepatitis C are thought to be unaware of their status.43

Some communities are disproportionally affected. For example, gay, bisexual and other men who have sex with men accounted for more than 50% of new HIV infections in 2016, although they represented approximately 3% of the male population in Canada. Indigenous peoples accounted for 11% of new HIV infections in 2016, but represented only 5% of the general population.41

Certain sub-populations are at high risk for Hepatitis C infections, such as people who inject drugs and people who are incarcerated.43

#### **Current Vaccination Rates are Not Reaching National Targets**

For many decades, vaccines have helped prevent and control the spread of serious infectious diseases in Canada and abroad. However, effective vaccine protection at the population level requires establishing and maintaining high vaccination rates across the country. Since 2011, little progress has been made towards reaching national childhood vaccination targets for several vaccine preventable diseases, such as measles and polio (Appendix A).44

In the case of measles, for example, the disease was declared eliminated from Canada in 1998. This was shortly after introducing a routine second dose of the measles vaccine to the childhood immunization schedule, prior to school entry. 45 In spite of this success, the national estimated measles vaccine coverage rate among two-year-olds was

only 90% in 2017, which is below the minimum 95% vaccination coverage needed at the population level to maintain measles elimination.<sup>46</sup> Over the past two decades, measles cases and outbreaks have occurred intermittently in Canada, ranging from a few secondary cases to over 680 cases per outbreak (Figure 6).47-51 They have been linked to individuals who acquired measles during international travel.

#### **Antimicrobial Resistance** and Unnecessary Antibiotic Use is an Emerging Threat

Antimicrobial resistance (AMR) describes the capability of disease-causing microorganisms to withstand antimicrobial treatments such as antibiotics, thereby limiting available treatment options. AMR has been identified by the World Health Organization as one of the ten most significant threats to global health. Globalization, travel, and medical tourism mean that Canada shares this threat. 52, 53 If left unchecked, it is estimated that AMR could cause 10 million deaths a year worldwide by 2050.54

Concerning national AMR trends were observed for several infectious diseases. For example, rates of community-acquired methicillin-resistant Staphylococcus aureus (MRSA) infections increased by 62% between 2012 and 2017; Neisseria gonorrhoeae infections resistant to azithromycin increased by 50% from 2015 to 2016.53 While infection rates of some of the most resistant organisms, carbapenemresistant Enterobactericeae (CRE), have been stable, a very worrisome trend can be found in the five-fold increase, between 2014 and 2017, in the number of people who are carriers of these bacteria.55 However, some progress has been made in Canada to reduce AMR, primarily in hospital settings. For example, healthcare-associated Clostridioides difficile and healthcare-associated MRSA infections decreased respectively by 36% and 6% from 2012 to 2017.55

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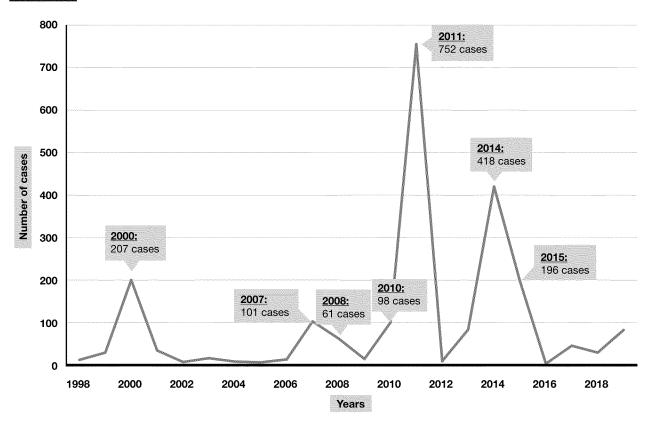
Threats from AMR are not restricted to those coming from bacterial infections. For example, multidrug-resistant fungal infections caused by *Candida auris* are also a concern. Initially reported in Japan in 2009, the first imported case described in Canada was in 2017. <sup>56</sup> As of July 2019, there have been 20 cases of *C. auris* reported in Canada. <sup>8</sup>

Antibiotics are used widely in both human and veterinary medicine as well as in the agricultural industry. The prevalence of AMR is strongly associated with antibiotic use, and lowering antibiotic use can reduce the development of AMR.<sup>57</sup> In Canada, 92% of all antibiotics dedicated to human health

care are prescribed in the community, primarily by general practitioners (65%), followed by dentists, nurses, and pharmacists (22%), as well as other specialists (13%).<sup>58</sup>

Greater efforts are required to reduce the unnecessary use of antibiotics.<sup>59</sup> In many cases, antibiotics are prescribed for indications where they are ineffective, such as for viral infections.<sup>57, 60</sup> Not only does this accelerate the development of AMR, it puts the patient at risk of side effects without offering them benefit. In some studies, it is estimated that 30–50% of all antibiotic prescriptions in outpatient settings are inappropriate.<sup>61, 62</sup>

#### FIGURE 6: Annual Number of Confirmed Measles Cases (1998–2019, Canada)<sup>v</sup>



v 75% or more of all confirmed annual measles cases were linked to one single outbreak that occurred the same year.

### Climate Change is Impacting Health and Well-being

Our climate is changing. Canada is warming at about double the global rate, and northern Canada has already warmed to almost three times the global rate. 63-65 Canada's Top Climate Change Risks report (2019) has identified health and well-being as one of the key areas of climate change risk facing Canada, while pointing out that such risks can be meaningfully reduced through adaptation measures that lessen vulnerability and/or exposure. 66

Climate change is having an impact on health and well-being both directly and indirectly. Extreme weather events such as flooding, wildland fires, and heatwaves can result in death, injury, and illness. For example, more than 90 people in Quebec died as a result of the July 2018 heatwave. <sup>67</sup> Changes in precipitation and temperature have also influenced the spread of climate-driven infectious diseases.

Social determinants of health such as housing, working conditions, and food security will be affected by climate change. Extreme weather events not only increase the risk of direct negative health impacts, but also pose challenges to health systems and health care facilities with consequences for patient care, safety, and healthcare costs.<sup>65</sup>

The impacts of climate change on health and well-being will also vary by region. In northern Canada, the consequences of climate change are significant and widespread. For example, loss of sea ice is associated with food insecurity and mental health impacts for populations that rely on ice to access hunting grounds and traditional sites, and to bring food and supplies from the South. In Rigolet, Nunatsiavut community members have reported feelings of displacement due to the disruption of hunting, fishing, foraging, trapping, and travelling from climate change impacts.

#### **Climate-driven Infectious Diseases**

Changes in precipitation and temperature can increase the spread of climate-driven infectious diseases, specifically, zoonoses (i.e., diseases that can spread between animals and people), vector-, food- and water-borne diseases:

- Changing climate has facilitated the spread of the tick responsible for Lyme disease, contributing in part to an increase in cases from 144 in 2009 to 2025 in 2017.<sup>69,70</sup> Other tick-borne diseases have also started to emerge in Canada including, for example, anaplasmosis and Powassan virus.<sup>69</sup>
- Four out of the five bacteria that account for over 90% of foodborne illness in Canada are influenced by climate change.<sup>71</sup>
- Over the last 20 years, the incidence rates of endemic mosquito-borne diseases, such as West Nile virus and Californian serogroup virus, have increased in Canada.

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#### Highlights of Other Factors Impacting Health

The health of individuals and populations is determined by a number of personal, social, economic, and environmental factors. These factors influence someone's place and position of power in society, and the access they have to the building blocks of good health. Examining key trends in the determinants of health is important to our understanding of public health and health inequities.

#### Strong Sense of Community Belonging

Community belonging has an important role in shaping mental health and a number of indicators related to community connectedness are included in the Public Health Agency of Canada's Positive Mental Health Surveillance Framework.73 In 2018, 68% of the population aged 12 years and older reported a somewhat strong or very strong sense of belonging to the local community. 13 Some Indigenous peoples rate their sense of community belonging much higher than the national average. For example, close to 81% of First Nations peoples declared a somewhat strong or very strong sense of belonging to their local community in 2015–2016.74 A strong sense of community belonging can be an asset for fostering resilience and mitigating the impact of societal inequities.

### Higher Education Attainment and Less Poverty

Income and education are two key social determinants of health exerting an influence on many important health measures such as overall life expectancy. In the period from 2009 to 2011, Canadians living in the lowest-income neighbourhoods had a life expectancy at birth that was

approximately four years lower than those living in the highest income neighbourhoods. Similarly, Canadians living in areas with the highest proportion of people having less than a high school education had close to three years lower life expectancy at birth compared to those living in areas with the highest proportion of university graduates.<sup>4</sup>

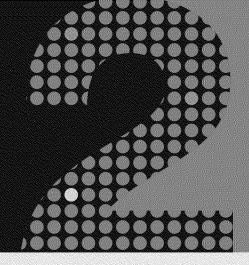
This year, important and encouraging trends are being reported for income and education.

The proportion of Canadians aged 25 to 54 years<sup>vi</sup> without a certificate, diploma or degree has decreased by 51%, from 14% in 2003 to 7% in 2018.<sup>75</sup> This trend may be influenced by a generational shift in the likelihood of completing postsecondary education.

There have also been considerable decreases in the proportion of Canadians living below Canada's Official Poverty Line, which is a measure of low income (based on the Market Basket Measurevii). In 2017, 10% of Canadians were living below the poverty line compared to 16% in 2006.<sup>76</sup> This represents a decrease of 39%. The change was even more pronounced among children living below the poverty line, with a decrease of 53% from 19% in 2006 to 9% in 2017.76 Despite this encouraging trend, childhood poverty remains a concern in some populations. For example, in 2015, high childhood poverty rates were reported for Indigenous children. ranging from an average of 47% for First Nations children to 25% and 22% for Inuit and Métis children, respectively. Moreover, data on non-Indigenous children indicate that recent immigrant and non-Caucasian children had poverty rates of 35% and 22% respectively, compared to 12% for all children in the remaining group.77

vi Note that the CPHO Health Status Dashboard reports on educational certification for persons 25 years old and older. A narrower age range was chosen here to minimize the risk of possible misleading effects from including older Canadians in analysis.

vii The Market Basket Measure (MBM) is a measure of low income based on the cost of a specified basket of goods and services representing a modest, basic standard of living.



#### CHAPTER 2

# Stigma is a Public Health Issue

Some Canadians experience worse social and health outcomes than others. The evidence tells us this is, in part, due to how we treat each other. When we stigmatize people, we affect their chances for a long and healthy life.

Stigma affects health through stress and other physical pathways. Many people are exposed to multiple stigmas, preventing them from attaining the resources they need to achieve optimal health such as education, employment, housing, and health services.

These stigma chapters will focus on the health system, which includes health care, public health, and other allied health services. Stigma in the health system can be particularly harmful, as people are prevented from accessing the health information services and resources they need, creating mistrust and further exclusion.

### The Experience of Stigma

Here we introduce you to Charles and Cynthia, fictional people who experience multiple and intersecting stigmas. They face stigma in society and the health system, which affects their well-being and health. We revisit Charles and Cynthia in the next chapter, to see how things could have worked out differently.

#### Charles

Charles recently moved to a mid-sized town in Ontario. He feels people staring at him and has even seen people crossing to the other side of the street when he walks by. He wonders whether this is because he is Black. Charles has been with his partner David for most of his adult life. During the AIDS epidemic of the 1980's, he contracted HIV. Thanks to current treatments, the virus is undetectable in his body. However, recently he has been experiencing some symptoms that he thinks may have something to do with cardiovascular disease, just like his parents had. He knows that he needs

to go see his new doctor and get this checked out, but he is hesitant because he had been treated with disrespect before by healthcare providers.

Charles attends an appointment with his new doctor to discuss his symptoms; however, she seems dismissive of his concerns. She instead asks Charles several questions about his HIV status and whether he is practising safe sex. At the end of the appointment, she only suggests that Charles change his diet, and she does not refer him for any further testing. Charles leaves feeling frustrated and ignored. He does not seek further care as he is worried that

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viii We recognize that these stories may be disconcerting. The purpose is to use these fictional characters to highlight how stereotypes and stigma are often attached to individuals and communities because of their racial or sexual identity background.

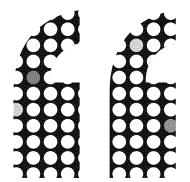
he will not be taken seriously again. Several months later, Charles suffers a heart attack and is rushed to the hospital. While recovering, Charles feels the hospital staff are apprehensive to touch him and he notices that they put on gloves to perform routine tests, such as taking his blood pressure, which they do not do with other patients. Charles overhears two nurses whispering about his HIV status. Charles feels unsettled about the care he received and is worried about his future health.

#### Cynthia

Cynthia is a Cree woman living in Saskatchewan with her two young children and is pregnant with her third baby. She is connected with members of her First Nations community and has been receiving health care in a First Nations health centre. She has just learned that she will need to be admitted to a large hospital to receive treatment for complications related to her pregnancy. She is afraid of going into the hospital because during her first pregnancy, her non-Indigenous doctor kept asking her questions about drug and alcohol use and insinuating that she may not be capable of providing for her child. She has delayed going to the hospital because she does

not want to face those kinds of questions or risk losing her children. The stress of worrying is causing her to not sleep or eat properly.

Due to her previous negative experiences, Cynthia avoids going to the hospital for treatment. Cynthia experiences severe complications during the seventh month of her pregnancy, and is rushed to the hospital, where she has an emergency C-section. Her baby is born with an extremely low birth weight and will need to stay in the neo-natal intensive care unit for at least one month. As she is recovering, the doctors and nurses repeatedly ask Cynthia why she did not get treatment to avoid these complications. Cynthia feels that they are implying she is a bad mother, and they are blaming her for the outcome of the pregnancy. Cynthia feels alone and is worried about the next steps for herself and her new baby. She is unsure how she can visit her new baby at the hospital without adequate childcare for her other children. Despite voicing her concerns, the hospital staff tell Cynthia these are "normal" emotions after having a baby, and they do not refer her to a hospital social worker or provide her with additional resources for support. Cynthia leaves the hospital feeling helpless and stressed, which adds to her existing eating and sleeping problems.



#### **INTERVIEW QUOTE**

"There are so, so many ways stigma stops people from reaching their full potential. And we as a society are poorer for that."

## The Pathways of Stigma to Health Outcomes

Stigma begins with the labeling of differences and negative stereotyping of people, creating a separation between "us" and "them." Those who are stigmatized are devalued and subjected to discrimination, which is unjust treatment. This can lead to disadvantage and inequitable social and health outcomes. Stigma happens in institutions (e.g., healthcare organizations), at a population level (e.g., norms and values), through interpersonal relationships (e.g., mistreatment), and internally (e.g., self-worth and value).

Stigma can be seen as both a cause and effect; it continues to justify the devaluing of people through stereotypes and exclusion. He less this cycle is actively stopped, the separation into "us" and "them" is reinforced by unequal power dynamics in society. People and institutions with resources and power, including health organizations, shape laws and social norms that can influence what is considered to be "normal" and "acceptable." In the health system, this power dynamic also exists between healthcare providers and patients.

Stigma can target different identities, characteristics, behaviours, practices, or health conditions. For example, stigma can be based on race, gender and gender identity, sexual orientation, language, age, substance use, ability, and social class. Stigma related to health conditions can include obesity, substance use disorders, mental illness, dementia, tuberculosis, and HIV infection. When stigmas intersect, they can exacerbate negative health outcomes.

Stigma includes discrimination, as "enacted" stigma. 81,82 While there is little data measuring stigma in Canada, discrimination is more commonly measured. The following section summarizes available self-reported discrimination data for some key populations. It is important to note that there is still limited data in this area and that experiences of discrimination may be underreported.

### Stigma can benefit those in power in several ways:80

By keeping people "in", that is, by enforcing preferred social norms and values

By keeping people "down", which maintains one's group advantage in society

By keeping people "away", in order to avoid disease or a perceived threat

#### Discrimination in Canada

Over one in four Canadians have reported experiencing at least one form of discrimination in their lifetime. <sup>83</sup> Many Canadians experience discrimination based on race, religion, ethnic origin, gender, or sexual orientation. The most common type of discrimination reported by Canadians is racial discrimination. <sup>83</sup> African, Caribbean, and Black Canadians are the most likely to report discrimination in Canada, followed by Indigenous peoples. <sup>84</sup> Alarmingly, hate crimes, one of the most extreme forms of discrimination, have been on the rise in Canada, primarily against people who are part of Arab, Muslim, Jewish, and Black communities. <sup>85</sup>

ix Stigma definition adapted from Bruce G. Link and Jo C. Phelan, 2001.81

New analyses of the 2013 Canadian Community Health Survey Rapid Response Discrimination Module, the only national discrimination survey in Canada, support these findings. Lesbian, gay, bisexual (LGB) participants (note that transgender identities were not included in the survey), African, Caribbean, and Black Canadians and Indigenous peoples in Canada were more likely to report being unfairly treated than the general population. More specifically, LGB community members were almost three times more likely, and African, Caribbean, and Black Canadians and Indigenous peoples were twice as likely, to report having faced discrimination than their general population counterparts.<sup>8</sup>

In a national Canadian survey, the majority of youth who identified as transgender (ages 19 to 25 years) reported having experienced discrimination in the last year based on their gender identity (70%), sex (63%), physical appearance (60%) or sexual orientation (59%).<sup>86</sup>

In 2012, 20% of Canadians with a mental health illness reported being affected by negative opinions or unfair treatment due to their poor mental health.<sup>87</sup> In 2014, 10% of Canadians with mental health disabilities<sup>x</sup> reported violent victimization in the 12 months prior to the survey, which was more than double the general population.<sup>88</sup>

In an online Canadian survey in 2016, 49% of people currently in recovery from addiction reported experiencing stigma or discrimination during their active addiction.<sup>89</sup>

#### The Costs of Stigma

Stigma imposes significant costs on society, although quantifying the direct economic cost of stigma remains a challenge. Researchers have examined productivity loss and the consumption of resources from experiencing stigma. 90 On an individual level, stigma is a significant barrier to housing, employment, income improvement, and health care. 91-94 By reducing the accessibility and quality of health care, stigma can drive avoidance or delay of health care and non-disclosure of health conditions. This can increase the severity of symptoms and result in higher rates of hospitalization, emergency room visits, and healthcare-related costs. 92, 95-97 As an example of stigma's economic impact, mental health stigma increases absenteeism and productivity loss in the workplace. 98, 99 It also discourages affected people from seeking health care and treatment, which increases costs to the healthcare system.95,99



#### **DISCUSSION GROUP QUOTE**

"I think there are actually two groups that are impacted by stigma, those groups who are negatively impacted... [and] another group that we don't think about very often, and that's the group that benefits from stigma, and benefits from the perpetuation of those mainstream ideologies that continue to maintain that settlers, people with European background, as being better."

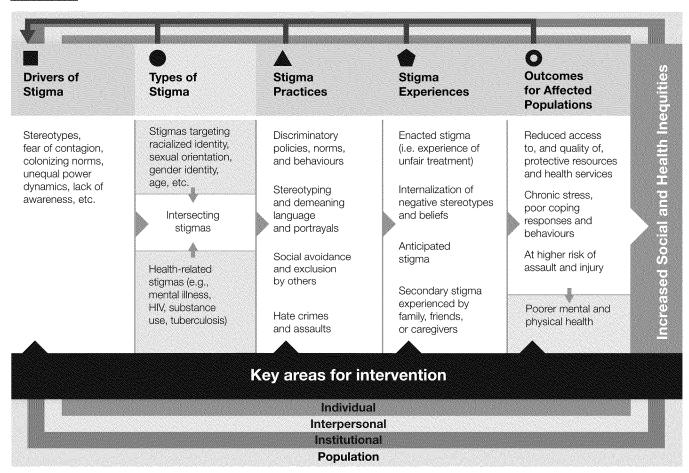
x A mental health disability refers to conditions that limit daily activities, including anxiety, depression, bipolar disorder, anorexia, and substance use disorders.

### Why a New Stigma Model is Needed

The following Stigma Pathways to Health Outcomes Model (Stigma Model) provides a new way to think about stigma and how it undermines health for individuals and contributes to population health inequities (Figure 7).xi It builds on recent efforts to understand the full impact and significance of stigma on health, including the experience of multiple and intersecting stigmas that many people experience.82, 100-102

Although stigma has been studied in social and health sciences for decades, the research is generally focused on isolated health conditions or social identities.82 This Stigma Model can be used to understand individual stigmas while also considering how different stigmas inevitably intersect to create worse outcomes for some people. The Stigma Model also offers the opportunity to understand the impact of stigma on different health outcomes simultaneously.

#### FIGURE 7: Stigma Pathways to Health Outcomes Model



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This model has been adapted from the novel Health Stigma and Discrimination Framework recently commissioned by the National Institutes of Health. 100

#### **Stigmas Intersect Differently to Affect Health**

Different types of stigma can intersect and work interactively to affect health.<sup>103</sup> Researchers use the term "intersectionality" to understand the complex connections, outcomes, and opportunities that can arise when people are subjected to multiple forms of stigma.<sup>104</sup> For example, the discrimination experienced by a racialized gay man living with HIV could produce poorer health outcomes because of the stigmas that arise from being racialized, identifying as gay, and living with HIV. Poorer outcomes might also result for an Indigenous, two-spirited person living with a mental illness. The reality is that many Canadians live with multiple stigmas. A key benefit of an intersectional approach is that it embeds an understanding of this complexity in our understanding of stigma's impact on health, and can therefore lead to a more complete and impactful response in addressing health consequences.

Importantly, the Stigma Model can be used by policy leaders, researchers, practitioners, and service providers to identify drivers of stigma and stigma practices in the health system that cut across areas of stigma. Interventions to address these broader issues are explored in Chapter Three and through the proposed Action Framework for Building an Inclusive Health System.

The Stigma Model works from left to right, but the components also influence one another. Applying the model to a particular stigma offers a way to understand how certain drivers lead to the "marking" and labelling of targeted groups. Once marked, people are then vulnerable to a variety of stigmatizing practices and discriminatory actions from other people, institutions, and society in general. Experiencing stigma can then lead to adverse health outcomes for individuals and increased inequities for populations.<sup>100</sup>

## Practical Application of the Model

To illustrate how the model can be used to explore stigma pathways in detail and identify both crosscutting and unique issues for different stigmas, seven examples are presented below (Table 1):

- 1. Racism as experienced by First Nations, Inuit, and Métis peoples
- 2. Racism as experienced by African, Caribbean, and Black Canadians
- 3. Stigmas as experienced by LGBTQ2+ people (sexual stigma and gender identity stigma)
- 4. Mental illness stigma
- 5. Substance use stigma
- 6. HIV stigma
- 7. Obesity stigma

Although the content for these examples has been drawn from the evidence, this is not a full examination of all possible pathways or the varied experiences within stigmas. Rather, the examples offer some areas for intervention across the health system. The Stigma Model can be used to further explore these stigmas as well as examine additional stigmas related to racial identities, religion, age, disability, and other characteristics or behaviours.

A detailed list of references for each stigma topic in Table 1 will be available on the 2019 CPHO annual report web page.

#### **Examples of How the Stigma Pathways to Health Outcomes Model Can be Applied** to Different Stigmas



**Drivers** of Stigma





Stigma **Practices** 



**Experiences** of Stigma



**Outcomes and Impacts** for Affected Populations

#### Racialized identities:

#### First Nations, Inuit, and Métis peoples (Racism)

Unequal racial power dynamics created by colonization and reinforced by ongoing colonialism; forced removal from traditional lands and creation of reservation system: the residential school system; historical and current disproportionate rates of apprehension by child welfare agencies (e.g., Sixties Scoop); race-based stereotypes

Other social identity stigmas (e.g., sexual stigma, gender identity stigma, ageism) and health-related stigmas (e.g., mental illness stigma, substance use stigma, HIV stigma)

Abolishing or not recognizing traditional language and culture; social avoidance and exclusion by others; hate crimes and assaults; negative media portrayals; demeaning language (e.g., racial slurs); discrimination in employment, education, criminal justice, and housing sectors creating health vulnerabilities

Health system: Discriminatory interpersonal behaviour of health professionals; Eurocentric health professional training (e.g., rejection of traditional knowledge, medicine, and healing practices)

Enacted stigma (the experience of unfair treatment): internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Overcrowded or inadequate housing; barriers to accessing post-secondary education; reduced economic resources due to employment barriers; increased risk of food insecurity; disconnection from family, community and culture: exposure to violence. particularly against Indigenous women and girls; reduced seeking, or avoidance of healthcare services and poorer quality of services received

Chronic stress leading to health harming coping strategies (e.g., smoking, alcohol and substance use)

Health outcomes: Increased risk of adverse physical health (e.g., lower life expectancy, tuberculosis) and mental health outcomes (e.g., intergenerational trauma, post-traumatic stress disorder, suicide and suicide attempts)

#### Racialized identities:

#### African, Caribbean, and Black Canadians (Racism)

Unequal racial power dynamics from slavery and colonization; forced removal from traditional lands; social, educational, residential, and occupational segregation; race-based stereotypes

Other social identity stigmas (e.g., sexual stigma, gender identity stigma, ageism) and health-related stigmas (e.g., mental illness stigma, substance use stigma, HIV stigma)

Social avoidance and exclusion by others; hate crimes and assaults; negative media portrayals; demeaning language (e.g., racial slurs); discrimination in employment, education, criminal justice, and housing sectors creating health vulnerabilities

Health system: Discriminatory interpersonal behaviour of health professionals; Eurocentric health professional training

Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Barriers to accessing postsecondary education; overcrowded or inadequate housing; reduced economic resources due to employment barriers; increased risk of food insecurity; exposure to violence; reduced seeking, or avoidance of healthcare services and poorer quality of services received

Chronic stress leading to health harming coping strategies (e.g., smoking, alcohol and substance use)

Health outcomes: Increased risk of adverse physical health (e.g., hypertension, diabetes) and mental health outcomes (e.g., intergenerational trauma, depression and anxiety)

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**Drivers** of Stigma



Intersecting **Stigmas** 



Stigma **Practices** 



**Experiences** of Stigma



**Outcomes and Impacts** for Affected Populations

#### LGBTQ2+ (sexual stigma and gender identity stigma)

Heteronormativity (expected sexual orientation is heterosexual); historical criminalization of same-sex relationships and sexual practices; societal expectation that gender identity matches biological sex at birth; gender bias that values men over women; historical medical diagnosis of alternative sexual orientation or gender identity as disordered; stereotypes based on sexual orientation

Other social identity stigmas (e.g., racism, sexual stigma, gender identity stiama. ageism) and health-related stigmas (e.g., mental illness stigma, substance use stigma, HIV stigma)

Assumptions of an individual's sexual orientation or gender identity; rejection and exclusion from family, peers, and/or community; lack of alternative gender identities on identification documents: hate crimes and assaults; negative media portrayals; demeaning language

Health system: Discriminatory interpersonal behaviour of health professionals (e.g., incorrect use of gender pronouns); insufficient training of health professionals pertaining to LGBTQ2+ health; inappropriate practices such as conversion therapy; insufficient tailored health information, resources, and services

Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Decreased social participation: concealment or denial of identity: increased risk of homelessness; reduced employment and income opportunities; exposure to violence; reduced seeking, or avoidance of healthcare services and poorer quality of services received

Chronic stress leading to health harming coping strategies (e.g., self-harm, disordered eating, smoking, alcohol and substance use)

Health outcomes: Increased risk of adverse physical health (e.g., sexually transmitted and bloodborne infections) and mental health outcomes (e.g., depression, anxiety and suicide ideation and attempts)

#### Mental illness stigma

Beliefs that mental illness is caused by "bad genes," behavioural problems, or social skills deficits; divergent perceptions and understanding about the meaning of [mental] health; beliefs that people with mental illness are dangerous; negative perceptions about prognosis of recovery

Social identity stigmas (e.g., racism, sexual stigma. gender identity stigma, ageism) and other health-related stiamas (e.g., substance use stigma, HIV stigma, obesity stigma)

Low investment in research and education; negative media portrayals; demeaning language; violence and assault; distrust and avoidance of people living with mental illness; failure to accommodate employees with mental illness

Health system: Limited training of health professionals to meet the needs of people with mental illness: using labels instead of person-first language (e.g., "schizophrenic" instead of "person living with schizophrenia"); low investment in mental health services

Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Decreased social participation; concealment of illness; limited access to and loss of work or advancement opportunities: decreased use of health and social services and poorer quality of services received

Health harming coping strategies (e.g., denial, self-isolation, substance use)

Health outcomes: Increased risks of poorer physical health, quality of life, and psychological outcomes (e.g., lower self-efficacy, selfesteem and hopeless); decreased patient safety when stigma prevents health professionals from seeking care for their own mental health problems



Intersecting Stigmas





Outcomes and Impacts for Affected Populations

#### Substance use stigmaxii

Belief that substance use is a reflection of poor willpower or moral failure, and that people are to blame for their condition; belief that people who use substances are dangerous and reckless; belief that substance use is not a real illness and people "could choose to stop"

Social identity stigmas (e.g., racism, sexual stigma, gender identity stigma, ageism) and other health-related stigmas (e.g., mental illness stigma, HIV stigma)

Negative media portrayals; social avoidance and exclusion by others; discrimination in housing (e.g., denial of applications, eviction), failure to accommodate employees with substance use disorders

Health system: Use of demeaning or inappropriate language; reduced empathy from professionals and less motivation to meet the needs of people who use substances; lack of training in harm reduction Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Decreased use of health and social services and poorer quality of services received; concealment of substance use disorder; loss of work and limited access to leadership positions; increased risk of homelessness

Health harming coping strategies (e.g., isolation, social withdrawal and avoidance, further substance use) and behaviours (e.g., needle sharing)

Health outcomes: Increased risks of poorer physical health, quality of life and psychological outcomes (e.g., lower self-efficacy, self-esteem and hopelessness); limited uptake of opioid agonist therapy; poorer outcomes for substance use disorder treatment

#### HIV stigma

Fear of infection or contagion; misinformation about transmission of HIV; incorrect assumptions about prognosis and treatment Social identity stigmas (e.g., racism, ageism) and other health-related stigmas (e.g., mental illness stigma, substance use stigma) Criminalization of nondisclosure; forced disclosure; social distancing and avoidance; negative media portrayals

Health system: Taking unnecessary precautions when interacting with people living with HIV; compartmentalized care (focus on HIV and not seeing the whole person); restrictions on blood and organ donations from gay, bisexual, and other men who have sex with men

Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Delayed or decreased use of health and social services and poorer quality of services received; concealment of HIV status; self isolation; limited access to employment

Health harming coping strategies (e.g., social withdrawal, substance use, denial, non-adherence to medications)

Health outcomes: Increased risks of poorer physical health, quality of life, and psychological outcomes (e.g., depression, loneliness, suicidal ideation); lower self-rated health

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xii The extent to which substance use is stigmatized varies by the particular substance and context of use. Much of the literature on substance use stigma focuses on substance use-related health conditions (e.g., substance use disorders) or use of substances in ways that might be harmful (e.g., drinking alcohol during pregnancy), though other contexts of substance use are also subject to stigma.



of Stigma



Stigma **Stigmas Practices** 



**Experiences** of Stigma



**Outcomes and Impacts** for Affected Populations

#### Obesity stigma

Belief that individuals are to blame for their weight due to lifestyle choices; stereotypes related to the behaviour or character of people living with obesity

Social identity stigmas (e.g., racism, sexual stigma, gender identity stigma, ageism) and other health-related stigmas (e.g., mental illness stigma, substance use stigma, HIV stigma)

Physical avoidance and exclusion by others; bullying; exclusion from the workforce; negative media portrayals

Health system: Refusal of care, or low quality of care from service providers; healthcare environment not adapted to larger bodies; lack of empathy from health professionals; use of demeaning language

Enacted stigma (the experience of unfair treatment); internalized stigma (e.g., shame and embarrassment for LGBTQ2+ people, people who use substances, and people living with HIV, mental illness or obesity); anticipated stigma; secondary stigma for family, friends, and/or caregivers

Reduced seeking of care and use of health and social services and poorer quality of services received; decreased social participation; socioeconomic consequences (lower personal income)

Health harming coping strategies (e.g., disordered eating)

Health outcomes: Higher acute and chronic stress and related physiological responses; maintenance of excess weight, poorer mental and physical health outcomes (e.g., anxiety, depression, decreased motivation for physical activity)

#### **Implicit Bias**

Implicit bias refers to attitudes and stereotypes that occur unconsciously and inform our thinking, beliefs, and behaviours about social groups. Implicit bias occurs involuntarily and beneath the level of conscious awareness.<sup>115</sup>

### Understanding Stigma Drivers and Practices in the Health System

Understanding how stigma drivers and practices manifest in everyday practices in the health system can inform the development of system-wide interventions. Below is a description of interrelated key drivers and practices that foster and sustain stigma in the health system.

#### The Language We Use

Language is a powerful tool that reflects and perpetuates biases in society. Words communicate assumptions, values, judgements, and stereotypes that create and reinforce negative portrayals of devalued groups. The way language is used in media, popular culture, health promotion initiatives, education, research, and policy shapes how people understand the world.

The use of outdated or incorrect language in the health system, such as an inaccurate pronoun or the negative labelling of a particular group,

perpetuates stigma and can influence health-care providers' perceptions of patients. 105, 106
For example, labelling people who use drugs as "addicts" or "junkies" marks them as less worthy of care and promotes fear. 107 In another example, describing the illness ahead of the person (e.g., using "schizophrenic" instead of "person living with schizophrenia") contributes to dismissive or demeaning behaviours by healthcare providers during treatment. 108 These types of labels also do not allow for other identities a person may have and suggest that everyone within that group has the same wants, needs, and challenges.

#### Implicit and Conscious Biases

Stigmatizing practices by health professionals may be a result of implicit or conscious bias.<sup>22, 106, 109</sup> Conscious bias occurs when an individual believes and reproduces negative stereotypes and myths about particular groups or individuals, resulting in discriminatory language or practices.<sup>106, 109</sup> For example, a health professional may use demeaning,



#### **DISCUSSION GROUP QUOTE**

"So in order to address that root cause of stigma, we absolutely need everybody to hold that mirror up and ask themselves that really important question, of how am I implicated in these systems and structures that discriminate, that stereotype, that hurt people. How can I be an agent of change, what can I do to arrest and disrupt those practices and policies that are so harmful to many of us?"

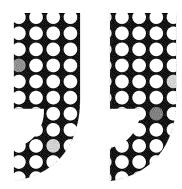
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A2021000114 Page: 928/1818 offensive, or incorrect language in reference to a patient's identity or condition, even after the patient has previously stated their preferred terminology.<sup>106</sup>

Implicit bias occurs when professionals are unaware that their actions or language is stigmatizing. <sup>22, 106</sup> Commonly held beliefs, stereotypes, and assumptions that pervade society make bias difficult to recognize. For example, many Canadians believe there are only two genders, and this assumption is widely reflected in everyday practices such as washroom signage, clothing labels, and healthcare intake forms. Assumptions are generally based on misperceptions or misinformation about certain groups, and may influence how a professional examines, treats, and assesses a patient. For example, patients with chronic pain may be denied medication on the assumption that they may be displaying "drug seeking" behaviour. <sup>110, 111</sup> Lack of training on appropriate care for health conditions or traditional cultural approaches to healing may contribute to the implicit bias of health professionals. <sup>22, 106, 112–114</sup> Although the avoidance of learning appropriate care is an example of conscious bias.

#### Lack of Respect and Understanding of People's Lives

Colonization and subsequent colonialism have been defining factors for Indigenous peoples and racialized populations. Colonialism has driven unjust attempts to erase cultural identity and practices, and has contributed to loss of language, exclusion from social and health institutions, and continued spatial segregation.<sup>22, 109, 114, 116</sup> The influence of colonialism is reflected in medical curricula that often do not incorporate or reflect the experiences of Indigenous peoples and other



#### **DISCUSSION GROUP QUOTE**

"We need to acknowledge that it [slavery] happened in Canada—if you don't ever acknowledge it, you leave us out there wondering if it even happened. You need to validate our reality."

#### The Death of Brian Sinclair

In 2009, Brian Sinclair, a 45-year old Indigenous man, died of preventable and treatable sepsis in an emergency room (ER). He was referred to the ER by a community physician for a bladder infection. Once he arrived, he did not get properly triaged and was told to wait in the waiting room. There he stayed for 34 hours before someone else let ER staff know that Brian did not seem to be breathing. The Winnipeg Regional Health Authority publicly apologized to his family for the preventable tragedy and has accepted all recommendations from a judicial inquest into this death. Recommendations include improving cultural safety for all staff at regional health authorities and recruitment of Elders for improved care in health centres. Indigenous leaders have asked the judicial inquest to seriously consider the ways in which Brian Sinclair's race, disability, and class led to his death.<sup>22</sup>

racialized populations, including diverse ways of knowing and understanding health and well-being. <sup>22, 113, 114, 118, 119</sup> The exclusion of these perspectives and ways of knowing shapes health professionals' practices and leads to culturally inappropriate treatment or care, which leads to further exclusion from health settings. <sup>106</sup>

Relatedly, healthcare providers are traditionally trained to focus on individual agency and lifestyle factors, without acknowledging the other factors that impact a person's life (e.g., the social determinants of health). Patients have reported a lack of empathy and compassion from healthcare providers, as they feel they are blamed for their circumstances while the systemic barriers that have contributed to these are ignored. 111, 122–124

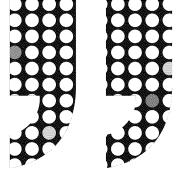
#### Fear of Danger and of Contagion

Fear is a significant driver of stigmas relating to infectious diseases. <sup>125, 126</sup> Quarantine-related policies, mandatory immigration screening, and notifiable disease frameworks can have unintended stigmatizing effects. <sup>127, 128</sup> For example, people with tuberculosis may be stigmatized due to their perceived incurable and contagious state. <sup>129</sup> In a low-disease incidence country like Canada, specific population groups such as migrants can be portrayed as a public health threat and blamed for being carriers of infectious diseases such as HIV. <sup>130, 131</sup> Fear can also drive stigmatization of other health conditions, such as mental illness, where affected people may be seen as dangerous, unpredictable, or aggressive. <sup>132</sup>

#### Stigmatizing Organizational Cultures

Organizational cultures influence whether stigmatizing practices are acceptable and how health providers interact with patients. <sup>108, 133–136</sup> The above drivers and practices can become embedded in the culture of health organizations and reinforced by clinical and non-clinical staff (e.g., administrative, management and support staff). This can manifest in stigmatizing language, making assumptions, breaching confidentiality, using unnecessary precautions, and even, in some cases, denying care or access to treatment. <sup>22, 106, 112, 113, 137</sup> For example, transgender women have been denied access to women-only services for appearing too masculine <sup>138</sup> and "flagging" files to distinguish particular medical records may also promote stigmatization. <sup>113</sup> Burnout and compassion fatigue of providers can further contribute to these practices. <sup>108</sup>

Service providers may convey power and distance through the utilization of unnecessary protection, their way of delivering diagnoses, and their reactions to diagnoses. 108, 131, 139 This may also be seen through the imposing of rules and policies that shape treatment and recovery opportunities for individuals seeking help for conditions such as mental



#### **DISCUSSION GROUP QUOTE**

"You need education throughout your career. Not one day on cultural sensitivity, or mental health sensitivity."

#### DISCUSSION GROUP QUOTE

"People often struggle with the idea that people can be different than them."

#### **DISCUSSION GROUP QUOTE**

"When you challenge [cultural norms] in your practice, you can get boxed in.... For example, when I talk about race, religion, gender, there is a defense mechanism that kicks in."

health problems, substance use disorders, and HIV infection.<sup>107, 140, 141</sup> These practices include refusing mental health care to people who use drugs or restricting treatment for recurrent drug use, and denying access to treatment because of particular sexual practices or gender nonconformity.<sup>107, 134, 138, 141–143</sup>

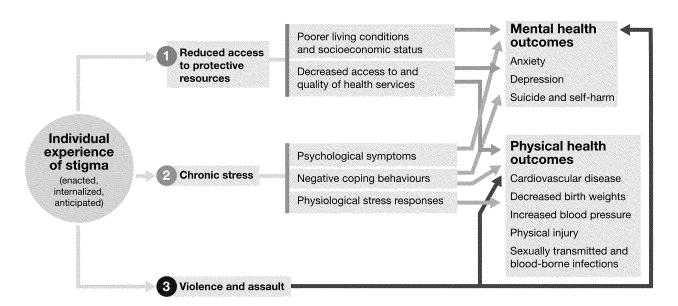
Stigma in organizational cultures may also have an impact on the health and well-being of staff. Healthcare providers may be reluctant to acknowledge or disclose their own stigmatized conditions, such as mental illness, in workplaces where stigma is persistent. This may result in self-treatment and a lack of peer support.<sup>108</sup>

#### How Stigma Leads to Adverse Health Outcomes

The following more fully unpacks how the experience of stigma leads to poorer outcomes and impacts overall health. Emerging research indicates that stigma affects health in **three key ways**:xiii

- It reduces access to and quality of protective resources and health services
- It increases the risk of chronic stress and poor coping responses
- 3 It puts stigmatized people at higher risk of assault and injury

FIGURE 8: How Stigma Affects an Individual's Health



While this is not a comprehensive list of all possible outcomes or mechanisms, it does summarize many of the proposed associations. 144

Source: Adapted from Paradies et al. 2013<sup>155</sup>

xiii These data generally comes from self-reported experiences of stigma in relation to health outcomes. Additionally, many of these studies were conducted in the US. Caution should be taken regarding the generalizability of the findings.

#### Stigma Reduces Access to and Quality of Protective Resources and Health Services

Stigma can be a barrier to accessing essential resources and opportunities in life, such as housing, jobs, education, interpersonal relationships, and health care. These barriers may be the result of direct and active exclusion through discrimination by gatekeepers (e.g., landlords, employers, teachers, and healthcare professionals) or may arise internally from one's anticipation of facing stigma and mistreatment based on previous exposure to negative environments or discriminatory practices. <sup>22, 106, 109, 111, 112, 123, 145</sup> When people are excluded from these opportunities in life, they are exposed to more health risk factors and fewer protective factors. <sup>109, 145–148</sup> Importantly, once accessed, the services may be culturally inappropriate or of poorer quality. <sup>118, 146</sup>

### Stigma Causes Chronic Stress and Poor Coping Responses and Behaviours

Stigma is a major source of psychological stress, whether it is enacted, internalized or anticipated. Because of their stigmatized status, people from stigmatized groups may experience shame, low self-worth, and blame, and are at increased risk of exposure to stressful and unfair conditions and situations. 106, 112, 152 Excessive and ongoing stress can affect the body in a negative way throughout the life course and can be particularly damaging for developing children. 153, 154 This repeated activation of stress responses can lead to an impaired immune system and interfere with the body's repair processes. It can also elevate blood pressure, heart rate, and stress hormones, which may have an effect on health over time. 120, 156, 157

#### 3 Stigma Can Expose People to Violence and Assault

Certain groups of people are feared or seen as less worthy of respect or dignity because of stigma. In combination with other social inequities, groups that are stigmatized are targets for explicit hatred and violence, including physical assault or abuse, sexual assault, bullying, harassment, and hate crimes. Verbal, physical and sexual violence against individuals or groups can occur at home, in school, in the workplace, in the community, or online. 106, 116, 149–151



#### **DISCUSSION GROUP QUOTE**

"We're kind of scared, when I say "we're" I'm speaking as a Black woman, we fear not being understood, and most times ... I find it more manageable for me to just handle it on my own, or to maybe seek out a friend or family. Where really, I should feel comfortable to go and seek help in these facilities."

#### **DISCUSSION GROUP QUOTE**

"Well I think for people it [stigma] sort of affects their self-worth, their self-confidence, even though they might be skilled, or very educated, or informed, that it creates the self-doubt in them."

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The effort required to deal with stigma reduces a person's psychological resources and resilience. It creates challenges in managing emotions and the ability to self-regulate, and an increased likelihood of having poor sleep habits, using substances, risky sexual behaviour, and unhealthy eating. 145, 158-161 These can place stigmatized people at even higher risk of acquiring further stigmatizing conditions (e.g., HIV infection, obesity). Although the outcomes may be harmful, these behaviours can be coping strategies and a way to survive challenging or even traumatizing events and experiences. 155 Through this lens, these responses can be understood as normal or expected responses to unjust and traumatic situations.

### Through These Three Avenues, Stigma Can Lead to Adverse Mental and Physical Health Outcomes

Measuring the health impacts specifically due to stigma is methodologically difficult; however, research indicates that poor mental health is often associated with many types of stigma. Adverse outcomes include anxiety, depression and depressive symptoms, post-traumatic stress disorder (PTSD), suicidal ideation and behaviours, self-harm, and low self-esteem and self-worth. 100, 146 Poor cardiovascular health has also been linked to discrimination and chronic stress, and is a major cause of morbidity and mortality. 146,188 For example, recent research has focused on examining how systemic racism can have an impact on hypertension, cardiovascular health, and diabetes. 162, 163 In other research, experiencing stigma and discrimination while pregnant has been associated with pre-term birth, low birth weight, and higher rates of infant mortality. 164, 192 Discrimination has also been associated with increased rates of diabetes, cancer, tuberculosis, increased Body Mass Index and obesity, and increased risk of sexually transmitted and blood-borne infections. 112, 125, 146, 188



#### **DISCUSSION GROUP QUOTES**

("Living while Black") "There isn't a moment when we are not calculating what does this mean, how will this be seen, how are they going to react, how am I going to react—it takes a lot of energy."

"Often I find people don't hear, listen to or see me."



#### **DISCUSSION GROUP QUOTE**

"When you kind of zoom out a little bit and realize that our social structures create situations in which people are silenced and can't get the resources they need to reach their full potential, then we see all kinds of poorer health outcomes."

#### Resisting the Impacts of Stigma

#### **Building Resilience**

Many people living with stigma resist devaluation and discrimination and build strength, resilience, and strategies to ward off stressors. 165, 166 These strategies can include invalidating the negative beliefs associated with stigma, attributing prejudices to ignorance and not to themselves, and drawing upon their identities (such as LGBTQ2+) or social roles for protection. 165, 166

Others may disclose their stigmatized status and educate others on their health condition. Disclosure can lead to having more informal and formal support. 172, 233 Although disclosure can be empowering, not everyone may feel comfortable or safe to do so. Resilience can mean choosing not to disclose in order to feel safe.167 In recent years, many people from stigmatized groups have come forward and

publicly disclosed experiences of stigma and discrimination (for example, women who experienced violence and sexual assault).

When groups mobilize, there can be psychological and social benefits, such as social support, that buffer them from some negative health consequences. 165 For example, Black Canadian women are less likely to self-report poor mental health compared to White Canadian women. 168, 169 Research from the US demonstrates that African Americans may develop resiliency strategies, such as strong family and community ties, to cope with and challenge racism and discrimination. 170 These strategies and strengths may act as buffers and help prevent mental health issues. 169, 170 Although this has not yet been researched in a Canadian setting, similar dynamics may be at play. 168, 169

#### Community Connection

Community culture and connection can play a protective role in supporting individuals who face stigma and discrimination. Among Indigenous peoples in Canada, cultural continuity has been associated with lower youth suicide rates.<sup>171</sup> Cultural continuity is measured in different ways, and can include factors such as self-government, community-level Indigenous language knowledge, and control over education, community, social or health services. As emphasized in the First Nations Mental Wellness Continuum Framework, culture - including values, sacred knowledge, language and cultural practices is the foundation of health and wellness.16



Addressing Stigma Towards a More Inclusive Health System

#### **DISCUSSION GROUP QUOTE**

"...we have to get back to finding our kindness, and our humanness, and recognizing that if we were all the same it would be a very boring place to be and that the difference is what makes us strong and what keeps us going."

36

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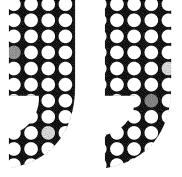
#### Collectively Changing the Health System

Populations subjected to stigma and oppression for generations have responded by engaging in collective responses and self-determination, and displaying profound group resilience. For example, despite a history of cultural genocide, assimilation, intergenerational trauma, and colonial policies, Indigenous peoples have survived and preserved their cultures and ways of being. <sup>22</sup> Learning about and incorporating traditional Indigenous health practices can build resilience and a sense of ownership over one's health. <sup>22, 173, 174</sup> First Nations, Inuit and Métis peoples in Canada have engaged in collective resistance to health system stigma by advocating for Indigenous education programs, promoting public education against negative stereotyping, and developing Indigenous-run governing health bodies and holistic approaches to health that respect and build on traditional ways of knowing. <sup>22</sup>

People living with HIV mobilized early in the AIDS epidemic to form a powerful social movement that helped to mitigate the stigma associated with HIV and AIDS and change the health system response by improving the patient-provider relationship, challenging stereotypes, and ensuring the meaningful participation of people living with HIV in research and health practices. <sup>175, 176</sup>

The call for meaningful representation has been echoed across other movements and communities, such as the disability movement that initiated the slogan "Nothing about us without us" as an act of resistance to the under-representation of people living with disabilities in research and in the media. 177 Similarly, Indigenous peoples have emphasized the importance of telling their own stories about Indigenous health and well-being, and leading the way forward through Indigenous-directed health and community services. 22

The mental health movement in Canada contributed to normalizing mental health, the deinstitutionalization of mental health services and the shift towards having mental health and social supports available in the community, which can all reduce stigmatization. TR. TR. TR. More recently, there has been a shift in approaches within the substance use movement in Canada. Utilizing a strengths-based and resilience approach instead of a risk-based perspective has led to increased availability and accessibility of harm reduction services and initiatives for reducing substance-related harms, such as supervised consumption sites, naloxone distribution and training, educational initiatives related to lower-risk substance use, and drug contamination testing.



#### **DISCUSSION GROUP QUOTE**

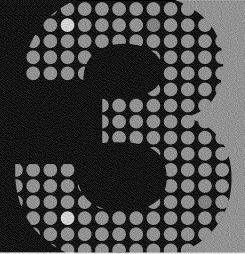
"Being Indigenous doesn't make you more prone to HIV. Living without hope does."

#### **DISCUSSION GROUP QUOTE**

"Members of communities who are affected by stigma should be involved. [They] should be leading the conversation."

#### **DISCUSSION GROUP QUOTE**

"What has happened to us, is not who we are! If you look at who we are, there in lies the solution."



#### CHAPTER 3

# Building an Inclusive Health System

The Stigma Pathways to Health Outcomes Model (Stigma Model) offers a comprehensive approach to understanding stigma and the real and measurable impact it has on physical and mental health outcomes. The Stigma Model also demonstrates that stigma is not simply an interaction between people but a process influenced by larger social, cultural, political, and economic forces.

Responding to stigma in the health system requires an equally comprehensive approach, through system-wide interventions in education, training, practice, and policy. This chapter presents a new **Action Framework for Building an Inclusive**  **Health System** (Action Framework), developed for this report. Whereas the Stigma Model helps to understand the nature and extent of the problem of stigma, the Action Framework explores where and how it can be addressed.

### The Experience of Stigma Revisited

Let's revisit Charles and Cynthia, who we met in Chapter Two. Previously, we examined the ways in which Charles and Cynthia experienced stigma in the health system and how this negatively impacted their overall health. Now, let's see how their experiences could have been different if they had been treated in inclusive environments that met their needs.

#### Charles

Charles, a Black, gay man who is living with HIV, recently moved to a mid-sized town in Ontario and believes he may have signs of heart disease. Charles books an appointment with his new doctor regarding his symptoms. At the appointment, his doctor takes the time to review his social and family history. As a routine part of getting to know each

patient, his new doctor always asks patients for their preferred name and pronoun. When Charles sees how much his new doctor prioritizes patient trust, he feels comfortable sharing that he is gay. She knows that Charles is at higher risk of heart troubles because of his age and family history, and also due to social determinants such as his racialized identity status. Charles' doctor determines that the best course of action is to refer him to a specialist at the hospital for further testing. Charles feels heard and respected by his doctor and appreciates her thoroughness. Charles is nervous about the tests with the specialist but when he arrives, he is treated with respect and dignity by the hospital staff. He also notices that the specialist and some of the other health professionals look like him. The specialist focuses on Charles' presenting symptoms and does not ask questions about his HIV status or sexual orientation when it is inappropriate to do so. Even when doing more diagnostic testing, the specialist and other health professionals do not take unnecessary precautions. The results of the tests show that Charles has early stage heart disease; however, because the disease was detected early, Charles' prognosis is good. Charles will continue to have follow-up appointments periodically with the specialist to monitor his health. Charles feels comfortable attending these appointments due to the excellent care he has received and the trust he has in his doctors.

#### Cynthia

Cynthia is a Cree woman living in Saskatchewan with her two young children. She is pregnant with her third child and has recently learned of complications with her pregnancy. Cynthia has been receiving care at a First Nations health centre in her community but needs specialist care at a large hospital. A nurse from the health centre refers her to the hospital's new Indigenous Health Program, where an Elder is available to provide guidance and cultural and spiritual support to Cynthia before, during, and after her treatments.

When it is time for her treatment, Cynthia's doctor introduces herself. She asks Cynthia about her experience and her priorities before thoroughly explaining the treatment, timelines, and next steps. Cynthia's doctor talks to Cynthia and encourages Cynthia to ask questions so they can make decisions together. The doctor began the appointment with this approach because the hospital recently implemented an institutional policy requiring and supporting all health professionals to learn and implement a cultural safety model of practice. Cynthia feels respected and the introduction eases her anxiety about the appointment. The Elder collaborates with Cynthia's healthcare team to facilitate communication and cultural understanding to create and maintain a culturally safe care plan. Cynthia continues to meet with the Elder during future treatments who also connects her to an appropriate, funded childcare facility where she can take her two children while she attends her ongoing appointments. Cynthia feels well supported by the Elder and her healthcare team at the hospital who successfully manage her pregnancy complications while providing culturally relevant care. Cynthia carries her baby to term and gives birth to a healthy baby.

# An Action Framework for Building an Inclusive Health System

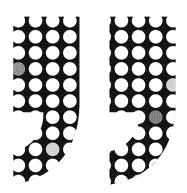
The complex and reinforcing processes that fuel stigma drivers and practices require system-wide responses. Using a public health lens, it is important to prioritize broad interventions that can have the most benefit to the greatest number of people. Population- and institution-level interventions to address stigma drivers and to prevent stigma practices are most aligned with this approach. To mitigate individual-level harms, it is also necessary to implement interventions to better support individuals who have experienced stigma.

While actions have been organized according to various levels, complementary and synergistic interventions will need to be implemented across all levels to achieve the most impact. Though much of the research in this field has explored the impact of one intervention at one level, researchers increasingly emphasize the importance of working at multiple levels to reinforce and sustain

change. 91, 100, 106, 113, 182–187 Additionally, attention to using de-stigmatizing language is important at all levels and in all interventions.

Policy leaders, researchers, practitioners, and service providers are encouraged to use the Stigma Model to understand different stigmas. The Action Framework then provides direction on developing multi-level and comprehensive approaches that respect differences across stigma experiences while offering the potential for lasting effects across stigmas (Table 2). The Action Framework can also serve as a starting point for other stigmas not summarized in this report, such as those related to age, class, and other health conditions.

An evidence summary on interventions to address stigma in the health system will be available on the 2019 CPHO annual report web page.



#### **INTERVIEW QUOTE**

"One of the things that gives me hope about addressing stigma is that first off, we're starting to realize that it needs to be addressed. That we're starting to recognize that this is one of those fundamental issues that is... that impacts everybody in society. Because if we don't name it, if we don't start to take action, if we don't start to see this as a problem, we can't move forward."

#### TABLE 2: Action Framework for Building an Inclusive Health System

• Inadequate legal protections, or lack

of enforcement of these protections

How stigma operates across levels (examples)	Interventions to address stigma across levels (examples)	Potential outcomes (examples)	
	Individual	Individual	
Level of Stigma: person who experien	nces stigma	MA (ppertunkter) popular segaranta in Anglio perunya pen teritoria ang sakero (panala segaranta pentunkter) pe	
<ul> <li>Enacted stigma (i.e., unfair treatment) (e.g., psychological stress)</li> <li>Internalized stigma (e.g., low self-esteem and feelings of shame)</li> <li>Anticipated stigma (e.g.,does not access support)</li> </ul>	Group-based supports to change stigmatizing beliefs, improve coping skills, support empowerment, and build social support	Reduction in internalized stigma     Improved psychological well-being and mental health	
	Interpersonal (person-to-person)		
Level of Stigma: family, friends, socia	I and work networks, healthcare and service	ce providers	
<ul> <li>Language (e.g., using derogatory terms or dehumanizing labels; refusing to use preferred name and/or pronoun)</li> <li>Intrusive attention and questions</li> <li>Hate crimes and assault</li> </ul>	<ul> <li>Education interventions to target myths and lack of knowledge. Include components that encourage examining personal values, biases, and beliefs</li> <li>Contact interventions, including sharing personal stories, to target stigmatizing beliefs and attitudes</li> </ul>	Better understanding of the facts about stigmatized health conditions     Increased understanding of diverse perspectives and experiences of stigma     Growing social acceptance     Reduction in stereotyping	
	Institutional		
Level of Stigma: health system organ social service organizations	izations, medical and health training school	ols, community sector organizations,	
<ul> <li>Being made to feel "less than" (e.g., having to wait longer than others to be seen; lack of empathy from staff)</li> <li>Physical environment is not inclusive (e.g., washrooms are single-sex; undersized chairs in public areas)</li> <li>Institutional policies that cause harm (e.g., unnecessary drug tests; low investment of services)</li> </ul>	Ongoing and continued training targeting conscious and implicit bias     Implementation of cultural safety and cultural humility models     Safe and inclusive physical environments     Workforce diversity initiatives     Institutional collaboration with community; policies that support and fund meaningful engagement with people with lived experience of stigma     Implement trauma- and violence-informed care models     Accountability and monitoring frameworks that include stigma reduction indicators	Institutional environment is inclusive, welcoming and diverse Organizations are able to meet the needs of all populations Reduction in stigmatizing beliefs and attitudes among staff Improved patient/client ratings of care, satisfaction and trust Patient/client outcomes improve	
Level of Stigma: mass media, policies	Population s, and law		
<ul> <li>Widely held stereotypes</li> <li>Negative portrayals in film and television (e.g., people with mental illness portrayed as violent)</li> </ul>	<ul> <li>Mass media campaigns to challenge stereotypes and prejudice</li> <li>Guidelines to reduce stigma in media reports</li> </ul>	Reduction in stigmatizing beliefs, attitudes, and intended behaviour among the public Reduction in discrimination practices	

• Addressing discrimination within existing

laws and policies

Table 2 provides a high-level summary of types of interventions that can be considered when addressing stigma in the health system, using examples rooted in evidence. The following section takes a deeper look into how these interventions have been applied in practice and how they might be expected to address stigma in and across different levels. It is noteworthy that considerable research on stigma comes from the field of mental health. This is in part due to a worldwide focus on mental health as well as leadership in Canada.

Also included in this section are examples of interventions (in text boxes) identified as promising by participants in CPHO discussion groups.

#### Individual- and Interpersonal-level Interventions

#### Strengthening Resilience

The Stigma Model emphasizes the importance of addressing stigma drivers and intervening to prevent stigma and discrimination. However, it is also necessary to support those who have experienced stigma. Reducing the impact of stigma on well-being is often the target of individual-level psychoeducation programs. These interventions are frequently in a group format with cognitive and behavioural elements, such as cognitive-behavioural therapy or acceptance and commitment therapy, and are intended to change internalized stigmatizing beliefs, improve coping skills, support empowerment, and/or build social supports. Promising results have been highlighted in systematic reviews of these approaches as a support for people living with HIV, people who use substances, and people living with mental illness, though the evidence is mixed. Paga-198 The potential for coping and community-support interventions to mitigate the impact of stigma have also been identified for LGBT communities.



#### **INTERVIEW QUOTE**

"I think that kind of dialogue is starting to occur, I would say and it is largely led by Indigenous communities and who are saying that is not appropriate to just focus on deficiencies. We need to focus on strength-based models. look at groups that are thriving and look at that as models for other groups to follow, and understand self-determination and other factors that remove stigma."

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#### Building Awareness, Changing Attitudes

Most of the stigma intervention research has focused on challenging stereotypes and prejudice held by individuals, with the goal of reducing stigma practices at an interpersonal level. This research base has generally focused on education and contact interventions to reduce stigma associated with stigmatized health conditions, but there is little research on long-term impact. Some systematic reviews suggest contact interventions are particularly effective in reducing stigma, while others suggest that education and contact interventions offer similar impacts. <sup>198, 200, 201</sup>

Education interventions use facts to target stereotypes and challenge prejudice. In contact interventions, people from groups that experience stigma share their personal stories. These connections are intended to challenge negative attitudes and behaviours, break down "us" vs. "them" categories, and highlight all the other aspects of someone's identity (e.g., mom, baseball lover, teacher). Education and contact interventions have both been associated with small-to-medium immediate effects upon self-reported stigma knowledge and/or attitudes in systematic reviews related to mental illness or HIV. 198, 201-204 These interventions have also shown promise in reducing self-reported stigma related to substance use. 190, 197



#### **DISCUSSION GROUP QUOTE**

"We [the broader health system] tend to be more and more involving, the people who are bearing the greatest burden of that form of stigma, of a particular form of stigma, we are tending to involve people in creating the solutions."

#### **Discussion Group Reflections on Addressing Stigma**

Participants highlighted the CHAMPS study (Community Champions HIV/AIDS Advocates Mobilization Project) as an example of a stigma reduction intervention that brought together community leaders and people living with HIV. CHAMPS enlisted people living with HIV and HIV-negative community leaders, including those from the faith, social justice, and media sectors to participate in a training workshop. As part of the workshops, participants engaged in reflection and experiential learning activities to become more aware of their own biases and responses to stigma and to develop strategies to address stigma. Results indicated that the training changed attitudes as well as behaviours over the course of several months in both people living with HIV and community leaders.<sup>205</sup>

#### Institutional-level Interventions

Stigma drivers and practices also exist at institutional and population levels, where stigma is embedded and sustained. The organization as a whole is an important target of change. 108, 206-210 This includes organizational-level interventions, such as creating inclusive physical environments, building workforce diversity, and policy and practice changes. This shifts the focus and responsibility for healthcare interactions from individuals to include the broader factors that shape these interactions. 22, 208, 210 Relatedly, multi-level interventions are also included in this section, to highlight important advances in the health field regarding anti-stigma and equity-oriented initiatives.

While institutions are at the core of this section, other interventions are included that target health providers at individual or interpersonal levels. These interventions are designed and delivered in the context of the participants' roles in health systems, and best implemented alongside other efforts across healthcare institutions. A whole-organization approach also emphasizes the bidirectional influence between individuals and institutions.

#### Addressing Bias in Health Practice

To improve practice and more adequately meet the needs of all patients, it is important to understand and address both implicit and conscious stigma beliefs and practices. There is a growing awareness of the nature and potential impact of implicit bias on health inequalities. 211-213 Common approaches targeting implicit bias among health providers include efforts to reduce implicit associations or to control how they influence judgement and behaviour.213 This kind of selfreflection can include perspective-taking (consciously assessing an interaction from a patient's perspective) and individuation (consciously focusing on specific information about an individual rather than assumptions based on social identity), 211-213 Though the field is still emerging, there are some promising findings. 212, 213 Addressing implicit bias has also been identified as being important to reduce stigma and discrimination for Indigenous peoples in Canada, people experiencing mental illness, LGBTQ2+ populations, and people who use substances. 22, 197, 214, 215



#### **DISCUSSION GROUP QUOTE**

"So many systems think our families are broken and they don't know what we need. People know what they need but we just don't listen to them." Education, contact and skill-building interventions for healthcare providers are the most common approaches targeting conscious stigma in health facilities related to HIV, mental illness, and/or substance use. 113 Many interventions include multiple approaches; contact and knowledge-building are the most common. In a recent systematic review, several anti-stigma initiatives were identified as having promising results, but methodological variations made it difficult to compare across fields or draw firm conclusions about effectiveness. 113

Narrative reviews focused on mental health, and extending farther back than five years, suggested more success. Though the research base is small, contact and education interventions showed promise in reducing self-reported stigma among health providers, specifically short-term improvements in knowledge and behaviour. 198, 204

# Mental Health Commission of Canada's Opening Minds Initiative (MHCC)

The "Understanding Stigma" workshop was developed to address mental illness stigma among healthcare professionals using social contact alongside educational and action-oriented components. <sup>216</sup> A meta-analysis of six replications of the program had encouraging results. The workshop was associated with self-reported changes in attitudes and intended behaviour. <sup>216</sup>

MHCC also supported the evaluation of a number of anti-stigma interventions across the country. This research identified a number of key program elements to address mental health stigma for health-care providers (see below), with multiple forms of social contact and an emphasis on recovery identified as most important for effective programs.<sup>217</sup>

#### Key program elements of "Opening Minds"

- 1. Social contact in the form of a personal testimony from a trained speaker who has experienced mental illness
- Multiple forms or points of social contact, where people with lived experience can be seen as educators rather than patients
- 3. Focus on behaviour change by teaching skills that help healthcare providers know what to say and do
- 4. Engage in myth-busting
- 5. Enthusiastic facilitator or instructor who models a person-centred approach
- 6. Emphasize and demonstrate recovery as a key part of messaging, including the important role of health providers in this process



#### **INTERVIEW QUOTE**

"What we have found is that education programs that share stories... We call it contact-based education or social contact. People hearing from individuals with lived experiences of mental health problems and mental illness who talk about their stories share what it was like when they had a mental illness, but talk about the importance of getting treatment and how their lives have changed dramatically once they got that help that was needed."

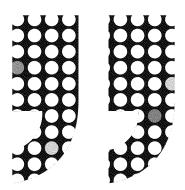
Educational curricula and training also have potential to build knowledge and change attitudes among health providers related to LGBT populations and their health.<sup>218</sup> While the stigma experienced by patients who are transgender has had limited focus in research, contact interventions have been identified as an approach that may address provider bias.<sup>106</sup>

As previously noted, addressing stigma in health systems requires concurrent efforts across health institutions. Research has identified emerging practices but there are no conclusions about effectiveness. Approaches to changing policy and practice include: targeting all levels of clinical, non-clinical and management staff including trainees; changing physical aspects of the environment; tailoring approach to organizational context and culture; and targeting multiple levels concurrently. 108, 113, 219, 220 For organizations providing services to people who experience stigma related to their health conditions, this can also involve changing what "success" looks like. For example, research in Canada explored varying ideas about success among health and social service providers who work with women who are pregnant and using substances; service providers suggested that success for clients could include having their self-defined needs met, experiencing stability and self-respect, recognizing strength and resilience, and healing in their own time.221

#### Cultural Competence to Cultural Safety

The field of cultural competency offers another approach to address stigma in healthcare institutions. Broadly, cultural competency interventions involve developing awareness, knowledge and attitudes among health providers to help them work more effectively in cross-cultural situations. This has generally been a focus for stigma and discrimination related to social identities, such as racialized and Indigenous populations, but the language and overall lens has broadened to include other groups such as LGBT populations. 106, 210, 218

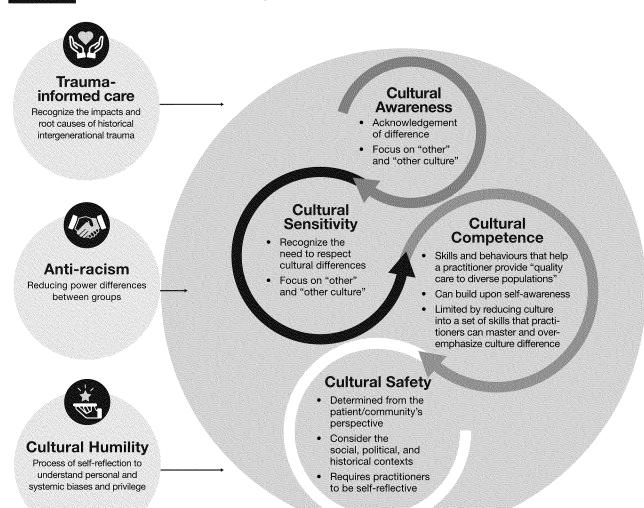
This is an evolving field. Previous approaches focused on teaching healthcare providers about the needs and experiences of particular racial or cultural groups, and these were criticized for oversimplifying and stereotyping "culture" and ignoring diversity within.<sup>222</sup> While training for healthcare providers remains the most common approach to building cultural competence in health systems for Indigenous peoples and racialized populations the scope has expanded to include a focus on institutional change. 206, 207, 210, 222 This includes culturally specific programs for patients, patient navigators, and workforce diversity. 206, 207, 219 In systematic reviews, some initiatives were associated with improvements in self-reported provider knowledge or attitudes as well as patient-reported health care access, and/or patient satisfaction. 206, 207, 222 However, results were mixed and the quality of research was low.<sup>210, 222</sup> There was no or weak evidence for impact on patient outcomes.<sup>210, 222</sup>



#### **DISCUSSION GROUP QUOTE**

"Health systems should look like the people who come to visit them."

#### FIGURE 9: Continuum of Cultural Safety\*



Adapted from NCCIH and BC First Nations Health Authority by the CPHO Health Professional Forum.

In response to critiques and alongside a growing focus on addressing racial health inequalities, factors such as trust/mistrust, bias, power, privilege, discrimination, and critical reflection have become a focus within "cultural competence". <sup>222</sup> Many different individual, interpersonal- and institutional-level initiatives are now considered "cultural competence" interventions, though there is considerable variation in approach and level of intervention.

Approaches focused on "cultural safety" have emerged in response to the limitations of previous practices. Cultural safety moves away from a focus on differences in culture to a view of the health system environment as a site for change (Figure 9).<sup>208</sup> As a model of health care created by Indigenous nurse educators in New Zealand, cultural safety was designed in response to the health implications of colonialism, and looks at power dynamics in health systems.<sup>22, 223</sup> It is intended to create spaces where everyone feels respected and physically, emotionally, socially, and spiritually safe.

While evidence is still emerging, research in Canada has identified a number of key components in cultural safety interventions. This includes provider self-reflection, addressing bias and discrimination, building relationships with patients, sharing power, validating a patient's way of knowing, and meaningful training for healthcare providers. <sup>22, 208, 223, 224</sup> Aspects of this are embedded in "cultural humility" which is an important related concept to be used by healthcare providers to enable cultural safety. <sup>225</sup> It is a process of self-reflection, to understand bias and build respectful approaches and relationships rooted in mutual trust. <sup>225</sup> Cultural humility involves an awareness of oneself as a learner in relation to understanding someone else's experiences. <sup>225</sup>

Institutional-level cultural safety interventions include building partnerships with communities, creating safe and welcoming physical spaces reflective of the populations they serve (e.g., signage in Indigenous languages, sacred spaces in hospitals), institutional commitments to cultural safety, and hiring and supporting Indigenous healthcare providers.<sup>22, 208, 223, 224</sup> Healthcare organizations can also change internal policies to support cultural safety, such as creating flexibility in appointment scheduling to increase responsiveness, while building trusting relationships.<sup>208</sup>

In addition to Indigenous peoples, cultural safety has the potential to support other groups facing discrimination. In particular, cultural safety has been identified as relevant for transgender populations and racialized populations. 109, 174, 227



#### **DISCUSSIONS GROUP QUOTES**

"...Holistic care is crucial, it is not a tick box, and you need to understand the whole person and the lived experience."

"What we do at the [interpersonal level] helps alleviate the individual stigma, but only if the structural [systemic] stigma is positively changed."

#### Discussion Group Reflections on Addressing Stigma

In response to British
Columbia's Transformative
Change Accord First
Nations Health Plan,
devolving First Nations
health services in the province of British Columbia
back to First Nations, the
San'yas Indigenous Cultural
Safety Training Program
was created and delivered
across all British Columbia
Health Authorities.<sup>226</sup>

#### **Cultural Safety Declarations**

On April 23, 2019, the Public Health Agency of Canada, along with Health Canada and Indigenous Services Canada, signed the Declaration of Commitment to Advance Cultural Safety and Humility in Health and Wellness Services and Organizations with the British Columbia First Nations Health Authority. The declaration reflects a shared commitment to creating an environment where Indigenous peoples feel safe in accessing the Canadian health system. The overarching goal is to identify opportunities to reduce the systemic barriers and harms that Indigenous peoples experience, raise awareness about existing systemic discrimination, and address inequities in outcomes for Indigenous peoples. Cultural humility requires self-reflection to understand biases, address power imbalances and develop respectful processes where people feel safe to access health systems. The Declaration addresses the Calls to Action numbers 23 and 57 put forth by the Truth and Reconciliation Commission of Canada that calls upon all levels of government to ensure that healthcare professionals and public servants are educated on the history of Indigenous peoples.



#### **DISCUSSION GROUP QUOTE**

"We need to bring humanness into this. More faces to narratives. There needs to be champions at the moment and leaders, but we do not want to tokenize either. We need to all want it."

#### Trauma- and Violence-informed Care

Stigma practices can include and are exacerbated by interpersonal and structural violence. Trauma- and violence-informed care has emerged in recognition of the many forms of trauma and the potential for sustained impacts of trauma. 230 This approach shifts thinking from "What is wrong with you?" to considering "What happened to you?". This supports an exploration of how trauma influences well-being and its potential impact on behaviour.<sup>231</sup> This approach is not intended to provide specialized therapeutic support to address trauma but rather to reduce the potential for harm and retraumatization. This includes attention to a variety of potentially traumatizing experiences in health care, including being in a physically vulnerable position during an exam, or loud waiting rooms. It also includes a recognition of the emotional intensity of disclosing trauma and the importance of asking about trauma in a sensitive, respectful, and appropriate manner. 231

The four principles of trauma- and violence-informed care are:232

- building awareness among health providers about trauma, violence and its impacts on people's lives and behaviour,
- 2 creating emotionally and physically safe and welcoming environments for everyone, including using non-stigmatizing language,
- fostering opportunities for choice, collaboration and connection, and
- using a strengths-based and capacity-building approach to support people.

#### Institutional Accountability

The broader policy environment can influence the success of institutional initiatives. For example, there is little focus within current accountability frameworks related to stigma reduction, which makes it hard to track existing activity or impacts, and means there is little structure or incentive to support new or ongoing efforts.<sup>235</sup> The potential of this approach has been identified in systematic reviews of organizational cultural competency initiatives.<sup>219</sup> While research is too limited and varied to support firm conclusions, audit and quality improvement activities have been found to provide a structure to identify and drive action on aspects of culturally competent healthcare for Indigenous peoples.<sup>219</sup>

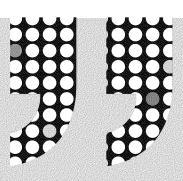
Accountability frameworks that focus on stigma reduction could be supported by monitoring the accessibility, quality and/or relevance of health services. This could include breaking down quality improvement data to explore the different experiences of groups most likely to experience stigma, which would require meaningful and respectful collection of patient demographic data.<sup>236–238</sup>

#### **Discussion Group Reflections on Addressing Stigma**

The Truth and Reconciliation Commission's (TRC) Calls to Action offer a path forward, to address racism experienced by Indigenous peoples in the health system and beyond. Discussion Group participants shared examples of a local and provincial initiative aiming to respond to the 94 Calls to Action:

Following the release of the TRC's Calls to Action, Saskatoon Health Region (now part of the Saskatchewan Health Authority) developed a framework for action and accountability across the health system. This framework refers to the Calls to Action numbers 18-24 surrounding health. For instance, Call to Action number 23 asks all levels of government to increase the number of First Nations, Inuit, and Métis professionals working in the healthcare field, ensure the retention of First Nations, Inuit, and Métis healthcare providers in Indigenous communities, and provide cultural competency training for all healthcare professionals. The TRC Engagement Framework outlines action at multiple levels where staff can respond to the Calls to Action in ways that "draw connections between everyday work as practitioners and systemic change in our community and beyond."228 This framework offers opportunities and examples on actions that empower staff to respond to the Calls to Action within the health system at the partnership, organizational, departmental and practitioner levels.

To respond to Call to Action number 22, regarding inclusion of Elders as a strategy to improve care of Indigenous patients, a primary care clinic in Vancouver's downtown east side engaged Indigenous Elders to provide cultural mentorship to patients through one-on-one sessions, group cultural teaching circles, and land-based ceremony. Of the 37 patients who participated in a follow-up interview, all but one participant described a benefit from their work with Elders.<sup>229</sup>



#### **DISCUSSION GROUP QUOTE**

"People just love the Elders being involved in health care with them. Then we also involved the Elders in the community, in advisory committees, in all our meetings. We would bring together quarterly meetings and have everybody's input, about the direction we're going in, so people really felt welcomed, wanted, felt heard, had their voices heard."

#### **EQUIP: A Canadian Health Equity Intervention**

One promising Canadian example of a theoretically-informed and empirically-tested health equity intervention that addresses stigma drivers and practices is <u>EQUIP Health Care</u>. EQUIP is a multi-level intervention that combines a focus on cultural safety, trauma- and violence-informed care, and harm reduction as key dimensions of Equity-Oriented Health Care (EOHC) that must be contextually tailored to the setting, community and diverse populations served. EQUIP involves staff education and focuses on changing practice, as well as the development and implementation of an organization-wide action plan for change.

In four Canadian primary health clinics, the EQUIP model was associated with an increase in self-reported awareness and confidence related to equity-oriented health care among staff.<sup>209</sup> It was also associated with organizational strategies to address racism at multiple levels, improving the physical space of waiting rooms, and organizational policy and practice changes to support harm reduction.<sup>209</sup> Longitudinal research completed with EQUIP clinic patients suggests that when patients received EOHC, they felt greater comfort and confidence in the care they received and, subsequently, greater confidence in their ability to manage and prevent health problems.<sup>234</sup> This increase in confidence predicted patient-reported improvements in depressive symptoms, PTSD symptoms, chronic pain, and quality of life.<sup>234</sup>

EQUIP is now being tested in three diverse emergency departments and is integrating the concept of Front-line Ownership, in which direct service providers identify priorities and lead changes towards destignatizing practices and EOHC.

#### Population-level Interventions

At the population level, interventions address stigma drivers and practices by targeting social norms as well as public policy. Interventions at this level cut across multiple systems, and can powerfully influence stigma within and beyond the health system.

#### **Changing Social Norms**

Population-level campaigns challenge stereotypes and prejudice using education and contact models similar to individual- and interpersonal-level interventions. Evaluation activities have generally focused on mass media campaigns targeting mental health stigma, including *Time to Change* (England) and *Beyond Blue* (Australia). There is evidence for small to moderate short-term positive impacts of population-level mass media campaigns to influence stigma, with all research from narrative reviews in the field of mental health. 189, 198 Alongside local initiatives, *Time to Change* targeted the general population through national mass media and social marketing activity, with a focus on education, reducing prejudice and changing behaviour. 189

There was an improvement in self-reported knowledge, attitudes, and intended behaviour at the population-level, as well as a reduction in discrimination reported by mental health service users. 189, 198, 239

Australia's *Beyond Blue* used population-level mass media activities, among others, to target public knowledge, beliefs, and skills related to mental health. 198

The campaign was associated with positive changes in self-reported public attitudes. 198

Stigma is also impacted by media representations, which can influence stigma drivers like fear and prejudicial attitudes. <sup>240</sup> In mental health, mediabased anti-stigma interventions include media coverage monitoring after national or local antistigma initiatives or the release of mental health reporting guidelines, as well as education for journalists or journalism students. There is little research on the effectiveness of these interventions, and findings are mixed, but the most promising approaches include contact-based educational interventions and guidelines developed and shared by authoritative institutions. <sup>240</sup>

# **Discussion Group Reflections on Addressing Stigma**

Participants discussed interventions that promoted empowerment through the arts. For example, documentaries such as "Take Me to the Prom" detail experiences of LGBTQ2+ people going to their high school proms decades after leaving high school.<sup>241</sup> Arts-based interventions can improve representation in the media and have the potential to change social norms.

#### Rights and Protections for All Canadians

Laws and policies can prevent and provide protections against discriminatory behaviour, while also signalling that stigma and prejudice are unacceptable. 183, 242 In Canada, this includes the Canada Human Rights Act and the Canadian Charter of Rights and Freedoms. Population-level policy interventions targeting stigma drivers and practices have the greatest potential for widespread impact. 106, 191, 242 This is evident in research exploring the relationship between policies and health inequalities.

An important example in Canada is the extensive research identifying associations between residential school attendance among Indigenous peoples and a wide variety of mental and physical health inequalities for former residential school attendees as well as subsequent generations. Residential schools attempted to erase the language, cultural practices and beliefs of Indigenous children, and many children also experienced physical, sexual, and/or emotional abuse. Residential schooling has been linked to poorer physical health, including increased rates of chronic and infectious diseases, as well as mental distress, depression, substance use, stress, and suicidal behaviour.

Much of the other population-level research on the link between stigmatizing policies and population health outcomes comes from the United States. Jim Crow laws—state and local laws that, until 1964, had legalized racial segregation—have been associated with health inequalities in breast cancer, infant death and premature mortality among Black Americans. <sup>244–246</sup> In another example, passing state-level laws permitting denial of services to same-sex couples was associated with an increase in the proportion of sexual minority adults reporting mental distress. <sup>247</sup> Conversely, laws that extend equal rights are linked to increased well-being. In a longitudinal study of bisexual and lesbian women in Chicago, civil union legislation was associated with lower levels of stigma consciousness, perceived discrimination, and depressive symptoms. <sup>248</sup>



#### **DISCUSSION GROUP QUOTE**

« Il faut aller au-delà des systèmes existants. [On a] besoin d'une sensibilisation et ... [un] message fort de société...Les autres personnes non-minorité doivent être influencé par la réalité – le prochain combat, c'est celui-là qui faut absolument traiter. »

"It is necessary to go beyond existing systems. [We] need awareness and... [a] strong social message... Other non-minority people must be influenced by reality—the next battle is the one that must be dealt with." There is limited research evaluating the impact of population-level policy initiatives related to stigma on health inequalities in the Canadian context. However, existing laws, such as the criminalization of HIV non-disclosure and personal drug use, have been identified for their role in furthering stigma. <sup>249–253</sup> Discrimination has also been codified into legislation such as the *Indian Act*. Passed nearly 150 years ago, this law continues to govern and restrict key spheres of life, such as land, identity, self-governance, and economic activity for First Nations. <sup>22, 254–256</sup> This occurs alongside inadequate resources for Indigenous education, housing and health and social services. <sup>22, 116</sup>

There is a recent example of how evidence has informed new policies to reduce stigma. In December 2018, Canada was the first country to sign on to the global U=U (Undectable is Untransmittable) Campaign. This campaign is based on evidence demonstrating that, when an individual is being effectively treated for HIV and maintains a suppressed viral load, there is effectively no risk of sexual transmission. Stigma remains one of the greatest barriers for Canadians in accessing HIV prevention, testing, treatment and support, and this shift has important implications for reducing HIV stigma. In response, Justice Canada announced it would issue a new directive related to the prosecution of HIV non-disclosure, based on the scientific evidence reviewed by the Public Health Agency of Canada.257

## Principles to Guide Anti-stigma Interventions

Despite an increase in anti-stigma intervention research, it is still difficult to know "what works", in what context, to address stigma and discrimination. This is a common challenge in intervention research. Time and/or resources are often inadequate to rigorously design, implement, and evaluate interventions (see text box). This process is even more complicated for population-level interventions. This has led to an uneven distribution of research across levels and a mismatch between the focus of most

intervention research (individual or interpersonal levels) and the levels where the greatest impact is possible (institutional or population levels).

A better understanding of what works also requires the greater inclusion of diverse voices and ways of knowing. While the responsibility for change rests in the hands of decision-makers and system leaders, it is communities themselves who have a long history of strength and leadership in the face of stigma and discrimination. The foundation of our efforts to address stigma and discrimination comes from the community, including people with lived experience and community-based organizations. Communities experiencing stigma have supported each other to build solidarity and challenge stigma drivers and practices, in order to mitigate the impacts of stigma experiences among individuals, families and communities.<sup>22, 258, 259</sup>

## Expanding Our View of Evidence

Colonialism and racism have influenced which knowledge systems are valued and which are not. This has resulted in the dominance of western biomedical knowledge, and devaluation of Indigenous knowledge systems or "ways of knowing".<sup>22</sup> It is important that our collective efforts are informed by Indigenous ways of knowing, as well as the experiential knowledge of people with lived experience of stigma. For this report, this knowledge comes from Indigenous and racialized scholars, as well as our discussion groups.

The Action Framework is a starting point that identifies promising interventions based on our knowledge to date. Our efforts to develop, adapt, implement, and evaluate anti-stigma interventions can create meaningful change now while also advancing this field into the future. Several principles were identified through the evidence review that, alongside key tenets in public health, can provide useful guidance for our next steps.

#### **Core Principles for Developing Anti-stigma Interventions**

- 1. Driven by collaboration between health system leaders and people with lived experience of stigma
- 2. Designed based on research evidence, diverse ways of knowing, and experiential knowledge
- 3. Multi-level, with particular attention to multi-level initiatives that prioritize institutional- and/or population-level interventions to address systemic stigma and discrimination in health systems
- 4. Guided by approaches such as cultural safety and trauma- and violence-informed practice
- 5. Attends to intersectionality, including the strengths, resources, and solidarity within communities who experience stigma
- 6. Grounded in principles of intervention research and implementation science, to advance knowledge in the field

FIGURE 10: What Does a Stigma-free Health System Look Like?xv

# commitment to improvement to improvement to improvement to improvement to improve trauma-informed prevention people-first language navigable navigable indultive pediality in provided in the provided interest in the provided in th

xv These ideas came from two discussion groups. Participants were asked what a stigma-free health system would look like to them.

## **Way Forward**

While stigma is shaped and kept in place by larger social and economic forces, including historical policies and practices, the health system can be a powerful leading sector to support change in Canada. If we use our full capacity at all levels across the health sector, we can influence change on a broader scale.

Those who work in health set out to help others live a healthy life and get quality care if they are sick, so critiquing our health system and examining our personal biases is difficult at both emotional and cognitive levels. However, for us to move forward, we have to acknowledge unacceptable policies and practices that perpetuate power dynamics and withhold resources from those who may need them the most.

To create a more inclusive health system, it takes brave leadership and sustained commitment to change the status quo through multiple actions, at multiple levels. It requires a more proactive approach to address common and distinctive barriers experienced by stigmatized individuals as they try to access health resources.

We each have a role in this.









#### As **HEALTH SYSTEM LEADERS**.

we need to ensure that health policies protect and support people who face stigma, and dismantle policies that discriminate and exclude them from receiving health services.

We can deliver high-quality services to all of our patients and clients in safe, respectful, and welcoming environments. This requires implementation of a range of complimentary actions including:

 cultural safety policies and practices that equip staff to provide sensitive and appropriate programs and services;

- trauma- and violence-informed approaches that ensure health professionals use non-stigmatizing language and understand trauma as a risk to achieving optimal health; and
- support and fund the collaboration and meaningful engagement with people who have living experience of stigma in developing health policies and programs.

Health education institutions and professional associations must work with partners, including stigmatized persons, to guide the transformation of practices, curricula, and professional competencies of health providers to ensure that stigma in our health system is no longer perpetuated.

It is crucial that we measure and monitor the progress of our actions. This is a key component of institutional change and necessary if we are going to make a difference. We can systematically stratify our data by groups that are most likely to be stigmatized and critically reflect on the results. Regular monitoring and setting goals and targets for the institution, staff, and patient improvement can lead to lasting, improved health outcomes and quality of care.



As **RESEARCHERS**, understanding health inequities is an important goal of our work. To do this, we must address the fundamental and unacceptable gaps in our national data-we do not have good dis-

aggregated data on the health status of diverse populations or their experiences of stigma. For example, we are not able to consistently report on life expectancy for people who identify as LGBTQ2+, those who are marginally housed, people who use substances, and other diverse populations. We must also facilitate collaborative research across health, social, and behavioural sciences that helps us look at the impact of multiple stigmas. Priority must be placed on strengthening intervention and implementation research so that we can determine what works for those experiencing stigma related to health conditions and social identities.



As INDIVIDUALS, we bring our worldviews and personal histories to our work. We have biases and we are vulnerable to the use of stigmatizing language.

What can you do about yours?

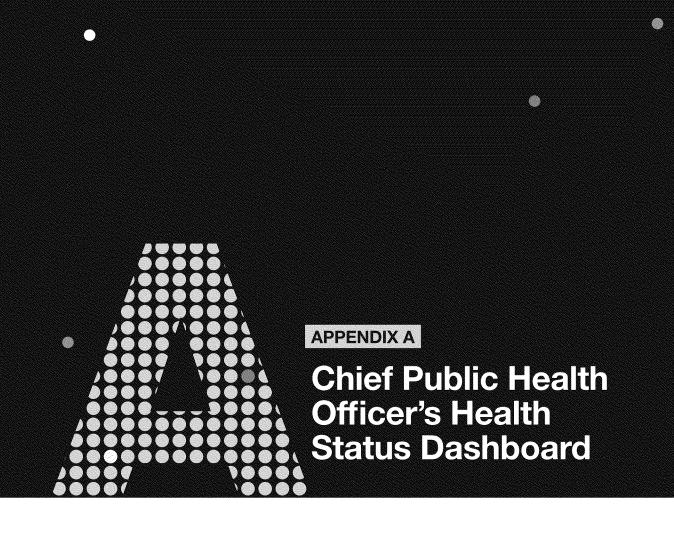
- 1. Work on your thought processes and challenge your filters. Stop using dehumanizing language. Biases can be unlearned. Identify and challenge negative stereotypes or myths in the media, and self-monitor your own thoughts.
- 2. Bring this awareness to your organization. Critically examine your organizational culture and make changes to any discriminatory policies or exclusionary practices. Implement the Action Framework described in this report within your organization.
- 3. Commit to ongoing learning. Acknowledging, understanding, and challenging your own biases and systemic stigma is a life-long commitment. Continue to challenge yourself and your organization, and look for ways to improve.

In Canada, we have deep and well-rooted values of respect, diversity, and inclusivity. This positions us to continue strengthening these foundations and promote optimal health for all.

Ending stigma and building an inclusive health system is an important legacy we can leave our future generations.

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### **Dashboard Overview**

The dashboard uses a diverse set of health indicators to provide a snapshot of the overall health of Canadians. Indicators are grouped in three broad categories: general health status (Table A), factors influencing health (Table B) and health outcomes (Table C). The dashboard is reviewed annually to ensure that most recent indicator results are included. Previous dashboard version results are used in cases where no updates are available. <sup>260</sup> Indicator results per sex are provided, as available. High-level trend analysis results

report positive ("better"), negative ("worse") or neutral ("similar") data trends over time. In a few cases, a trend conclusion may not be available ("N/A") due to data or methodological limitations. International benchmarking results compare Canada relative to similar high-income countries, such as the Organisation for Economic Cooperation and Development (OECD) member average. Possible results are "better" or "worse" than benchmark and "N/A" in the event that no comparable international indicator was identified.

#### TABLE A: General Health Status

Topic	Indicator	Result	Res		Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Life expectancy at birth	Overall life expectancy in years	82	F 84	M 80	2015–2017	Vital Statistics	Better	Similar <sup>i</sup>
Health adjusted life expectancy (HALE) at birth	Overall HALE in years	70	F 71	M 69	2010–2012	Multiple sources <sup>ii</sup>	Better	Better <sup>iii</sup>
Perceived health	% of population aged 12 years and older reporting "very good" or "excellent" health	61	F 60	M 61	2018	Canadian Community Health Survey	Similar	Better <sup>iv,v</sup>
Perceived mental health	% of population aged 12 years and older reporting "very good" or "excellent" mental health	69	F 66	M 71	2018	Canadian Community Health Survey	Worse	N/A

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i Organization for Economic Cooperation and Development, Health at a Glance 2017.

ii Statistics Canada, Canadian Vital Statistics, Birth and death databases and population estimates; Canadian Community Health Survey; National Population Health Survey, Health institutions component; Residential Care Facilities Survey; Canadian Health Measures Survey; Census of population.

iii World Health Organization, World Health Statistics 2018.

iv Organization for Economic Cooperation and Development, Society at a Glance 2016.

v Compared to most other countries, Canada had a different set of survey question response categories, creating a positive bias for this estimate.

#### **Factors Influencing Health** TABLE B:

Topic	Indicator	Result	Result by sex	Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Social factors							co decemb
Community belonging	% of population aged 12 years and older reporting a "somewhat strong" or "very strong" sense of belonging to local community	68	F M 70 67	2018	Canadian Community Health Survey	Similar	N/A
Poverty (Canada's Official Poverty Line)	% of population living below Canada's official poverty line, based on the Market Basket Measure	10	F M 10 9	2017	Canadian Income Survey	Better	N/A
Childhood poverty (Canada's Official Poverty Line)	% of children living below Canada's official poverty line, based on the Market Basket Measure	9	F M 9 9	2017	Canadian Income Survey	Better	N/A
Education	% of population aged 25 years and older with- out a certificate, diploma or degree	13	F M 13 14	2018	Labour Force Survey	Better	Bettervi
Core housing need	% of house- holds in core housing need <sup>vii</sup>	13	N/A	2016	Census	Similar	N/A
Food insecurity	% of house- holds that are food insecure (moderate or severe) <sup>viii</sup>	8	F M 10 7	2018	Canadian Community Health Survey	Similar	N/A

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Organization for Economic Cooperation and Development, Education at a Glance 2018.

A household in core housing need is one whose dwelling is considered unsuitable, inadequate or unaffordable and whose income levels are such that they could not afford alternative suitable and adequate housing in their community.

Moderately food insecure: indication of compromise in quality and/or quantity of food consumed; severely food insecure: indication of reduced food intake and disrupted eating patterns.

Topic	Indicator	Result	Result by sex	Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Substance L	lse						The second secon
Smoking	% of population aged 15 years and older who report being a current daily or occasional smoker (cigarettes only)	15	F M 13 17	2017	Canadian Tobacco, Alcohol and Drugs Survey	Similar	Betteri
Cannabis	% of population aged 15 years and older who report daily or almost daily cannabis use in past 3 months	3	F M 3 4	2017	Canadian Tobacco, Alcohol and Drugs Survey	Similar <sup>ix</sup>	Worse <sup>x</sup>
Alcohol	% of population aged 12 years and older who report heavy drinking <sup>xl</sup>	19	F M 15 24	2018	Canadian Community Health Survey	Similar	Similari
Opioids	Rate of apparent opioid-related deaths per 100,000	12	N/A	2018	Opioid surveillance	Worse	N/A
	Rate of hospitalizations due to opioid poisonings per 100,000	17	F M 15 18	2017	Hospital Morbidity Database	Worse	N/A

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ix Limited number of available data points—interpret with caution.

x World Health Organization, Cannabis use lifetime.

xi Heavy drinking: males having five or more drinks, or women having four or more drinks, on one occasion, at least once a month in the past year.

Topic	Indicator	Result	Result by sex				Data source	Trend over time (up to 15 years)	International benchmark
Childhood risk	and behavioural	factors						The second secon	
Bullying	% of grade 6–10 students who were victims of bully- ing more than once or twice in the past two months	28	F 29	M 27	2018	Health Behaviour in School-aged Children	Similar	Similar <sup>xii</sup>	
Physical activity	% of children and youth (aged 5 to 17 years) that accumulate an average of at least 60 min- utes of moderate- to-vigorous physical activity per day	39	F 26	M 52	2016–2017	Canadian Health Measures Survey	Similar	N/A	
Sedentary behaviour	% of children and youth (aged 5 to 17 years) who report meeting seden- tary behaviour recommenda- tionsxiii	54	N	'A	2016–2017	Canadian Health Measures Survey	N/A	N/A	
Overweight and obesity	% of population aged 5 to 17 years classified as overweight by WHO definition	18	F 21	M 16	2016–2017	Canadian Health Measures Survey	Similar	Similar <sup>i,xiv</sup>	
	% of population aged 5 to 17 years classified as obese by WHO definition	11	F 9	M 12	2016–2017	Canadian Health Measures Survey	Similar	Similar <sup>i, xiv</sup>	
Child abuse	% of population aged 15 years and over who experienced any of three types of child abuse <sup>xv</sup> before age 15	34	F 32	M 37	2014	General Social Survey	N/A	N/A	

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Organization for Economic Cooperation and Development, PISA 2015 Results (Volume III). χii

Sedentary behaviour recommendations: spending two hours or less per day watching television or using a computer xiii during leisure time.

The indicator used combined children who are overweight and obese. XİV

Types of child abuse considered are physical abuse, sexual abuse and/or witnessing violence by a parent or guardian against another adult.

Topic	Indicator	Result	Result by sex		Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Early childhood	d protective facto	rs						e version de la companya de la companya de la companya de la companya de la companya de la companya de la comp
Early development index	% of children vulnerable in one of five areas of development**i prior to entering grade 1	26	F 20	M 34	Pool of various years	Offord Centre for Child Studies, McMaster University	N/A	N/A
Immunization	% of 2-year-old population that has received one dose of measles vaccine	90	F 92	M 89	2017	Childhood National Immunization Coverage Survey	Similar	Worse <sup>xvii</sup>
	% of 2-year-old population that has received the recom- mended 4 doses for dip- theria, pertussis and tetanus	76	F 78	M 74	2017	Childhood National Immunization Coverage Survey	Similar	Worse <sup>xvii</sup>
	% of 2-year-old population that has received three doses of polio vaccine	91	F 91	M 90	2017	Childhood National Immunization Coverage Survey	Similar	N/A
	% of 2-year-old population that has received one dose of varicella (chickenpox) vaccine	83	F 84	M 82	2017	Childhood National Immunization Coverage Survey	Similar <sup>xviii</sup>	N/A

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xvi The five areas of development are Physical Health and Well-Being; Social Competence; Emotional Maturity; Language and Cognitive Development; and, Communication Skills and General Knowledge.

xvii Organization for Economic Cooperation and Development, OECD Family Database.

xviii Interpret with caution due to data quality concern.

Topic	Indicator	Result	Result by sex	Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Maternal and in	nfant health facto	rs					
Low birthweight	Birth-weight less than 2,500 grams (% of live births)	7	F M 7 6	2017	Vital Statistics	Similar	Similar <sup>i</sup>
Breastfeeding	% of female population aged 15 to 55 years who had a baby in last 5 years that report exclusively breastfeeding for at least 6 months, without additional liquid/water or solid food	37	N/A	2018	Canadian Community Health Survey	Similar	Similar

#### TABLE C: **Health Outcomes**

Topic	Indicator	Result	Result by sex		Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Chronic disease	s and injuries							
Cancer	Incidence rate of all newly diagnosed cancers, per 100,000 (all ages)	516	F 496	M 548	2017	Canadian Cancer Registry	N/A	Similar
	Incidence rate of all newly diagnosed colo- rectal cancers, per 100,000 (all ages)	66	F 55	M 80	2017	Canadian Cancer Registry	Similar	N/A
Cardiovascular disease	Incidence rate of all newly diagnosed cases of ischemic heart disease, per 100,000 (age 20 years and older)	599	F 489	M 716	2016	Canadian Chronic Disease Indicators	Better	Better <sup>i</sup>
Diabetes	Incidence rate of all newly diagnosed cases of diabetes, per 100,000 (age 1 year and older)	604	F 541	M 668	2016	Canadian Chronic Disease Indicators	Better	Similar
Mood disorders	% of population aged 12 and over who reported that they have been diagnosed by a health professional as having a mood disorder <sup>xix</sup>	9	F 11	M 7	2018	Canadian Community Health Survey	Worse	N/A

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xix Mood disorder includes depression, bipolar disorder, mania or dysthymia.

Topic	Indicator	Result	Result sex	t <b>by</b>	Most current year	Data source	Trend over time (up to 15 years)	International benchmark
Chronic disease	es and injuries							
Dementia (including Alzheimer's disease)	Rate of newly diagnosed dementia cases, including Alzheimer's disease, per 100,000 (age 65 years and older)	1351	F 1489	M 1193	2016	Canadian Chronic Disease Indicators	Better	Similar
Suicide	Suicide mortality rate per 100,000	11	F 6	M 17	2017	Mortality Database	Similar	Similar
Unintentional injuries	Rate of hos- pitalizations due to unintentional injuries per 100,000 (age- standardized)	599	F 550	M 636	2017– 2018	Canadian Institute for Health Information Health Indicators	Better	N/A
Communicable	diseases							
Tuberculosis	Incidence rate of active tuberculosis disease cases per 100,000	5	F 4	M 6	2017	Canadian Tuberculosis Reporting System	Similar	Better**
Hepatitis C	Rate of reported Hepatitis C disease cases per 100,000	32	F 24	M 39	2017	Notifiable Diseases Surveillance	Similar	Better <sup>xxi</sup>
HIV	Incidence rate of HIV diagnosis per 100,000	7	F 3	M 10	2017	Notifiable Diseases Surveillance	Similar	N/A

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World Health Organization. (2017). Global Hepatitis Report. xxi

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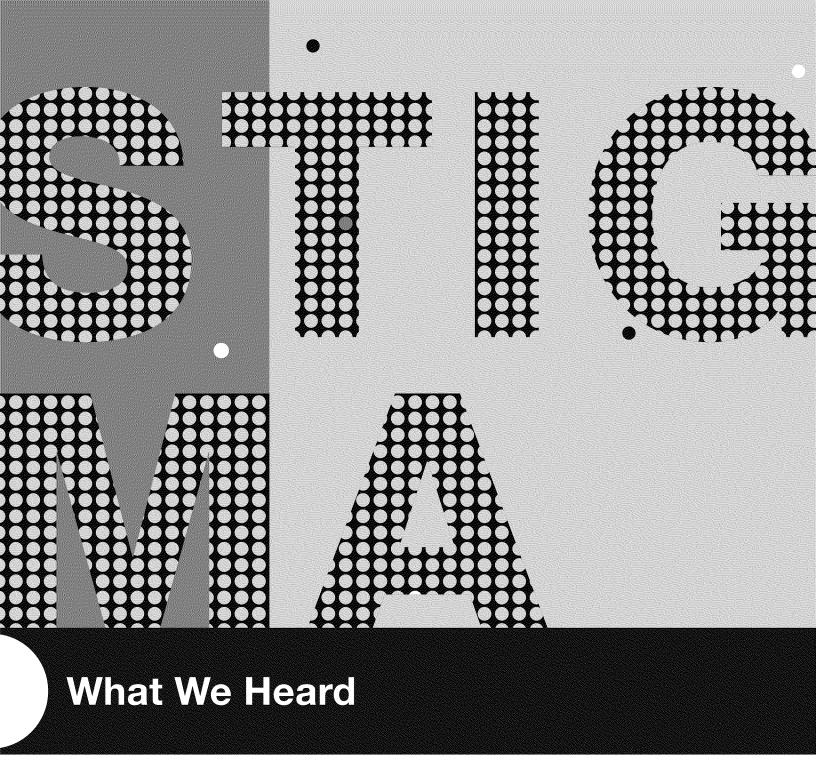
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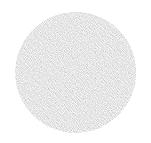
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The Chief Public Health Officer's Report on the State of Public Health in Canada 2019

Addressing Stigma: Towards a More Inclusive Health System

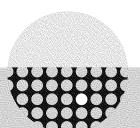


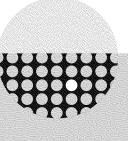


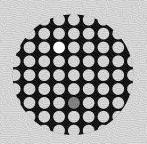
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Officer of Canada







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# Message from the Chief Public Health Officer of Canada

Every year, the Chief Public Health Officer of Canada writes a report on the state of public health in Canada. This year my annual report provides a snapshot of key public health trends in Canada and shines a light on a driver of health inequities; stigma. With a topic as complex and personal as stigma, it was important to me to hear from Canadians impacted by stigma.

This report summarizes themes from five discussion groups and eight key informant interviews, with a range of people across Canada who have expertise in, and experience of, stigma in the health system. Participants included people working in the health system and those who experience different kinds of stigma, such as health-related stigmas, racism, sexual stigma, and gender identity stigma.

I would like to thank those who shared their experiences of stigma and resilience, and vision for how we might collectively mobilize to address stigma in the health system. Your stories and perspectives give life to the report and grounds the data in reality. This input amplifies the need for all Canadians to work toward building a more inclusive health system.

### Dr. Theresa Tam

Chief Public Health Officer of Canada

We would like to respectfully acknowledge that the land on which we developed this report is in traditional First Nations, Inuit, and Métis territory, and we acknowledge their diverse histories and cultures. We strive for respectful partnerships with Indigenous peoples as we search for collective healing and true reconciliation.

We would also like to acknowledge the territories in which we conducted discussion groups that contributed to this report:

- We acknowledge that the discussion group in Ottawa took place on the traditional unceded territory of the Algonquin people.
- We acknowledge that the discussion group in Toronto took place on the traditional territory of the Wendat, the Anishnaabeg, Haudenosaunee, Métis, and the Mississaugas of the New Credit First Nation.
- We acknowledge that the discussion group in Montreal took place on the traditional unceded territory of the Mohawk people.
- We acknowledge that the discussion group in Vancouver took place on the traditional unceded territory of the Coast Salish peoples, including the territories of the Musqueam, Squamish, Stó:lō, and Tsleil-Waututh Nations.

# **Executive Summary**

The Public Health Agency of Canada (PHAC) launched an engagement process in April 2019 to gather perspectives and insights from people with expertise in stigma. The purpose was to understand how individuals experience stigma and potential ways to address stigma in the health system. A range of stakeholders provided their input, including those representing First Nations, Inuit, and Métis peoples, African, Caribbean, and Black Canadians, LGBTQ2+ people, and people who experience multiple stigmas, such as those related to health conditions, language, and age. This input informed the Chief Public Health Officer's Report on the State of Public Health in Canada 2019: Addressing Stigma - Towards a More Inclusive Health System.

The engagement process included a series of five in-person discussion groups and eight key informant interviews. In total, 100 stakeholders participated in this process, including health professionals, representatives from community-based organizations, service providers, policymakers, researchers, individuals with lived experience, and others working to help improve the health of their communities.

This report summarizes the ideas shared by these stakeholders.

### **Key Themes of What We Heard**

- 1. What holds stigma in place? (Stigma drivers and practices)
  - Cultural injustice in Canada: Experiences with stigma often reflect Canada's history of colonization and cultural assimilation. The lack of recognition and appreciation for other cultures and histories has resulted in many people not having access to culturally appropriate care and mistreatment by health providers and systems.
  - **Invisibility of structural discrimination:** Many people experience stigma in their everyday lives, as discrimination pervades structures and systems in society. However, this is largely unknown to, and overlooked by, most Canadians.
  - Outdated policies and laws: Stigma is embedded in, and shaped by, existing policies and laws that enforce dominant cultural values and disproportionally affect certain groups of people.

- Biases and stereotypes: Stigma is often driven by attitudes and beliefs that reflect entrenched biases and prejudices, as many people cannot relate to or are fearful of those who are different from them. As a result, their behaviours and actions are often based on false assumptions.
- Power imbalances and lack of engagement and representation:

Many patients/clients who experience stigma are not being meaningfully engaged in the health system - their voices are not being heard and they are not well represented. Additionally, there are power imbalances between providers and patients/clients that serve as a barrier for a more inclusive health system.

- Stigma and social determinants of health intersect to affect health: Socioeconomic factors, particularly education, poverty, and employment, intersect lead to poorer health outcomes and shape people's experiences of stigma. There is not enough understanding in the health system of these circumstances.
- **Limitations of current knowledge** practices: The lack of high-quality data perpetuates stigma, as there is not sufficient information on the experiences and health outcomes of certain groups to inform the development of programs, services, and policies.

- 2. What can be done to address stigma in the health system? (Interventions and promising initiatives)
  - Make visible and address systemic stigma: There needs to be broad, fundamental recognition of the systemic and historical issues – particularly the legacy of colonization and the ongoing effects of colonialism – underpinning many individuals' experiences with stigma, not only in health but across Canadian society more generally.
  - Counteract stigma from a social determinants perspective: To properly address stigma, more holistic approaches are needed to target the social determinants of health, such as education and employment.
  - Meaningfully engage people with
    lived experience: Health providers and
    organizations need to reach out to, engage,
    and learn from those who experience stigma.
    This will help build greater awareness of
    their realities and could be used to inform
    planning and decision-making related to
    health services and individual care.
  - Greater diversity and inclusion in the health system: The health system workforce needs to be more diverse and represent people from a variety of backgrounds. This will require more efforts to engage youth, ensure equitable hiring and advancement practices, and re-think what skills are needed and valued, particularly in leadership positions.

- Offer ongoing training to health providers to be aware and inclusive of difference: Health providers need relevant, meaningful cultural competency training, which will help them develop greater self-awareness of their biases and build the skills needed to deliver quality care for all patients. This training needs to be provided early on and throughout their careers.
- Create more positive public health messaging: A positive approach could help address stigma in the health system by focusing on hope and empowerment and sharing stories of recovery and success, rather than relying on "scare tactics".
- Increase funding and resources for community-based work: There is a need for more funding and resources, particularly for smaller, community-based organizations that address stigma through prevention programs, training and capacity building, and targeted research and evaluation.
- Improve knowledge generation practices: Data collection and research on stigma needs to be improved to help build greater understanding of how people experience stigma and how it impacts their health. This includes valuing other forms of knowledge and ways of knowing.

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# Introduction

In April 2019, the Public Health Agency of Canada (PHAC) launched an engagement process to gather insights from a wide range of health leaders and stakeholders on stigma and health, with a focus on the health system. The data collected through this process has been used to inform this year's <u>report</u> on the state of public health in Canada prepared by the Chief Public Health Officer (CPHO), Dr. Theresa Tam. This annual report helps to raise the profile of public health issues, stimulate dialogue, and catalyze action to improve and protect the health of Canadians.

With this year's focus on stigma, the CPHO and colleagues engaged Canadians with expertise in stigma, including health professionals, representatives from community-based organizations, service providers, policymakers, researchers, individuals with lived experience, and others working to help improve the health of their communities. Through a series of in-person discussions and key informant interviews, various dimensions of stigma were explored, including definitions and concepts, stigma drivers and practices, and interventions. Additionally, there was a focus on certain groups who experience multiple layers of stigma, specifically First Nations, Inuit, and Métis peoples, LGBTQ2+ people, and African, Caribbean, and Black Canadians. The discussion groups and interviews also addressed health-related stigmas (e.g., mental illness stigma, substance use stigma, tuberculosis stigma, obesity stigma).

This What We Heard report summarizes the key findings from this process, with a focus on synthesizing common ideas shared by stakeholders across the in-person discussion groups and key informant interviews. The goal of this report is to represent the voices of all participants who provided their time and energy to meaningfully contribute to the annual report. However, all of the data gathered through this process has been subject to analysis and interpretation.



## **Process Overview**

### **In-person Discussion Groups**

To engage a diversity of stakeholders, PHAC held a series of five in-person discussion groups between April and June 2019. Each session had a slightly different focus in terms of participants and communities served, including health professionals, African, Caribbean, and Black Canadians, LGBTQ2+ people, and First Nations, Inuit, and Métis peoples. These sessions also included people who experience multiples stigmas including those related to health conditions, language, and age. Discussion groups took place as follows:

- **April 4 in Ottawa** (part of the CPHO Health Professional Forum)
- April 29 in Ottawa (Canadian Public Health Association pre-conference session)
- May 23 in Montreal (hosted by DESTA Black Youth Network)
- May 29 in Toronto (held at the YWCA)
- 5 June 7 in Vancouver (held at the First Nations House of Learning)

The purpose of the sessions was to gather stakeholders' input on the following key areas:

- 1 What holds stigma in place? (Stigma drivers and practices)
- How do we address stigma in the health system?
  (Interventions and promising initiatives)

Each discussion session was 3.5 hours in length and included a mix of presentations, small group discussion, and plenary dialogue. Each session was hosted by the CPHO or her delegate with members of the Office of the CPHO's Reports Unit and PHAC regional offices supporting the event (as well as the CPHO Health Professional Forum Secretariat). PHAC engaged an outside consultant, Hill and Knowlton Strategies to support facilitation and note-taking for session's #2-5.

In total, 92 stakeholders participated in these discussion groups. Please see Appendix A for the list of participating organizations.

### **Key Informant Interviews**

In addition to the in-person discussion groups, eight key informant interviews were conducted by *Hill and Knowlton Strategies* in June and July 2019. The purpose of the interviews was to further engage stakeholders representing critical perspectives and expertise on stigma in health, particularly those who could not attend the in-person sessions. The interview questions followed similar lines of inquiry as the discussion groups, with a focus on stigma drivers and interventions. Each interview was approximately 45 to 60 minutes in length and conducted by an independent facilitator and note-taker. Please see Appendix A for the list of organizations/perspectives represented.

### Data Collection, Analysis, and Reporting

Qualitative data was collected via detailed notes taken by a note-taker during all of the in-person discussion groups and key informant interviews. Worksheets were completed by participants and used for reporting on their table discussions. Notes and worksheets were analyzed to inform summary reports for each session, which included a synthesis of key ideas.

To develop this What We Heard report, session summary reports, session notes, and interview notes were reviewed and analyzed to identify overarching themes from stakeholders across all forums. The focus was on highlighting the most common themes (i.e., most frequently discussed). Non-attributed participant quotes are highlighted throughout this report to help illustrate participants' perspectives pertaining to each of the themes.



# **Key Findings**

This section provides a synthesis of the key findings from both the in-person discussion groups and key informant interviews. Findings are presented by discussion question and theme.

### What Holds Stigma in Place?

# Cultural injustice in Canada Invisibility of systemic discrimination Outdated policies and laws Power imbalances and lack of engagement of lack of engagem

**Cultural injustice in Canada:** As one of the top themes, participants across all sessions highlighted how stigma experienced in the health system often reflects Canada's history of colonization and cultural assimilation, in which people from certain groups continue to face injustice and trauma. As a result of the disruptive and ongoing impact of colonialism, First Nations, Inuit, and Métis peoples have a

long history of being mistreated by health providers and not having access to care in their language or reflecting their culture. Participants described a lack of recognition of First Nations, Inuit, and Métis culture and knowledge (including holistic concepts of health such as including spirituality, one's role and contribution to their community), the impact of historical traumas like residential schools and

missing and murdered Indigenous women, and differences between and within different Indigenous groups. One participant discussed how children in their community have been misdiagnosed and have died from serious but treatable conditions like strep throat, and how some patients are not given sufficient information about their drugs/treatment.

Similarly, some participants described the need to raise awareness of Canada's history with the transatlantic slave trade and build appreciation for the contribution of African, Caribbean, and Black Canadians. Some discussed how others do not fully recognize the agency and capacity of people belonging to groups that have historically been stigmatized, such as African, Caribbean, and Black Canadians and First Nations, Inuit, and Métis peoples.

**Invisibility of systemic discrimination:** For many participants, systemic discrimination pervades structures and systems, not only in health, but also in education, employment, justice, and housing systems. While this stigma is felt deeply by many individuals, it is largely unknown to and overlooked by most Canadians. For example, one participant described the experience of "living while Black": "There isn't a moment where we are not calculating what does this mean, how will this be seen, how are they going to react, how am I going to react. It takes a lot of energy."

Participants expressed strong concerns with the lack of support or willingness to change the structures that perpetuate stigma: "People are complacent with the status quo... There is a 'don't talk about it' attitude." Many Canadians do not recognize that they are "implicated in racist systems" – they often do not know these issues exist or choose to ignore them. For example, some believe that racism can only occur through "extreme" behavior, rather than through prevailing cultural privilege or a narrative that benefits some but not others. Additionally, some health professional participants acknowledged that there is complacency in their work settings and/or profession to make necessary changes.

A major challenge is achieving broad recognition that the legacy of historical and cultural injustices continues to re-enforce stigma and perpetuate health inequities. Many participants discussed how it is difficult to advance the dialogue with the broader public in this area, as many Canadians do not want to acknowledge their conscious and/or unconscious biases. Participants described examples including the controversial legacy of certain historical sites or undermining the level of violence committed against missing and murdered Indigenous women.



### **DISCUSSION GROUP QUOTES**

"It goes back to the incapacity of white people to understand that other people who are not white have the capacity to inform and transform their environment."

- Montreal participant

[As a Black physician]
"A doctor wanted me to
do a consult for one of
his patients with a thick
Caribbean accent. He had
depicted her as a "gypsy"
and indicated that he was
afraid of them. In reality,
the challenge was that
he couldn't understand
her accent."

- Discussion group participant

Similar feedback was provided from the perspective of linguistic minorities, who often feel discriminated against and forced to communicate in the language of the majority to access health services. For example, participants described patients from both English- and French-speaking minority populations being criticized and nearly refused services by health providers. In one participant's perspective, this reflects often unspoken expectations for assimilation between English- and French-speaking Canadians.

**Outdated policies and laws:** Several participants discussed how stigma is embedded in and shaped by existing policies and laws, can be outdated and disproportionately discriminate against First Nations, Inuit, and Métis peoples, African, Caribbean, and Black Canadians and LGBTQ2+people. Some emphasized that policies and laws are not written by or for people from these communities. In the health sector, some examples include those related to HIV non-disclosure, blood donor eligibility criteria, and partner notification of sexually transmitted infections (STIs). Additionally,

some participants discussed how the *Indian Act* enforced significant changes to First Nations culture and tradition. For example, enforcing colonial values on First Nations communities by taking respect and "power away from the matriarch." As a result, many participants called for updating policies and laws to incorporate new research/evidence and reflect lived experiences of stigma.

Biases and stereotypes: Similar to previous themes, some participants discussed how stigma is driven by attitudes and perspectives that reflect entrenched prejudice and biases. In many cases, these embody a "fear of difference" or "fear of the unknown" among many Canadians. For example, one participant suggested that many people "believe that drug users put themselves in those positions through their own decisions." Within the health system, some participants shared how they have been treated differently as a result of their ethnic or cultural background, even though they have the same health needs as other patients. Some



"Racism that has been written into policy is hard to see. You can't see that the policies are written by people with a certain lens – white, elite, male, etc. Everyone has a bias."

- Key informant interview participant

"People make assumptions of Inuit capacity if they don't speak proper English... They look at our population as "less" rather than "in need of support."

- Key informant interview participant

"There is an assumption that you can't possibly be as bright as they are, and invariably someone thinks I'm there to wash their bloody floor... Before any conversation, I always have to introduce myself as a doctor."

- Montreal participant

suggested that this could be the result of false assumptions or narratives, such as African, Caribbean, and Black Canadians having a higher pain tolerance or being more likely to get pregnant. In the context of the health system, several participants talked about their own experiences with racism and discrimination. As a patient, this includes receiving care based on false assumptions, being blamed for their health issues and experiencing barriers to care for their children and family members. Over time, these negative experiences have caused many people to be reluctant to seek out and receive care. From an Indigenous and linguistic minority perspective, some participants discussed not having access to services in their first language. In some cases, this leads health providers to make assumptions about the capacity of a patient when there is actually language barrier.

Similar experiences of both patient and health professional biases and stereotypes were also shared from the perspective of health providers. For example, both First Nations, Inuit, and Métis and African, Caribbean and Black Canadian participants who are service providers described experiences of patients refusing care from them, being questioned about their level of education and profession, and being ostracized by their colleagues.

Participants also discussed how patients are categorized and pathologized based on their health conditions. Rather than being seen as a whole person and assessed in the context of the wide variety of life experiences that can impact health (including social determinants of health), people can be "singled out" and "slotted into a group or labelled" as, for example, someone who uses substances, has HIV, or has a mental illness. These categories often have stereotypes and stigma attached to them, which can lead providers to make false assumptions about the person and their needs. Stigma is further perpetuated when patients are treated in a transactional manner, rather than a person-centred and compassionate approach.



"We've been good at creating silos. Everything is organized around one thing... But what are my needs as a person? I'm not just a patient or client. That's too transactional."

 CPHO Health Professional Forum participant

### Power imbalances and lack of engagement and representation:

Many participants highlighted that patients, particularly those from groups who experience stigma, are not being engaged in the health system – whether through meaningful conversations around their own care or being included in decision-making processes related to making improvements to the health system. Their voices are not being valued if health providers and organizations do not actively reach out and listen to their stories. Some felt that better engagement is critical in ensuring that health providers understand upstream factors impacting a person's health and so that patients are treated more as unique individuals rather than "treating them like their illness." Some participants discussed how, for First Nations, Inuit, and Métis peoples, meaningful engagement means working collaboratively to build customized person-centered approaches that incorporate Indigenous knowledge. Without this person-centered approach, these patients may not seek the care they need, leading to further stigmatization and poorer health outcomes.

Additionally, some participants shared their concerns about power imbalances between health providers and patients. One participant stressed that these power imbalances are the reason why stigma can have a real impact on health outcomes. For example, providers are typically "middle class or highly privileged people" who may not be able to communicate effectively with or relate to their patients. There is often a "provider knows best" mentality, in which their preferred methods are prioritized over a patient's individual needs, which may not be sufficiently considered in care planning discussions.

One participant suggested that some providers are not always aware of the power and privilege they hold over patients. This influences patient/provider interactions, especially among patients who are highly stigmatized. For example, some patients are reluctant to request services in their language of choice because they worry that it will create problems with their provider.



"[As an Indigenous person] often I find people don't hear, listen to or see me."

- Vancouver participant

"[The patient] is afraid of being judged if they don't stay quiet and accept the services."

Key informant interview participant

"Living in an impoverished community increases their [African, Caribbean, and Black Canadians] likelihood to get into criminal activities because it's available to them. That then reinforces stigma that Black people are more likely to be involved in crime."

 Key informant interview participant Stigma and social determinants of health intersect to affect health: Several participants described how other factors, like income, education, and geography, intersect and shape their experiences of stigma. For example, some emphasized barriers due to low income, not only for accessing health services but also for broader participation in society in terms of education, employment, housing, and justice systems. Additionally, greater income inequality can create more divisions and make people "less accepting of differences": "When [income inequality] gets bigger, you get bigger social problems that breaks societies." Some participants explained how poverty can lead to race-based stigma and discrimination towards, for example, African, Caribbean, and

Participants provided similar feedback on the impact of low levels of education (e.g., less employment prospects) and geographical isolation (e.g., limited access to services in communities) on health outcomes.

Black Canadians.

Additionally, participants discussed how experiences with exclusion and discrimination can be amplified for individuals who face multiple layers of stigma, such as being racialized and gay, or homeless and experiencing mental health or substance abuse issues. In these cases, these individuals are often blamed for making "bad life choices."

Some participants emphasized that understanding the impact of multiple and intersecting stigmas remains challenging, as it is currently not a well-researched area and is difficult to study when multiple factors are involved.

### Limitations of current knowledge practices:

Participants discussed challenges around what and how knowledge is valued and used to make decisions that impact health. Some participants discussed the lack of high-quality data available to health providers and policy makers, especially pertaining to African, Caribbean, and Black Canadians, First Nations, Inuit, and Métis peoples, and LGBTQ2+ people. There is a need for expanded health data collection and administration to better represent underserved groups. For example, one participant highlighted: "If you are trans you are not counted in a lot of data collection, so you don't exist within the system." Additionally, some participants discussed how data categorization practices (e.g., epidemiological categories) and the incorrect interpretation of data contributes to stigma in health. Participants also challenged how Eurocentric knowledge systems are valued over other ways of knowing. For example, Indigenous knowledge and traditions such as powwows and drums are linked to health, though these ways of knowing are not "written down as actual evidence or science."



"People who are homeless are often viewed as unwelcome, frequent flyers [in the health system], who are coming in with issues that aren't viewed as legitimate or real problems."

- Key informant interview participant

### How Should We Address Stigma in the Health System?

# Counteract stigma from a social determinants perspective

Meaningfully engage people with lived experience

Greater diversity, inclusion, and leadership in the health system

Create more positive public health messaging

Increase funding and resources for community-based work

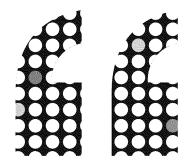
Improve knowledge generation practices

Make visible and address systemic stigma

### Make visible and address systemic stigma:

For many participants, addressing stigma requires a broad, fundamental acknowledgment of the systemic and historical issues underpinning many people's experiences, not only in the health system but society

more generally. In particular, the legacy and ongoing effects of colonialism need to be recognized and addressed, as they reinforce discriminatory perspectives and attitudes towards First Nations, Inuit, and Métis peoples and African, Caribbean, and Black



"Anybody who is part of racialized work would tell you that Canada is deeply racist and [only] changing health services doesn't change that."

- Key informant interview participant

[On systemic issues] "You can smack people in the face with evidence and they will refuse to believe it... The everyday Canadians that are taught this behavior need to acknowledge and change it."

- Vancouver participant

Canadians, while also creating divisions between different groups in society. Some participants stressed that actions to reduce stigma cannot be limited to the health system – they should be extended more broadly across all structures in society. To help recognize and build greater awareness of the factors underpinning stigma in Canadian society, participants suggested developing public campaigns that could, for example, teach children about various cultures and histories. Additionally, participants noted that this issue is complex as there is need for change at both a systemic and individual level.

### Counteract stigma from a social determinants perspective:

Participants discussed the need for more holistic approaches that include prevention and actions to address the social determinants of health. This could include addressing the lack of education and employment opportunities for African, Caribbean, and Black Canadians through mentorship and education programs. Among Indigenous participants, there was discussion about how, in Indigenous contexts, the concept of health should not be separate from the concept of wellness, unlike in Western medicine.

Many participants shared the realities of working within the confines of existing systems that do not recognize the broad needs of patients and clients. For example, a community organization that receives funding for arts programs that, in reality, is supporting mental health work but does not have the resources to hire trained mental health professionals. More "flexible, sustainable funding" models could help community organizations address these issues, as the current models are "too rigid."

### Meaningfully engage people with lived experience:

Participants across all sessions emphasized the importance of engaging people who have experienced stigma. This involves reaching out and learning from people's realities in order to build greater awareness among health providers and the health system more broadly. Additionally, engagement could focus on health system redesign to improve patient navigation.



"You can't divorce the social from the health."

### - Montreal participant

"Actually listen to patients on what their lived experience is... They will come up with solutions that will meet their needs better than what we can come up with."

 CPHO Health Professional Forum participant Participants suggested that meaningful engagement could be achieved in a variety of ways. Many will require changes in how organizations operate. These include:

- Using a flexible, adaptable, person-centred approach, recognizing that people can experience stigma in many different ways.
- Deploying a multitude of engagement methods to help encourage individuals to tell their own stories to inform health system change in a variety of ways, such as through Photovoice – a participatory research methodology that has been used in different contexts.
- Providing opportunities for those with lived experience to be leaders
  of not just participate in important discussions, for example, to
  shape training and inform decision-making.
- Bringing together individuals with lived experience and health system actors at all levels (e.g., health care administrators, physicians, nurses, educators) to share experiences and discuss collective goals.
- Adapting culturally safe frameworks and developing meaningful partnerships to facilitate authentic engagement and help minimize tokenism, such as through Indigenous Advisory Circles (IACs). An example of a current culturally safe partnership is Tungasuvvingat Inuit's regional cancer program gatherings held in partnership with the Canadian Partnership Against Cancer (CPAC).

Many participants identified the need to engage youth to help address stigma over the long term. For some participants, this means educating young Canadians about diversity and inclusion in ways that are relevant to them, such as through school-based programs. This could help minimize the drivers of stigma in the future. Similarly, health professionals discussed how healthcare facilities can meaningfully engage youth and involve them in shaping the patient experience. For example, the Children's Hospital of Eastern Ontario (CHEO) has a Youth Advisory Committee that is engaged on a regular basis by the hospital's administration and board, which has led to policy changes (e.g., clinic hours).



[On engaging Indigenous people] "If we listen to our families and go right to folks [impacted by] stigma... that means self-determination... People know what they need but we just don't listen to them."

- Vancouver participant

"Do what you did here today, but with children. Invest in our future generations to ensure stigma does not continue for years to come."

- Toronto participant

Greater diversity, inclusion, and leadership in the health system: Several participants discussed how barriers to employment - particularly for African, Caribbean, and Black Canadians and First Nations, Inuit and Métis peoples - helps drive stigma in the health system, both as patients, providers and co-workers on health teams. To address this, there needs to be greater workforce representation from a diversity of backgrounds across the health system, particularly in senior leadership and decision-making positions. This requires more equitable hiring, pay and advancement practices in the health sector, as well as more general "re-thinking" of what skills are valued in positions of leadership. Some participants also mentioned the importance of greater diversity and inclusion in institutions beyond health, such as in the education system and employment sector. Additionally, some highlighted the importance of supporting youth to pursue careers in the health sector: "Our kids need role models and supports." They discussed the importance of reducing barriers to post-secondary education, such as through scholarships and targeted recruitment programs (e.g., Dalhousie University's Promoting Leadership in Health for African Nova Scotians (PLANS) program).

Offer ongoing training to health providers to be aware and inclusive of difference: Many participants emphasized the importance of health providers receiving relevant, meaningful training early on and throughout their career. Health professionals need to develop greater self-awareness of their biases and should be required to complete cultural competency training to build the skills and competencies needed to deliver quality care for all, such as being more accepting, respectful, and culturally aware, and using non-stigmatizing language with their patients. They need to develop a greater understanding of the impact of the social determinants of health and barriers that some individuals may face. This could involve anti-racism, in addition to cultural competency, training for health providers to get "at the root of the issue": "White people are more comfortable talking about culture than race. We need to change the language."

Additionally, training needs to be ongoing – not just through "one-time events" – to help support the full, continuous changes in attitudes and behaviours needed to address stigma, as well as to help ensure accountability. Training could also involve more "field opportunities" to be exposed to, and learn about, communities.



"When you address stigma, you need to start at the top by setting an inclusive playing field as a standard."

- Toronto participant

"You need education throughout your career. Not one day on cultural sensitivity, or mental health sensitivity."

- CPHO Health Professional Forum participant

### Create more positive public health

messaging: Some participants underscored the value of using positive messaging in public health campaigns. This could include using messages that focuses more on hope and empowerment and sharing stories of recovery and success, as opposed to relying on "scare tactics", which can add to stigma already associated with some health conditions. Additionally, some participants discussed the need to learn from and leverage promising public health initiatives that take a strengths-based approach, rather than focusing on people's deficits. For example, the First Nations Health Authority uses a strengths-based approach to draw on collective and personal strengths for public health messaging and to treat people with complex trauma.

Increase funding and resources for community-based work: Several participants highlighted the impact of community-level actions in addressing stigma through the development of upstream prevention programs, building downstream capacity, and conducting more targeted research. Many community-based organizations and initiatives have been very successful in this area; one participant suggested that, in contrast to larger organizations, the community-based organizations have a better understanding of, and connection to, individuals who may face stigma. However, these community-based organizations need more sustainable funding and resources, especially if they are a smaller operation. Montreal participants highlighted how funding tends to be focused on supporting larger organizations, which "continues to keep [community-based organizations] in a position of third class."

To better support community-based organizations, participants discussed how more project- and program-based funding is needed to develop training programs and hire experts to conduct workshops

to engage both health providers (including social workers) and community members. Long-term funding models also need to be less rigid and more flexible to support long-term sustainability for community-based organizations. Additionally, one participant discussed how funding applications need to be simplified to increase accessibility to resources for these organizations: "You practically need a PhD to apply for these grants."

### Improve knowledge generation practices:

Valuing different ways of knowing and improving research and data could help address stigma by building a greater understanding of people's experiences and, ultimately, informing the design of more inclusive policies, programs, and practices. Participants representing and/or working with First Nations, Inuit, and Métis communities emphasized the importance of incorporating Indigenous knowledge into healthcare approaches and beyond (e.g., K-12 education system). Additionally, one participant discussed their experience with a research project focused on suicide prevention in Vancouver's Downtown Eastside, which became more effective in reaching those in need of help with the inclusion of elders to work alongside physicians.

Efforts to improve knowledge generation could include collaboration with people and communities impacted by stigma to reduce biases in health data, conduct more targeted race-based research (e.g., mental health of African, Caribbean, and Black Canadians), and collect more stigma-related health data: "We need the numbers to be able to say this is where stigma and racism is coming from." Some participants also emphasized the importance of evaluation and knowledge sharing to help spread promising initiatives, foster collaboration across stakeholder networks, and hold health system leaders accountable.

**20** 



# Conclusion

By engaging with key leaders and stakeholders interested in stigma and health, the CPHO gained valuable insights to inform the 2019 CPHO Annual Report.

Participants generously gave their time to have open and honest conversations about the challenges facing many Canadians as they interact with the health system. The key findings throughout this report reiterate that fundamental change is needed across various systems and structures, not just in the health system, but more broadly across society.

# APPENDIX A



# **Participants' Organizations**

### Chief Public Health Officer Health Professional Forum Discussion Group

- Centre for Addiction and Mental Health
- Canadian Public Health Association
- Association of Medical Microbiology and Infectious Diseases Canada
- · Canadian Dental Association
- Canadian Indigenous Nurses Association
- Canadian Medical Association
- Canadian Nurses Association
- Canadian Paediatric Society
- Canadian Pharmacists Association
- College of Family Physicians of Canada
- · Community Health Nurses of Canada
- HealthCareCAN
- Infection Prevention and Control Canada
- Royal College of Physicians and Surgeons of Canada
- Society of Obstetricians and Gynaecologists of Canada

# Canadian Public Health Association Pre-conference Discussion Group

- Assembly of First Nations
- Canadian Centre on Substance Use and Addiction
- Canadian Coalition for Seniors Mental Health
- Canadian Institute for Health Information
- Canadian Public Health Association
- Community Addictions Peer Support Association
- Egale Seniors National Advisory Council
- Institut National de Santé Publique du Québec
- Mental Health Commission of Canada
- Métis National Council
- National Collaborating Centre for Indigenous Health
- National Collaborating Centre for Determinants of Health
- Ottawa Senior Pride Network
- Public Health Ontario
- Simon Fraser University
- St. Paul's University
- University of Ottawa
- University of Toronto
- Youth Services Bureau

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### **Montreal Discussion Group**

- Afrique au Féminin
- · Arts, Racines & Thérapies
- Black Community Resource Centre
- CIUSSS du Centre-Sud-de-l'Île-de-Montréal
- Dalhousie University
- DESTA, The Black Youth Network (Little Burgundy)
- Général ACCÉSSS
- L'Association Médicale de Personnes de Race Noire du Québec
- Lique des Noirs du Québec Maison d'Haïti
- McGill University, Lady Davis Institute for Medical Research

### **Toronto Discussion Group**

- Africans in Partnership Against AIDS
- Black Health Alliance
- Hospital for Sick Children
- McMaster University
- National Collaborating Centre for Determinants of Health
- Rainbow Health Ontario
- Toronto Senior Pride Network
- Toronto Public Health
- Wilfrid Laurier University
- Li Ka Shing Knowledge Institute
- Wellesley Institute
- · University of Toronto

### **Vancouver Discussion Group**

- BC Nurses Union
- First Nations Health Authority
- Métis Nation British Columbia
- Pacific AIDS Network
- Provincial Health Services Authority
- The Cedar Project
- University of British Columbia, School of Nursing
- Winnipeg Boldness Project
- YouthCo

### **Key Informant Interviews**

- Centre for Urban Health Solutions, St. Michael's Hospital
- Community Health and Social Services Network
- · Faculty of Health, Dalhousie University
- Inuit Tapiriit Kanatami
- IWK Health Centre
- Quebec Black Medical Association
- Tungasuvvingat Inuit
- Wellesley Institute

**ATIA - 14 From** 2019-12-31 4:30 PM Sent: Tam, Dr Theresa To: (PHAC/ASPC) Subject: Re: Emergency preparedness in health facilities Hi Theresa and I'm sorry for responding late. I had a response much like in progress. But I thought, rather than duplicate, I would elaborate or thoughts. system transformation proceeds, we hope to take the opportunity to reset expectations for the system, including hospitals. The framework we had released calls for a more adaptive state of readiness to reflect the complexity of our environment. That does lean towards a more all-hazards, common consequence approach a described. Hospitals in just completed a large mass casualty exercise, while hospitals in also participated in a terrorism exercise with the This reflects the numerous mass casualty and terror-related events of the past couple of years. However, there was also a lot of work in preparing for the current influenza season, some of which is also transferable experience for a pandemic. We have also been watching the situation in the DRC closely. We also have a very concerning emerging threat of cyberattacks on the healthcare industry, which have taken hospitals and other health agencies offline over the past two years. I think

ATIA - 19(1)

I think our context is always multi-hazard vs. single hazard. A mass casualty incident tomorrow is taking place during a flu season on top of an opioid crisis amidst constant cyberattacks with concerning pathogens and conflict overseas.

hospitals should be focusing on this more.

I think we can build on that question to ask how our health systems can maintain a harmony of specific and all-hazards readiness and what are the capacities needed to address a more complex adaptive system.

A2021000114 Page: 1000/1818 ATIA - 19(1)

**ATIA - 17** 

ATIA - 14

Very happy to discuss further and Happy New Year to you both!



### Get Outlook for iOS

From

Sent: Tuesday, December 31, 2019 4:07:11 PM

To: 'Tam, Dr Theresa (PHAC/ASPC)'

Cc:

Subject: RE: Emergency preparedness in health facilities

# CAUTION -- EXTERNAL E-MAIL - Do not click links or open attachments unless you recognize the sender.

Sounds good Theresa. While not directly related, I thought this video of a major exercise we did last year might be of interest. We had nearly 400 staff participating in this multi-site event. <a href="https://youtu.be/xDrdOQkK7n0">https://youtu.be/xDrdOQkK7n0</a>

Cheers,

From: Tam, Dr Theresa (PHAC/ASPC) [mailto

Sent: Tuesday, December 31, 2019 11:45 AM

To:

Cc:

Subject: Re: Emergency preparedness in health facilities

Hi 📗

Thank you for taking the time to give me such a thorough answer. Perhaps the question you posed at the end could be one that we ask during our PHN / PHISC pandemic exercise discussions. It would be interesting to get at least a round table update on the state of health facilities preparedness. For sure ensuring routine foundational capacities such as triage, IPC etc are key.

Happy New Year.

Theresa

Sent from my iPhone

On Dec 31, 2019, at 13:20,

wrote

Hi Theresa, good to hear from you. I have a sort of long answer below, hope it helps!

Generally speaking, our health authorities conduct a pandemic exercise each year, and the lessons learned from these exercises are used to update the health authorities' pandemic plans, and to improve any other processes as appropriate.

s Guiding Framework for Public Health requires each health authority to conduct an exercise with a public health component at least every two years.

Conducting an after action review and developing improvement plans based upon the findings is standard practice following any exercise, or response to an actual ATIA - 19(1) ATIA - 17 ATIA - 14

event (this is also required by Accreditation Canada's Leadership standards, and by CSA Z1600 [CSA standard on Emergency Management and Business Continuity Programs]).

Our hospitals have all hazards plans, that include structures and process for establishing emergency operations centres to coordinate a response to any event. Most of our hospitals have at least one exercise each year that includes the activation of their EOC. Often these exercises use a mass casualty (Code Orange), or evacuation (Code Green) scenario. The scenario would rarely be an infectious disease event at the facility level however the facilities' all hazards plans, structures, and processes would be activated for an infectious disease event, and these are practiced, and updated regularly based upon lessons learned.

In terms of other activities that would be relevant to preparing for an infectious disease event at the facility level, there is significant time and effort spent on ensuring staff are trained and prepared for infection prevention and control, including fit testing of masks / respirators, and hand washing. In addition, is updating its approach to managing pandemic stockpiles to ensure we have a more efficient and economical approach while maintaining an appropriate level of preparedness.

I suppose a different question would be: "should hospitals and other health facilities conduct regular pandemic / infectious disease exercises?". I'm not so sure — I think our approach allows us to have general preparedness for a range of emergency scenarios at the facility level, and we practice with more likely / higher risk scenarios like evacuations

mass casualty events (we have had numerous mass casualty events over the past few years). With limited resources, and face time with our health facilities, we need to be thoughtful about how we spend those resources and time.

I'm happy to discuss this further – give me a call on my cell at any time

All the best, and happy new year!

----Original Message-----

From: Tam, Dr Theresa (PHAC/ASPC) [mailto

Sent: Monday, December 30, 2019 4:24 PM

To:

Subject: Emergency preparedness in health facilities

Dea

Hope you are getting a bit of rest over the holiday season.

I am trying to write an article for the Healthcare Management Forum.

I was wondering whether it would be true to say that hospitals/health facilities in general do not conduct regular exercises for pandemic/infectious Disease epidemic scenarios. I know that a severe influenza season can strain the system but not sure if the lessons learned from these, as well as from H1N1 2009, are fully incorporated into health emergency management.

TT

Sent from my iPhone

ATIA - 1

From: Tam, Dr Theresa (PHAC/ASPC)

Sent: 2019-12-31 2:46 PM To: Namiesniowski, Tina (PHAC/ASPC); Thornton, Sally (PHAC/ASPC)

Subject: Fwd: Emergency preparedness in health facilities

FYI

Sent from my iPhone

Begin forwarded message:

From

Date: December 31, 2019 at 13:20:06 EST

To: "'Tam, Dr Theresa (PHAC/ASPC)'"

Subject: RE: Emergency preparedness in health facilities

Hi Theresa, good to hear from you. I have a sort of long answer below, hope it helps!

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Conducting an after action review and developing improvement plans based upon the findings is standard practice following any exercise, or response to an actual event (this is also required by Accreditation Canada's Leadership standards, and by CSA Z1600 [CSA standard on Emergency Management and Business Continuity Programs]).

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A2021000114

ATIA - 19(1)

**ATIA - 17** 

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Sent: Monday, December 30, 2019 4:24 PM

To

Subject: Emergency preparedness in health facilities

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TT

Sent from my iPhone

A2021000114 Page: 1004/1818 From:

**Sent:** 2019-12-05 11:04 AM

To: Caroline.Desbiens@parl.gc.ca

Cc: Justin.Trudeau@parl.gc.ca; Chrystia.Freeland@parl.gc.ca; Patty.Hajdu@parl.gc.ca;

Diane.Lebouthillier@parl.gc.ca;
Carla.Qualtrough@parl.gc.ca;
Lawrence.Macaulay@parl.gc.ca;
Navdeep.Bains@parl.gc.ca;
Bill.Morneau@parl.gc.ca;
Ahmed.Hussen@parl.gc.ca;
Maryam.Monsef@parl.gc.ca;
Bardish.Chagger@parl.gc.ca;
Catherine.McKenna@parl.gc.ca;
Deb.Schulte@parl.gc.ca; Tam, Dr Theresa (PHAC/ASPC); Michael.Strong@cihrirsc.gc.ca; Coordinator@AlliesForMe.ca

Subject: Encéphalomyélite myalgique

Madame Desbiens.

Je suis un citoyen de votre circonscription atteinte d'encéphalomyélite myalgique (ou EM, anciennement connue sous l'appellation stigmatisante « syndrome de fatigue chronique »), une maladie chronique invalidante. Je vous écris afin de vous demander d'aider les Canadiens comme moi dans leurs efforts de sensibilisation à cette maladie dévastatrice.

Merci de prendre connaissance de la lettre qui suit. Salutations distinguées,

Le 2 décembre 2019

Caroline Desbiens

Député de Beauport

Chambre des communes, Ottawa

K1A 0A6

Objet: Trois actions pour accroître la sensibilisation à l'encéphalomyélite myalgique

Madame Desbiens,

A2021000114 Page: 1005/1818 Je vous écris en tant que citoyen(ne) de votre circonscription. Je fais partie des 580 000 Canadiens et Canadiennes atteints d'encéphalomyélite myalgique (EM), une maladie chronique débilitante anciennement connue sous le terme stigmatisant « syndrome de fatigue chronique » ou « EM/SFC » et j'aimerais obtenir votre aide dans mes efforts de sensibilisation à cette maladie dévastatrice.

### Qu'est-ce que l'EM?

L'EM est une maladie multisystémique complexe classée par l'Organisation mondiale de la santé (OMS) comme une maladie neuro-immunitaire se présentant sous forme sporadique et épidémique. Elle peut toucher n'importe qui, quels que soient son milieu et son âge, même les enfants.

«L'EM se manifeste souvent de façon soudaine, habituellement après une infection virale ou autre, mais peut également survenir à la suite d'autres types de traumatismes physiques. Dans d'autres cas, la maladie se développe graduellement, sur plusieurs semaines ou plusieurs mois. Les patients disent ressentir des symptômes pseudogrippaux de façon chronique. En plus du malaise post-effort caractéristique de la maladie, les patients peuvent également souffrir de troubles cognitifs, d'un sommeil non réparateur, de manifestations du système autonome telles la variabilité du rythme cardiaque, de douleurs musculaires et articulaires et de sensibilité au bruit, à la lumière et aux produits chimiques. Un titre élevé des anticorps aux virus peut aussi être présent ainsi que de faibles niveaux de sérologie auto-immune. Le degré de sévérité varie grandement d'un patient à l'autre » [1].

### D'abord, les mauvaises nouvelles : le contexte canadien de l'EM

Tout d'abord, parlons un peu du contexte entourant cette maladie encore dans l'ombre au Canada. Selon l'enquête sur la santé dans les collectivités canadiennes de 2016 de Statistique Canada, la maladie touche plus d'un demi-million de Canadiens de façon sévère, en plus d'affecter des centaines de milliers de leurs proches et membres de leurs familles. Environ 75 % des personnes atteintes d'EM, soit 435 000 personnes, sont incapables de travailler et 25 % d'entre elles (145 000 personnes) sont confinées à leur lit ou à leur domicile [2]. Les personnes gravement malades requièrent l'obscurité totale, le silence et l'isolement complet, un tube d'alimentation et un cathéter.

Tout ceci a des répercussions importantes sur notre économie canadienne. Aux États-Unis, où l'on compte entre 1 et 2,5 millions de personnes vivant avec l'EM, l'impact sur l'économie se traduit par une perte de productivité et des coûts médicaux directs d'environ 17 à 24 milliards de dollars chaque année [3]. Au Canada, une estimation comparable et conservatrice donnerait entre 11 et 15 milliards de dollars de pertes annuelles. On ne peut, ne serait-ce que d'un point de vue économique, continuer à ignorer cette maladie et les personnes qui en souffrent.

### La petite histoire de la maladie

Bien que la description des symptômes de l'EM puisse remonter à des centaines d'années, l'EM a été reconnue pour la première fois lors de l'épidémie de Los Angeles de 1934. On croyait à l'époque être face à une forme atypique de la poliomyélite. Au cours des décennies suivantes, des épidémies similaires ont eu lieu entre autres en Islande, en Suisse et en Australie. De 1984 à 1992, les épidémies d'EM étaient endémiques en Amérique du Nord. Puis, en 2015, le nombre de personnes atteintes d'EM au Canada a bondi de 37 % par rapport à l'année précédente.

Pendant près de 35 ans, cette maladie chronique fut reléguée à la catégorie « problème d'ordre psychologique » et affublée de l'appellation condescendante « syndrome de fatigue chronique », empêchant ainsi les discussions d'ordre médical et les efforts de recherche sur cette maladie biologique. Les patients ont beaucoup souffert de cette négligence de la part des institutions médicales et certains en sont même morts.

Malheureusement, de façon historique, le corps médical a tendance à classer dans la catégorie « psychologique » les maladies physiques qui touchent principalement les femmes (sclérose en plaques, endométriose, lupus, syndrome d'Ehlers-Danlos, fibromyalgie). L'EM n'échappe pas à cette règle. Au coût de décennies de stigmatisation ayant causé la perte de vies humaines, nous avons maintenant la certitude que ces maladies sont d'origine biologique. Aujourd'hui encore, malgré les nombreuses découvertes scientifiques réalisées à l'international sur le dysfonctionnement métabolique, les modifications épigénétiques et ce « quelque chose dans le sérum » des patients, cette façon délétère de pratiquer la médecine affecte encore les Canadiens atteints d'EM. Et malheureusement, l'EM n'est pas enseignée dans les écoles de médecine ; même

A2021000114 Page: 1006/1818 les collèges des médecins et chirurgiens accusent un accablant retard dans la compréhension de cette maladie.

Les effets délétères des soins médicaux conjugués à la maladie chronique augmentent le risque de suicide

Bien que cette maladie ne soit pas causée par la dépression ou l'anxiété, il est courant que les patients envisagent le suicide en raison de la douleur et de la souffrance constantes dont ils sont affligés. On ressent aisément de l'empathie pour ces personnes qui ont passé des décennies à souffrir d'une maladie intraitable, incurable et encore à ce jour largement stigmatisée par le système de santé — système de santé qui n'est pas encore au fait des dernières découvertes de la science et qui, au quotidien, nuit aux patients et à leurs familles.

De nombreuses études, dont une étude espagnole récente, ont démontré que les patients atteints d'EM ont un taux de suicide environ cinq fois supérieur à la moyenne nationale en raison des douleurs physiques perpétuelles et non traitées dont ils souffrent, de la perte de leur revenu et de leur carrière, de la perte de leur autonomie et parce qu'ils ont la plus faible qualité de vie [4] parmi tous les malades atteints de maladies chroniques. Et pourtant, ils sont rejetés par les médecins, lesquels ne se tiennent pas informés des recherches en cours sur l'EM, pas plus que les administrateurs de leurs collèges.

Cette méconnaissance de la maladie fait non seulement du tort aux patients dans les sphères médicales et sociales, mais elle a presque annihilé le financement pour la recherche. Jusqu'à tout récemment, les IRSC n'avaient aucuns fonds consacrés à la recherche biomédicale sur l'EM.

### La bonne nouvelle

Les IRSC se sont engagés à faire avancer la recherche biomédicale sur l'EM

En décembre 2018, en collaboration avec les IRSC, les parties prenantes se sont rencontrées à Montréal pour mettre sur pied le Réseau canadien de recherche concertée interdisciplinaire sur l'encéphalomyélite myalgique (ICanCME) en prévision d'une possibilité de financement des IRSC pour la recherche biomédicale sur l'EM. Le financement fut ensuite annoncé en avril pour un montant de 280 000 \$ par an sur cinq ans.

Le 22 août, la communauté des malades de l'EM assistait à l'annonce de la ministre de la Santé, Ginette Petitpas Taylor, selon laquelle les IRSC s'engagent à financer le Réseau canadien de recherche concertée interdisciplinaire sur l'EM.

La communauté voit cette annonce comme une assise importante qui servira à élargir davantage la recherche biomédicale. La communauté est reconnaissante du fait que les IRSC aient reconnu l'origine biologique de cette maladie et compris la nécessité d'investir dans la recherche collaborative afin de renverser la vapeur et cesser le tort fait aux malades. Cependant, le financement octroyé ne couvrira que la base nécessaire à l'élaboration d'un réseau.

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Il faudra beaucoup plus pour attirer les meilleurs chercheurs et réussir à résoudre les mystères scientifiques de l'EM. Malgré tout, la communauté des malades est motivée à tirer le meilleur parti de cette opportunité et entend participer aux efforts visant à augmenter la cadence en matière de recherche afin de recevoir de plus importantes subventions dans le futur.

Les patients atteints d'EM ont des besoins qui nécessitent des investissements ciblés beaucoup plus importants. Le gouvernement doit mettre en place les conditions idéales pour attirer les plus brillants chercheurs dans ce domaine.

Tout commence par la sensibilisation sur l'EM. Nous avons besoin de vous pour y arriver. Nous avons besoin que nos élus soient avec nous, debout à nos côtés.

### Trois choses que vous pouvez faire dès maintenant

Comme représentant élu, j'aimerais vous demander de faire trois démarches qui aideront à soutenir les patients tout en accélérant le mouvement vers l'obtention d'un financement équitable, de soins accessibles et de traitements:

- 1 Écrire à la nouvelle ministre fédérale de la Santé, l'honorable Patty Hajdu, pour exprimer votre soutien à notre cause et lui demander de faire appel aux ministres concernés et à leurs équipes afin d'organiser une rencontre avec des patients et des chercheurs. Cette rencontre leur permettra d'en apprendre davantage sur notre maladie et sur les obstacles à franchir pour accéder à des soins et du soutien convenables au sein de leurs départements respectifs. La liste des ministres en question est incluse dans la section « CC » ci-dessous.
- 2 Au nom de vos électeurs, distribuer la résolution SO31 aux membres de la Chambre des communes pour attirer leur attention sur la maladie et la nécessité d'obtenir du financement pour la recherche biomédicale équitable.
- 3 Vous joindre à notre groupe non partisan d'alliés, Allies for ME, afin de nous aider à sensibiliser le public et les médecins à la stigmatisation dont souffrent les gens atteints de cette maladie chronique invalidante et parler d'EM dans vos infolettres, dans vos rencontres à l'hôtel de ville et lors des consultations publiques et autres actions citoyennes auxquelles vous prenez part. Pour en savoir davantage, rendez-vous sur AlliesForME.ca ou faites parvenir un courriel à : Coordinator@AlliesForME.ca

Voici quelques exemples de ce que vous pourriez faire :

- 1) Organiser une discussion sur les enjeux de l'EM dans le cadre d'une assemblée d'électeurs ayant pour thème la santé.
- 2) Aller faire la connaissance de vos électeurs atteints d'EM (et d'autres maladies co-morbides).
- 3) Sur les réseaux sociaux, appuyer la Journée internationale de la sensibilisation à l'EM, le 12 mai, ainsi que la Journée internationale de la sensibilisation à l'EM sévère, le 8 mai. L'ancienne ministre de la Santé, Ginette Petitpas Taylor, s'est servie de sa plateforme en ligne pour attirer l'attention sur notre maladie, les défis qu'elle présente et nos besoins et l'impact en fut très significatif.
- 4) Vous abonner à notre bulletin mensuel en écrivant à : Coordinator@AlliesForME.ca

Votre empressement à entreprendre ces démarches sans tarder servira non seulement à démontrer votre soutien envers plus de 500 000 Canadiens atteints d'EM, mais il constituera également la prochaine étape essentielle vers l'obtention de financement équitable pour la recherche, la sensibilisation de nos médecins et la diminution du tort infligé aux malades sur le plan médical, social et financier.

Ces démarches pourraient figurer parmi vos plus belles réalisations comme représentant élu. En espérant avoir une réponse rapide de votre part, je vous remercie à l'avance de votre engagement.

Salutations distinguées,

A2021000114 Page: 1008/1818



CC:

Le très honorable Justin Trudeau, premier ministre

L'honorable Chrystia Freeland, vice-première ministre et ministre des Affaires intergouvernementales

L'honorable Patty Hajdu, ministre de la Santé

L'honorable Diane Lebouthillier, ministre du Revenu national

L'honorable Carla Qualtrough, ministre de l'Emploi, du Développement de la main-d'œuvre et de l'Inclusion des personnes handicapées

L'honorable Lawrence MacAulay, ministre des Anciens Combattants

L'honorable Navdeep Bains, ministre de l'Innovation, des Sciences et de l'Industrie

L'honorable William Morneau, ministre des Finances

L'honorable Ahmed Hussen, ministre de la Famille, des Enfants et du Développement social

L'honorable Maryam Monsef, ministre des Femmes et de l'Égalité des genres et du Développement économique rural

L'honorable Bardish Chagger, ministre de la Diversité et de l'Inclusion et de la Jeunesse

L'honorable Catherine McKenna, ministre de l'Infrastructure et des Collectivités

L'honorable Deb Schulte, ministre des Aînés

Dre Theresa Tam, administratrice en chef de la santé publique du Canada

Dr Michael Strong, président des IRSC

Allies for ME (Coordinator@AlliesForME.ca)

- [1] Dimmock, M., Levine, S., Wilder, T. (2018). Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: What every family physician needs to know. Family Doctor, 6 (Winter 2018), 23-25. http://www.nysafp.org/NYSAFP/media/PDFs/Family%20Doctor/Family-Physician-Winter-2018WEB.pdf#page=23
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- [3] Dimmock, M., Levine, S., Wilder, T. (2018). Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: What every family physician needs to know. Family Doctor, 6 (Winter 2018), 23-25. http://www.nysafp.org/NYSAFP/media/PDFs/Family%20Doctor/Family-Physician-Winter-2018WEB.pdf#page=23
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 From:
 Evans, Cindy (PHAC/ASPC)

 Sent:
 2019-12-05 1:44 PM

To: Namiesniowski, Tina (PHAC/ASPC)

Cc: <u>Tam, Dr Theresa (PHAC/ASPC)</u>; Thornton, Sally (PHAC/ASPC); Gooding, Elizabeth (PHAC/ASPC);

Mead, Jobina (PHAC/ASPC)

**Subject:** EVD update

Tina,

Further to your question at Daily this morning, below is more detailed information on the case counts in

You are correct that the downward trend is continuing.

Thanks Cindy 613-941-6084



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### WITHHELD / RETENUE

Is(Are) exempted and/or excluded pursuant to section(s) est(sont) exemptée(s) et/ou exclus en vertu de(s)(l')article(s)

13(1)(b)

Subject to subsection (2), the head of a government institution shall refuse to disclose any record requested under this Act that contains information that was obtained in confidence from (b) an international organization of states or an institut

Sous réserve du paragraphe (2), le responsable d'une institution fédérale est tenu de refuser la communication de documents contenant des renseignements obtenus à titre confidentiel : b) des organisations internationales d'États ou de leurs organ

A2021000114 Page: 1012/1818 From: Hollington, Jennifer (HC/SC)

Cc:

**Sent:** 2019-12-20 9:38 PM

To: <u>Lucas, Stephen (HC/SC)</u>; Namiesniowski, Tina

(PHAC/ASPC); <u>Tam, Dr Theresa (PHAC/ASPC)</u> <u>White, Belinda (HC/SC)</u>; <u>Johnstone, Marnie</u> (<u>PHAC/ASPC</u>); <u>Earley, Jaimie (HC/SC)</u>; <u>Della</u>

Penta, Carol (HC/SC); Lafkas, Cathy (HC/SC)

Subject: Executive Sessions with Ashley Good from Fail Forward

Attachments: Symposium Program-December 20.docx; Overview of Executive Coaching

session..docx

Categories: Follow-Up

Steve, Tina, and Theresa

As you know, we are planning a learning symposium in February to help enhance employees' capacity for experimentation and innovation.

This event will take place on February 19 in Richcraft Hall at Carleton University, and will be live-streamed to regional employees. This all-day event will include a variety of workshops and panel discussions along with exhibits that showcase innovation and experimentation within the Health Portfolio.

One of our speakers at the Symposium will be <u>Ashley Good from Fail Forward</u>. Ashley is a leader in supporting organizations in recognizing and benefiting from failure as a part of the innovation process.

As I have previously mentioned, in conjunction with the Symposium, we are organizing two 90-minute sessions—one for HC EC and one for PHAC EC or a mix of participants from both organizations. These sessions would be led by Ashley on either February either 18 or 20. The discussions are designed to help senior leaders in areas such as applying the learnings from failed projects and encouraging smart risk-taking. As promised, I have attached a more detailed description of the session and a draft program of the Symposium.

We will reach out to EC members to confirm their interest and availability for the session and will then confirm the dates. Please let me know if you have any questions.

Jen

### Jennifer Hollington

Assistant Deputy Minister | Sous-ministre adjointe

Communications and Public Affairs Branch | Direction générale des communications et des affaires publiques

Health Canada | Santé Canada

Public Health Agency of Canada | Agence de la santé publique du Canada 70 Colombine Driveway, Tunney's Pasture | 70, promenade Colombine, Pré Tunney Ottawa, ON K1A 0K9

jennifer.hollington@canada.ca
Telephone | Téléphone 613-960-2176

A2021000114 Page: 1013/1818 Cell | Cellulaire 613-816-6073 PIN EF051032 Government of Canada | Gouvernement du Canada



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# Proposed HC and PHAC Executive Committee Sessions Failing Forward: How senior leaders can embrace intelligent failure February 18 or 20, 2020

### Overview

- The Health Canada and PHAC learning symposium entitled "Innovation and Experimentation: Your Mindset Matters" will take place on Wednesday, February 19 in Richcraft Hall at Carleton University and will be live-streamed to regional employees.
- This all-day event will include a variety of workshops and panel discussions along with exhibits that showcase innovation and experimentation within the Health Portfolio.
- We are proposing to organize—in addition to the Symposium—90-minute sessions for the HC and PHAC Executive Committees on Tuesday, February 18 or Thursday, February 20.
- These sessions would be facilitated by Ashley Good, founder of Fail Forward Inc. Ashley
  has considerable expertise in helping organizations learn from failure and become more
  innovative in the process.
- When failure happens, the real failure is not the mistake but our failure to learn from it, she says. From Ashley's perspective, the importance lies in learning *through* failure as opposed to learning *from* failure. The former is about detecting failure quickly, understanding it and adjusting along the way. The latter is about looking back after the fact.
- Each session would be designed to help senior leaders:
  - o Become more comfortable with failure;
  - Detect failure early and adjust course;
  - o Apply the learnings from failed projects; and
  - Encourage the smart risk-taking that comes with innovation and experimentation.
- Ashley would stress how the words and actions of senior leaders encourage or discourage employees from identifying, learning from and speaking up about projects that did not go as planned.
- Through facilitated dialogue, participants will learn what they can do, or should stop doing, to successfully integrate intelligent failure into the work of their teams.

### **Session Agenda**

- Introduction session goals (5 minutes)
- What does intelligent failure look like? (10 minutes)
- What are the challenges and barriers to intelligent failure (20 minutes)
- What is already in place? (15 minutes)
- What can leaders do to embrace intelligent failure? (40 minutes)

### Questions for attendees to consider in advance

Failing intelligently includes:

- · trying new things and taking smart risks;
- · accepting some failure as inevitable;
- · detecting failure quickly;
- analyzing and learning from what didn't work;
- remembering that we are learning so we change, improve and not repeat mistakes; and
- not letting failure make us more risk-averse but rather letting it motivate us to try again, only more wisely.
- 1. Often we know we should do these things, but still don't. Based on your experiences, what is the most important challenge or barrier you face to failing intelligently?
- 2. What are some examples of where intelligent failure is already happening in your organization?
- **3.** What are you already doing that might be used to promote intelligent failure (e.g., hiring, training, mentoring, performance reviews, project evaluations, feedback mechanisms, goal setting, newsletters)?

# Your MNDSET Matters:

# HC and PHAC Innovation and Experimentation Symposium

Wednesday, February 19, 2020

### **PURPOSE OF SYMPOSIUM:**

To create awareness about mindset (skills and behaviours) for innovation and experimentation; build employee's knowledge and capacity; showcase employee-led initiatives.

8:00 - 9:00 Registration

### 9:00 - 10:00

### Hosted by Innovation Champions Jen Hollington and Kendal Weber

- Welcome participants (Jen and Kendal)
- Invite Elder to open symposium (Intro by Jen)
- Deputy Minister Video (Intro by Kendal)
- PHAC President (Intro by Jen)

10:00 – 10:30 Keynote Speaker – Alex Ryan, Vice President of MaRS (Intro by PHAC President)

Topic: Cultivating a mindset for innovation and experimentation

10:30 - 11:00 Health Break | Networking | Exhibition Viewing

11:00 - 12:30 Concurrent Breakout Sessions - 90 minutes each

### Session 1

# What is experimental design?

GC context, methods, how to identify the right experimental method, HC examples

Presenters: Sarah Chan, Pierre-Oliver Bedard – TBS

### Session 2

# Innovative Approaches to Explore a Problem

Various approaches, how to identify the right one, HC and PHAC examples, how it aligns to experimentation

Presenters: Julie Greene – PCO, Michelle Musgrove – HC, PHAC rep TBD

### Session 3

### Policy and Experimentation

What is policy innovation? Approaches such as behavioural economics, what is experimental policy?

Presenter: Tamara Girard, Canadian Heritage

12:30-1:30 Lunch | Networking | Exhibition Viewing

1:30 – 2:30 Plenary Panel: Failing to Learn and Learning to Fail – What Can We Learn from Our Failures

Moderated by: Leanne Labelle (CDS) or Fabio Onesi (HC)

Presenters TBC: Ashley Good (Fail Forward Inc.), Chad Hartnell (PCO), James McAllister (HC), PHAC representative (TBD)

2:30 - 3:00 Networking | Exhibition Viewing

3:00 – 4:30 Concurrent Breakout Sessions

### Session 4

### HC Approaches to Innovation and Experimentation

How is HC defining its work within this context? What is the Solutions Fund? How is it developing capacity? Challenges? Successes?

Presenters: Cathy Bennett, Benny Ling (TBC)

### Session 5

### Evolving World of Digital Government – Panel Discussion

The digital shift, how we manage technology and technological change, open government, innovation

Panel participants TBC

### Session 6

Innovation and Experimentation at PHAC

PHAC to organize

# VENUE AND TECH:

# Richcraft Hall, Carleton University

\*Live-streamed for NCR and regional employees using Webex.

Exploring the feasibility of using a QR code to access symposium program and links (e.g., Slido) via our phones.

'Greening' practices will be in place (e.g., no plastics, recyclable signs, recycle bins, etc.

### ADDITIONAL RESOURCES:

Each session will have additional resources including videos, articles, blog posts, etc. to learn more about the topics on GCcollab, GCpedia, or web platform.

### **EXHIBITIONS:**

Up to 15 exhibits showcasing innovation and experimentation in the Health Portfolio and GC.

### **MINI HACKATHON HC DATA TEAM**

Led by Jenni Bennet-Gilmour

Text and times to be confirmed.

**4:30** Closing Remarks by Innovation Champions

From:	Tam, Dr Theresa (PHAC/ASPC)
Sent:	2019-12-30 11:27 AM
То:	Rendall, Jennifer (PHAC/ASPC)
Subject:	Re: Federal government asked Canadians if they're 'comfortable' with LGBT people - National   Globalnews.ca
Thanks for passing this on.	
It is good to see some positive data. We do know have to stand back further and take a longer term	that society has changed over time for the better. We just view.
This is why I like the book Factfulness. People fo we need to build on the positive and not just focu	erget how much better society as a whole has become and s on the negative.
Great start to our 2020 attitude!	
Sent from my iPhone	
> On Dec 30, 2019, at 10:23, Rendall, Jennifer (P >	PHAC/ASPC) < jennifer.rendall@canada.ca> wrote:
> Interesting - had not seen this POR report altho >	ugh I'm sure others have as it was done pre-election
> Nice to see evidence of positive trend/not all do	oom-and-gloom messaging for messaging.

 $> \underline{https://globalnews.ca/news/6344287/canadian-government-asked-canadians-comfortable-lgbtq2/2}$ 

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From: Sent:

To:

Cc:

Tam, Dr Theresa (PHAC/ASPC)

2019-12-23 2:13 PM

Wong, Tom (SAC/ISC)

CCMOH SECRETARIAT / CMHC (PHAC/ASPC);

**SKPHNCsecretariat** 

Subject: RE: final (hopefully) version of CCMOH position

statement #4 on nicotine vaping

I will have to do the internal check ins now that we have a draft that is near final. I don't expect I will be able to respond until the beginning of January as people have started their vacation already.

I have alerted Comms and the Secretariat that the aim is to get this statement out the third week of Jan.

P.S. This team will be working to get the Cannabis statement out on Jan 6.

Theresa

From:

**Sent:** 2019-12-23 11:47 AM

To:

Wong, Tom

(SAC/ISC); Tam, Dr Theresa (PHAC/ASPC)

Cc: CCMOH SECRETARIAT / CMHC (PHAC/ASPC); SKPHNCsecretariat

Subject: final (hopefully) version of CCMOH position statement #4 on nicotine vaping

Colleagues,

Please find attached (clean and track changes versions) a hopefully final version of the proposed 4<sup>th</sup> CCMOH position statement of nicotine vaping products for your consideration. There have been relatively minor language changes suggested by our federal colleagues Tom and Theresa.

I propose that we aim to release this during National Non-Smoking Week (week of Jan 19-25, 2020) so can you please let me know by January 10<sup>th</sup> (earlier is better if you are able) if you agree with the letter and are able to be a signatory.

Thank you and I wish each of you a joyful and peaceful holiday time.

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From: Tam, Dr Theresa (PHAC/ASPC) Sent: 2019-12-20 7:59 AM To: Bell, Tammy (PHAC/ASPC) Cc: Rendall, Jennifer (PHAC/ASPC) Subject: Re: Follow up to your talk with the Chiropractors I am OK with the article if someone drafts this. At some point we need to transition the focal point of interaction to CIRID. Setting up a Booth is easier said than done especially if there are costs. Program needs to be the lead, working with Regions and Comms. So, I think CIRID need to do the assessment as to whether they want to and can do this. TT Sent from my iPhone On Dec 19, 2019, at 21:51, Bell, Tammy (PHAC/ASPC) < tammy.bell@canada.ca> wrote: Hi, we didn't have time to discuss today but wanted to flag that the CCA released their statement and so far feedback has been positive. They have invited you to write a guest feature article (800-1000 words) in their membership magazine. Aim would be for March edition and topic proposed is value of collaboration in public health. They also would like us to share some other public health materials with them and have suggested we might consider a booth at their upcoming national conference in Halifax

Thoughts? It would be good to do the article now that you've made such a good impression:) And Maybe the regional office could set up a booth at their

convention and we could recruit someone from Gina's group to go, as well as someone working on pain TF.

More details below...

From:

**Sent:** 2019-12-16 4:38 PM

To: Rendall, Jennifer (PHAC/ASPC)

<jennifer.rendall@canada.ca>
Subject: Ongoing collaboration

Good afternoon, Jennifer. I hope this note finds you well!

Dr. Tam's presentation at our recent Presidents' Meeting was a real success! Thank you so much for all of your assistance in making it happen. As a follow up, we released our updated vaccination statement and feedback was overwhelmingly neutral to positive. Thank you to you and your team for the insights and collaboration. It was helpful and very much appreciated.

I'm writing today to offer a few more opportunities to collaborate. The first is to ask if Dr. Tam would be willing to provide a 'guest feature' article for our upcoming Back Matters magazine (currently scheduled to be published in March 2020). The proposed focus would be "the value of collaboration in support of public health" or something similar, between 800-1000 words, accompanied by some visual (likely photos we took at the meeting in November.) If Dr. Tam approves this, we'd appreciate having your final draft by early February – the 7<sup>th</sup> to 10<sup>th</sup>. Please let me know if this is doable.

We'd also like to take you up on your offer to provide us with materials we can share with members — info on various issues of public health importance, any infographics you think would be useful to them/their practice, etc. If you have materials (pdf's, infographics, etc.), we would use them in member communications to help educate and inform on items of importance to Canada's health.

Finally, I'd also like to let you know about an opportunity that may be of interest. Our upcoming National Convention includes a trade show that allows organizations to reach convention participants. The rates are reasonable and would provide PHAC an opportunity to build awareness of PHAC and its important work with Canada's chiropractors, chiropractic researchers and a variety of stakeholders within the health care field. Please let me know if this is of interest and I'll connect you/your team with our event team.

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Many thanks in advance! Hope you're having a lovely day!

