



1:30pm – 3:00pm

Mitigating disruption: Integrating social, ethical and policy research into the development of disruptive technologies

*Panel Organizer: Rob Annan
Genome Canada*

Mitigating Disruption: Integrating Social, Ethical and Policy Research into the Development of Disruptive Genomic Technologies



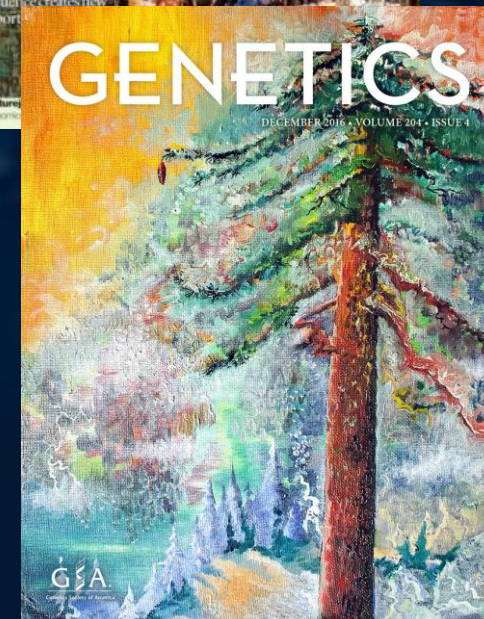
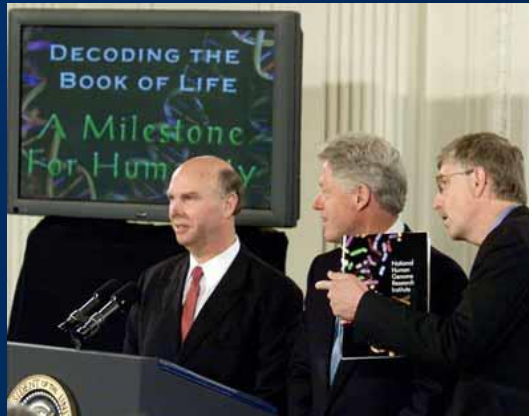
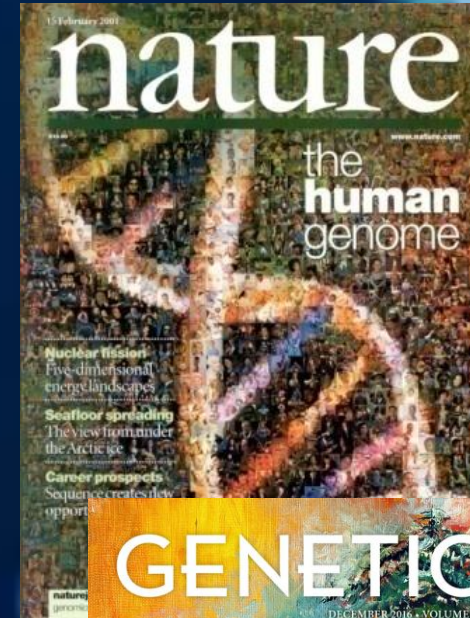
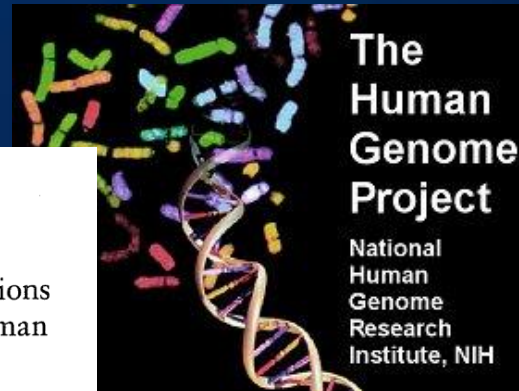
Canadian Science Policy Conference
Thursday, November 8, 2018



Bioethics Inside the Beltway

The Ethical, Legal, and Social Implications
Research Program at the National Human
Genome Research Institute

ERIC M. MESLIN, ELIZABETH J. THOMSON, AND JOY T. BOYER





RESEARCH PRIORITIES

ELSI 2.0 for Genomics and Society

June Kaye,^{1*} Eric M. Meslin,² Barbara M. Knoppers,³ Eric T. Juengst,⁴ Mylena Deschênes,⁵ Anne Corbin-Thomson,⁶ Donald Chalmers,⁷ Justine De Wree,⁸ Kelly Edwards,⁹ Nisha Hays,¹⁰ Alastair Kent,¹¹ Clement Adamowicz,¹² Patricia Marshall,¹³ Kazuo Kato¹⁴

Anticipating and addressing the ethical, legal, and social implications (ELSI) of scientific developments has been a key feature of the genomic research agenda (1-4). Research in genomics is advancing by developing common infrastructures and research platforms, open-access and sharing policies, and new forms of international collaborations (5-7). In this paper, we outline a proposal to establish a "collaboratory" (18) for ELSI research to enable it to become more coordinated, responsive to societal needs, and better able to apply the research knowledge it generates at the global level. Current ELSI research is generally nationally focused, with investigator-initiated approaches that are not always aligned with the developments in international genomics research. This makes it difficult to efficiently leverage findings that impact global practice and policy. Moreover, as translational genomic research design challenges become more pressing (14), ELSI research will need to develop greater capacity to respond rapidly to new developments. The ELSI 2.0 initiative is designed to catalyze international collaboration in ELSI genomics and to enable those in the field to better assess the impact and dynamics of global genomic research.

Vision
The aim of ELSI 2.0 is to accelerate the translation of ELSI research findings into practice and policy. To do this, we will build on successful examples of international ELSI research. To succeed, ELSI 2.0 must be grounded in a commitment to the shared values of mutual respect, trust, and active collaboration. It will require the development of new methods and frameworks for the strategic targeting of research to overcome current barriers to international, interdisciplinary research. Through ELSI 2.0, ELSI researchers can be globally connected while still carrying out locally sensitive research. By enabling large-scale global collaborations among a range of stakeholders, ELSI research will become more effective, efficient, and economical—leading to development of better local, regional, and international practice and policy.

Design and Methods: The Collaboratory
The collaborative Web-based infrastructure (see the figure) will be open to all ELSI researchers, national and international agencies, and other research "consumers," including the general public and advocacy groups. It will provide ways for ELSI research to make an impact on policy and practice. It will be an active, generative space, distinct from discussion boards or networks. The Collaboratory will provide information on research resources, prospective projects, and workspaces for online collaboration, as well as additional software and workshops. ELSI 2.0 will facilitate a variety of activities—including networking, rapid response, "crowd-sourcing," modeling, forecasting, and the development of proactive strategies to coordinate and enable international ELSI research. It will give a sense of the terrain of the international ELSI landscape, which will be used to identify overlaps and similarities that exist in different localities despite there being different national cultures, legal systems, and policy regimes in place. Identifying and appreciating regional differences can strengthen our understanding of the complexity of bioethics issues and provides a basis for shared learning. For example, the works of Pichon *et al.* (15) and Sankar *et al.* (16) on genetic discrimination are proving to be extremely informative in designing a project on stigma in genomics in Africa. By using ELSI 2.0, tracking and coordinating ELSI research will also be possible at a global level and will accelerate the impact of research on policy.

For an ELSI scholar in Africa, ELSI 2.0 could be a place to connect with other scholars or to tap into resources not otherwise readily available. For a US-based advocacy organization, the Collaboratory will provide essential services to extend the reach of work otherwise locked up in the academic literature. A funder in the European Union could request a rapid response team to respond to ad hoc, short-notice requests related to emerging issues or to forecast important policy directions. A patient could become an active participant in ELSI research or find literature and experts on subjects such as direct-to-consumer testing. For a scholar in Asia looking to fund a multicountry effort, the Collaboratory could help identify funding sources, collaborators, and workspaces for the idea. Scholars could choose to be observers or builders and creators (posing projects for a workspace or a crowd-sourced effort) or to motivate collaborators who would not otherwise be accessible (clinicians, patients, policy-makers). In this way, ELSI 2.0 will continually build and support global ELSI research and policy-making capacity.

The Collaboratory will stimulate creativity and communication between researchers, diverse policies, funders, and policy-makers in a variety of ways. It will provide a Web-based infrastructure with the same capabilities as the collective platforms used in large-scale, international genomics science and elsewhere and will draw on a variety of approaches to maximize interactions, including networking, rapid response, crowd-sourcing, modeling, forecasting, and the development of proactive strategies and comparative methodologies to enable international ELSI research in genomics. This will include modeling exercises for the construction of international frameworks and approaches to issues. These provisions will promote efficient use of research and resources, avoiding redundancy.

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Making sense of a changing world

D/ISRUPTION

WINTER 2018

The 18 disruptive technology trends impacting business in 2018

Genomics

Mapping life itself

The digital revolution was for starters, says Professor Dr Koen Kas, CEO of Healthskouts. Welcome now to the genomic revolution...

GENOMICS IN SOCIETY Expert Panel

Integrated GE²LS Research Review Report

September 2018

GenomeCanada

GLOBAL CHALLENGES • GENOMIC SOLUTIONS

Embedding New Technologies into Society

A Regulatory, Ethical and Societal Perspective

edited by
Diana Bowman
Elen Stokes
Arie Rip

Panelists



Jacques Simard

Université Laval

Bartha Maria Knoppers

McGill / Centre of Genomics
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UBC / Centre for Forest
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UBC

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Mitigating Disruption:

Integrating Social, Ethical and Policy Research into the Development of Disruptive Technologies

Jacques Simard

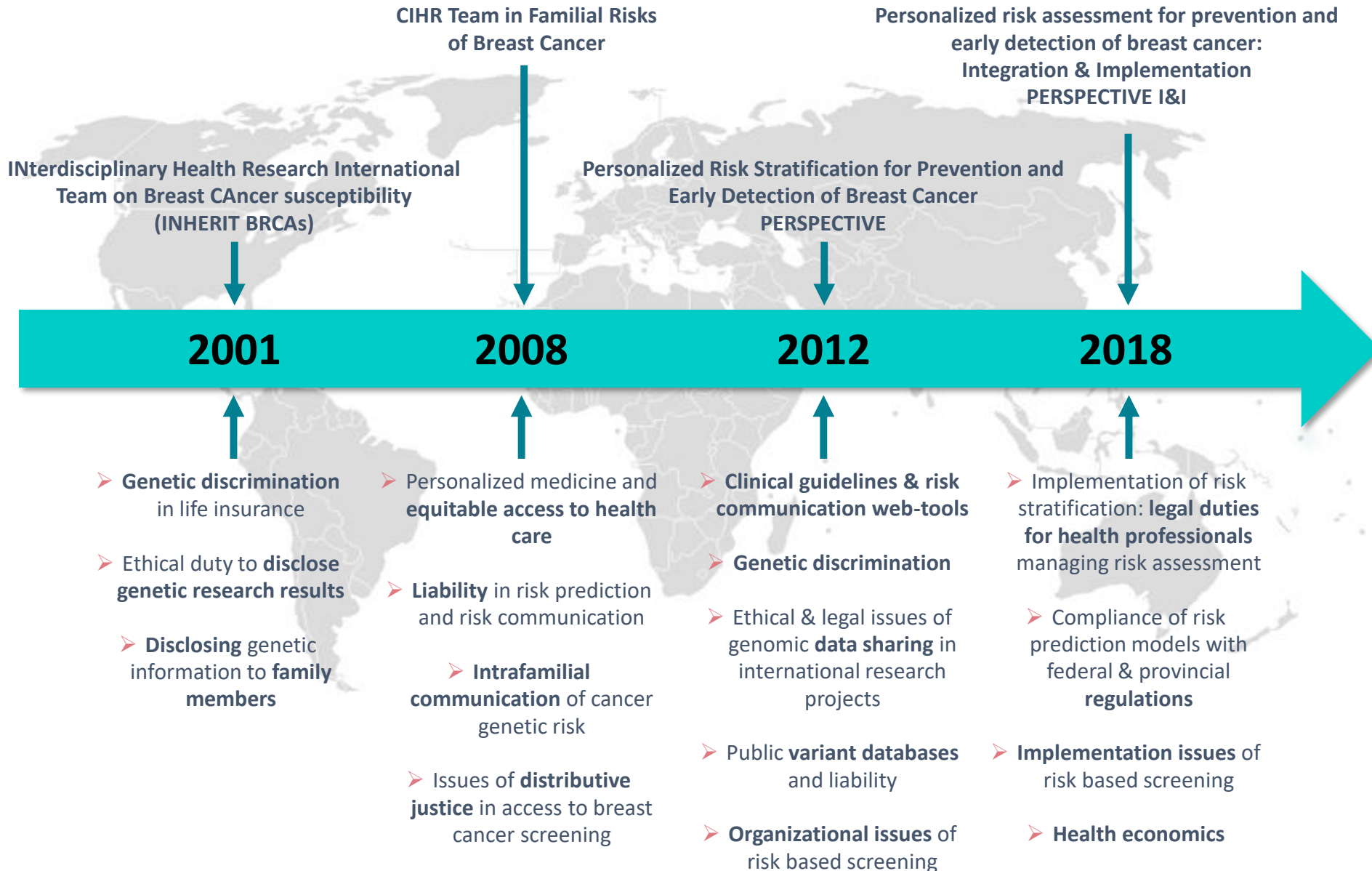
CHU de Québec - Université Laval Research Center
Université Laval

Bartha Maria Knoppers

Centre of Genomics and Policy
McGill University

Canadian Science Policy Conference
November 8, 2018

Longstanding Collaborations in Large-Scale International Projects



Breast Cancer Risk Stratification



Importance of risk stratification for efficient population health management

- Will help identify individuals in the population that are at low-, moderate-, and high-risk of the disease.
- Will improve screening outcomes and risk reduction interventions by targeting those women most likely to benefit.
- Could lead to improvement in survival and in quality of life.
- Will allow more efficient allocation of health care resources.

➤ Risk stratification tools developed in the PERSPECTIVE project

Clinical-grade polygenic
risk score genetic test

Comprehensive risk
prediction web-tool
(BOADICEA)

Economic
microsimulation
model

Clinical guidelines and
web-based risk
communication tool

Identification of a Genetic Risk Profile for Breast Cancer



RESEARCH TEAMS FROM

50

COUNTRIES

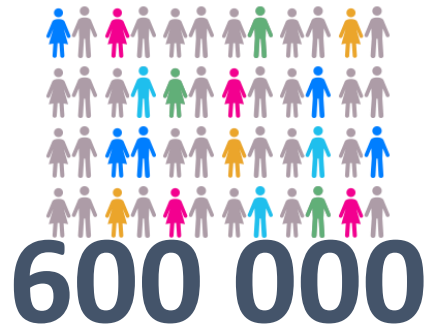


“ONCOARRAY”

INTEGRATION OF
DATA



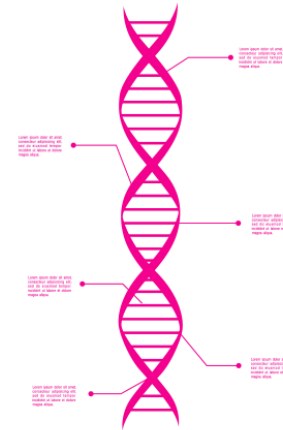
MEDICAL HISTORY
TUMOR PATHOLOGY
TREATMENT RESPONSE
ENVIRONMENT
FAMILY HISTORY



600 000

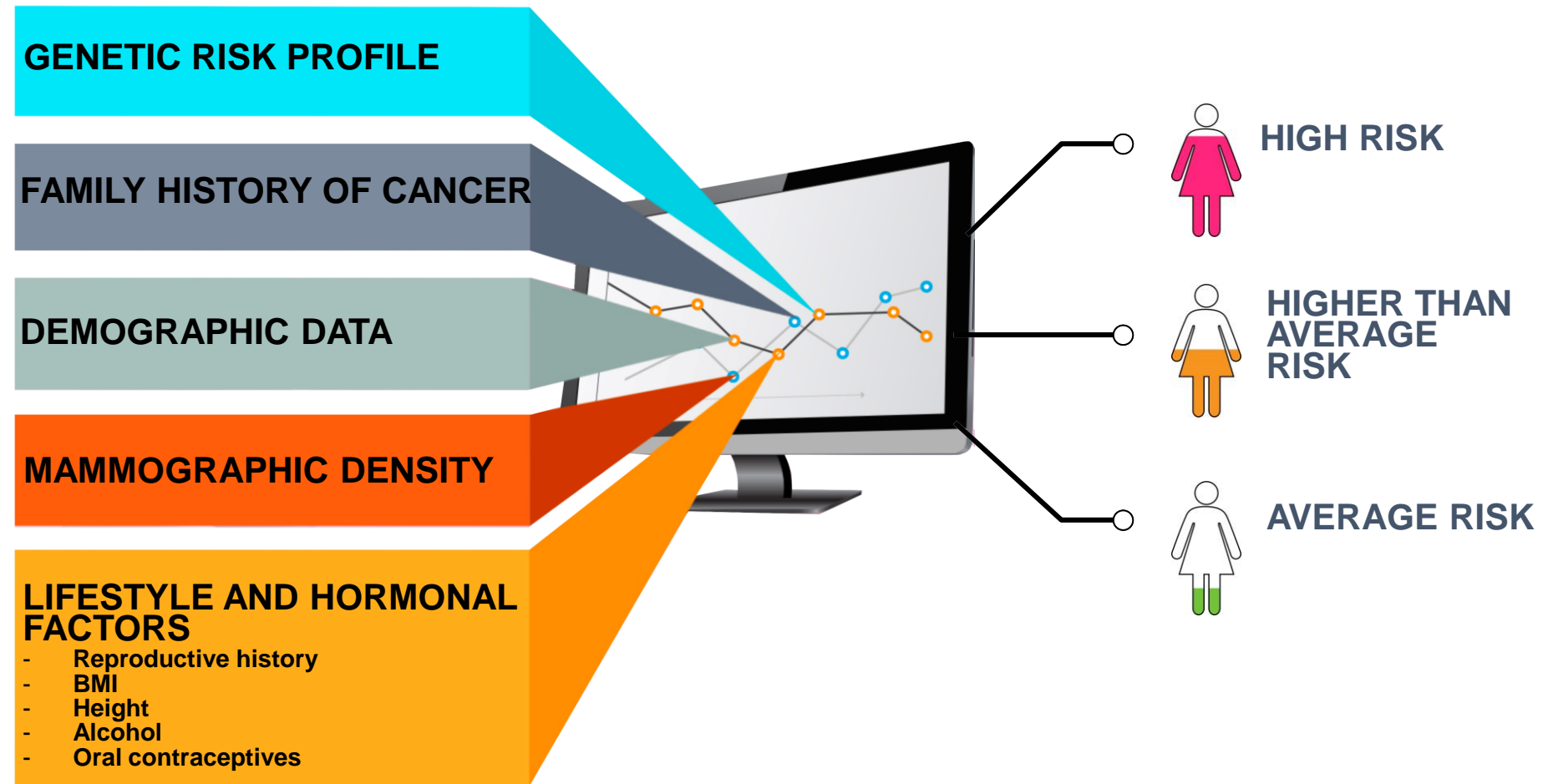
PARTICIPANTS

BREAST
PROSTATE
LUNG
OVARY
COLORECTAL



ANALYSIS OF
GENOMIC
DATA

Breast cancer risk profiling



Seeing the forest (and the people) for the trees: Genomics, social science and climate adaptation

Shannon Hagerman and Sally Aitken
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CSPC 2018

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Natural Resources
Canada
Ressources naturelles
Canada



Climate change is impacting forests widely

The New York Times

U.S.

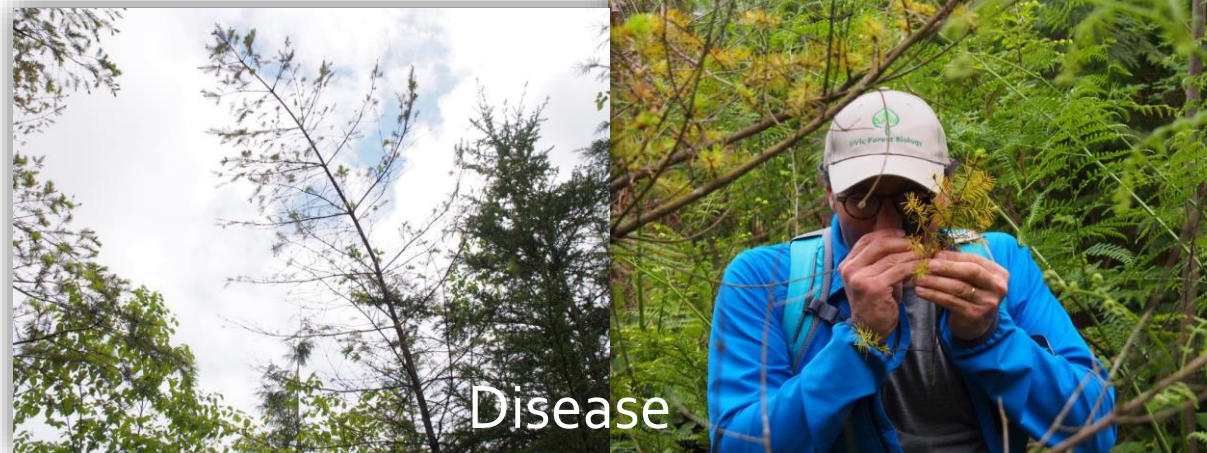
California Today: More Than 100 Million Trees Are Dead. What Now?



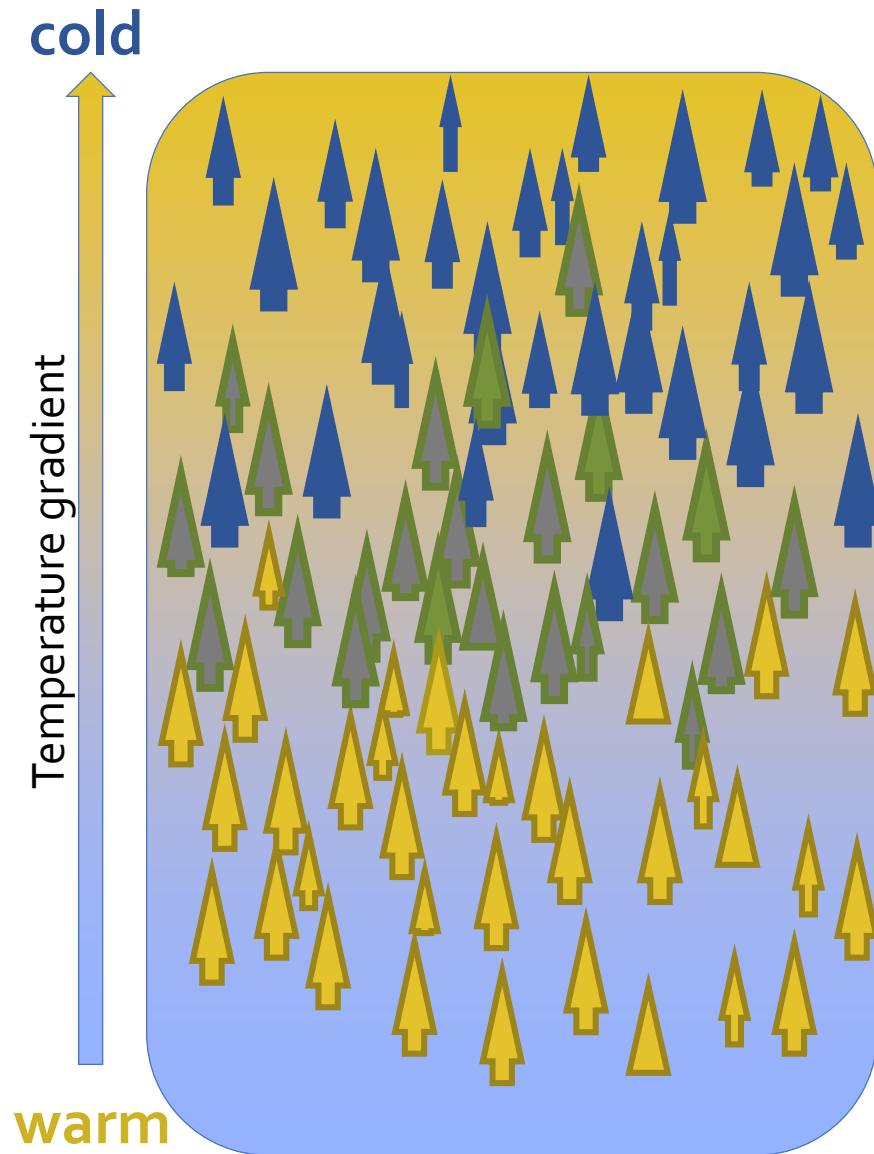
Mike McPhate
CALIFORNIA TODAY NOV. 21, 2016



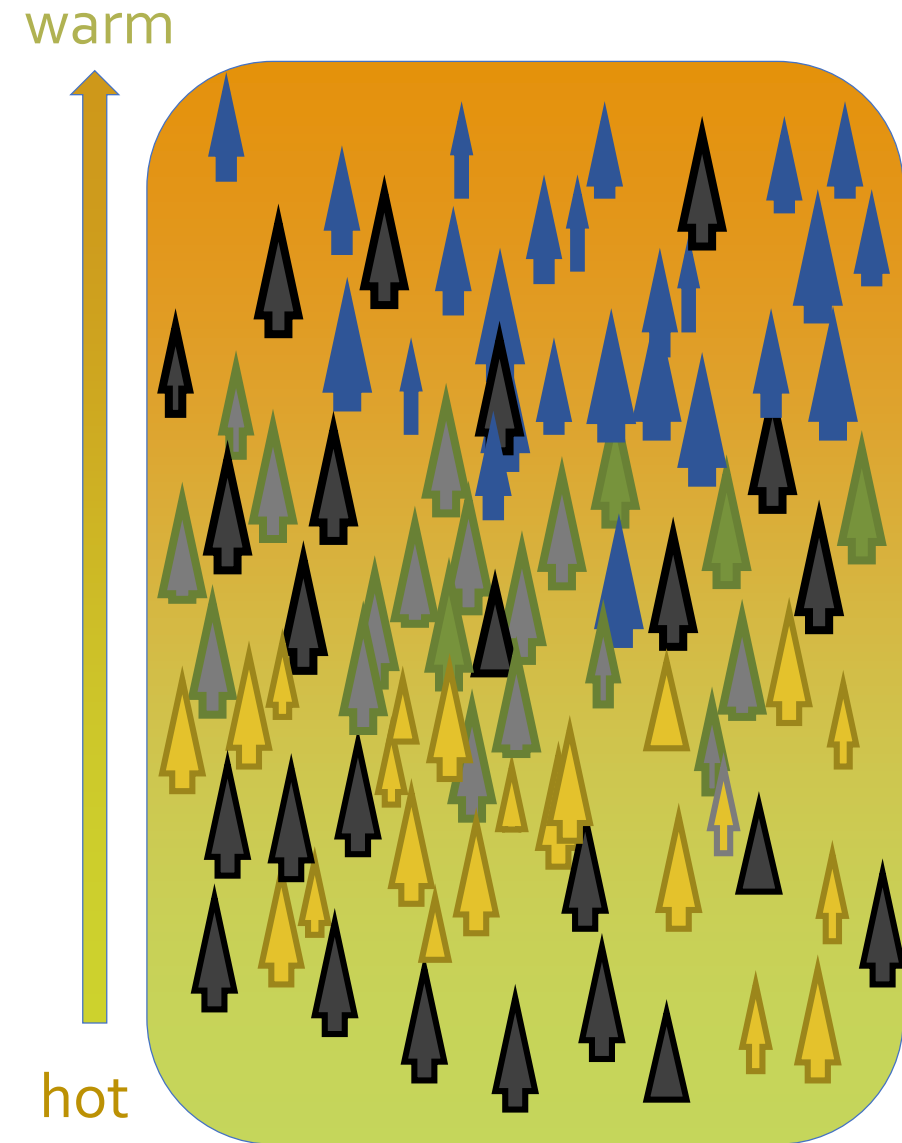
By Veronica Rocha and Hailey Branson-Potts • Contact Reporters



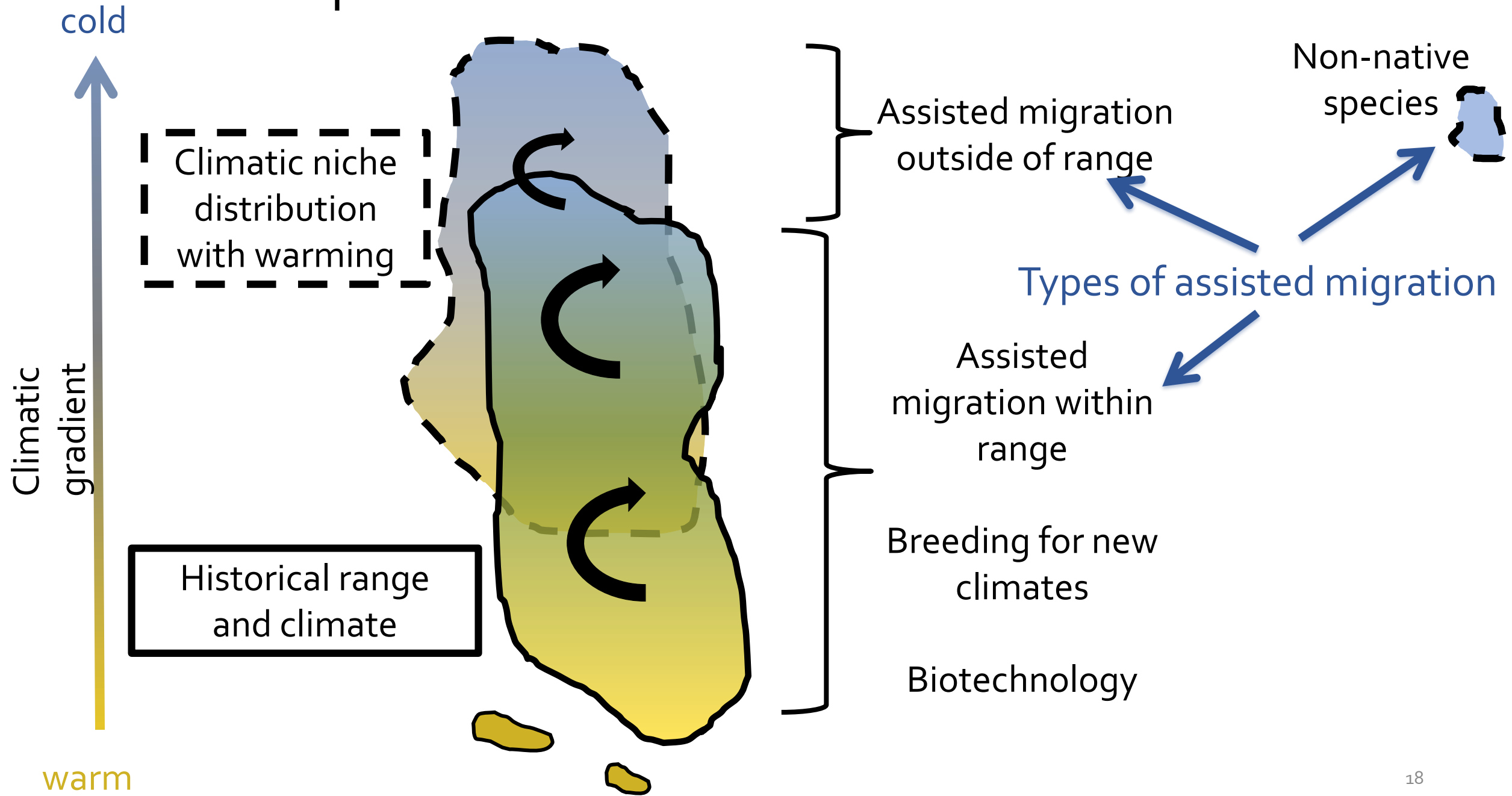
Trees are genetically adapted to historic climate

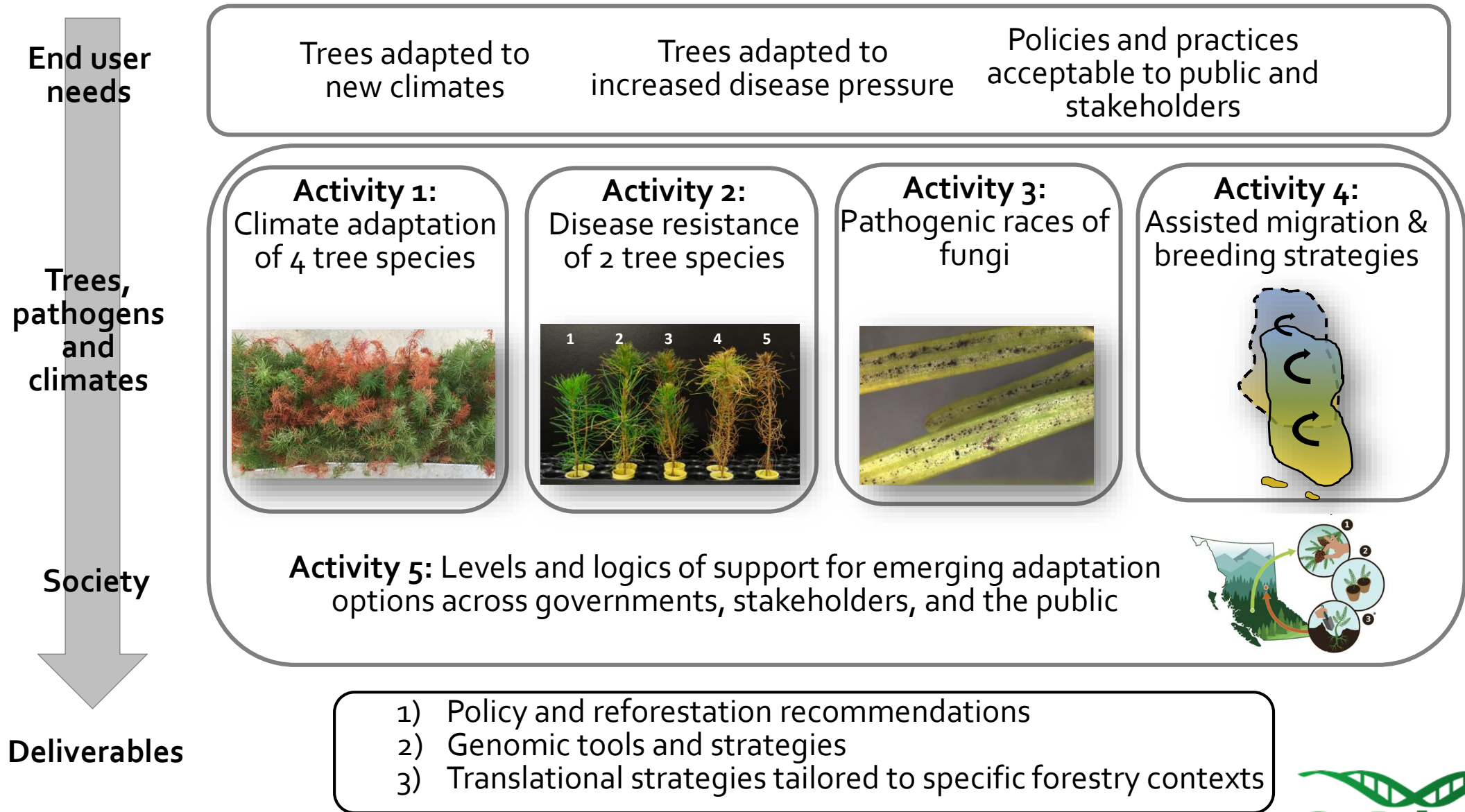


And mismatched with future climate



One option: Plant trees matched with new climates



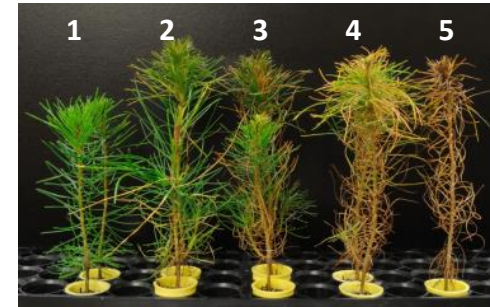


How are we using genomics to inform climate adaptation and manage disease risk?

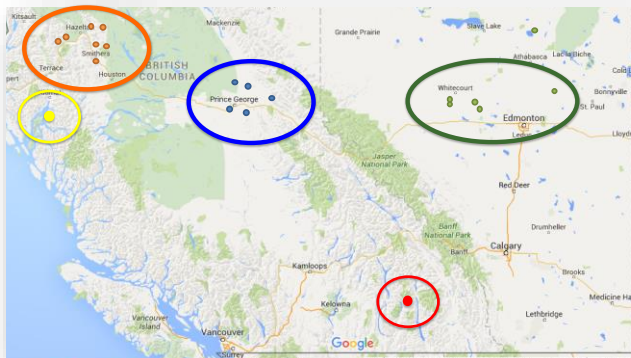
- 1) Identify genes involved with climate adaptation of tree species



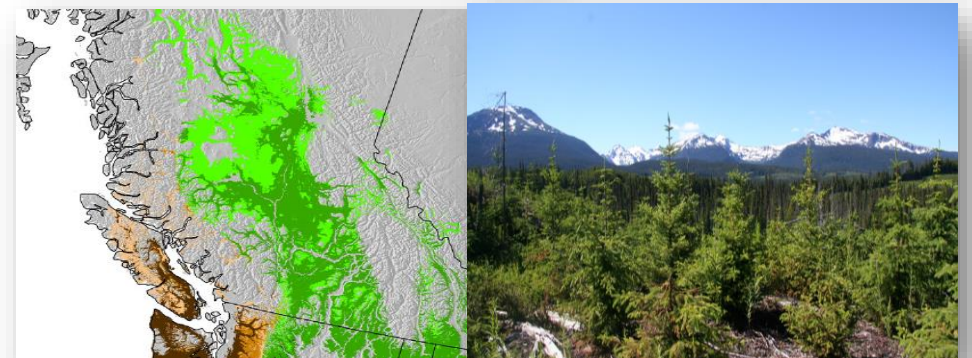
- 2) Identify genes associated with disease resistance or tolerance



- 3) Identify pathogenic races of fungi

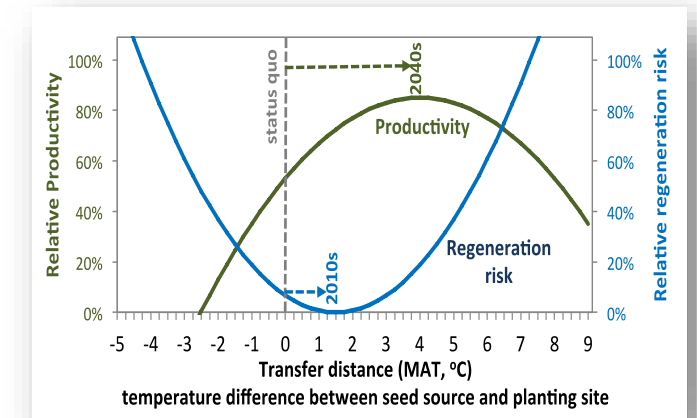
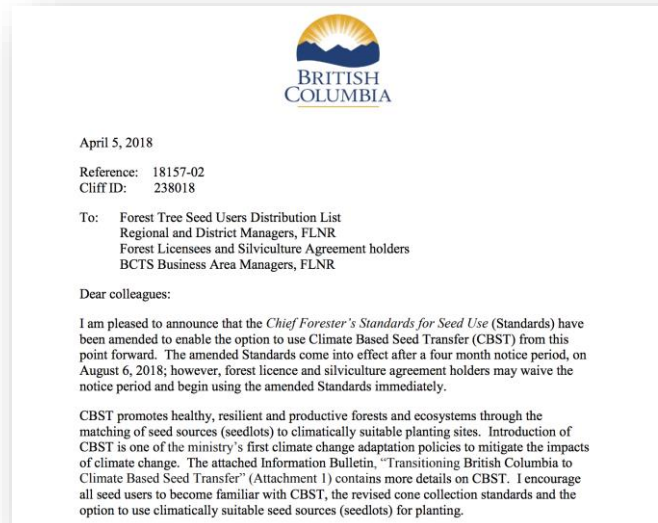


- 4) Develop genomic tools and strategies for selecting trees for reforestation

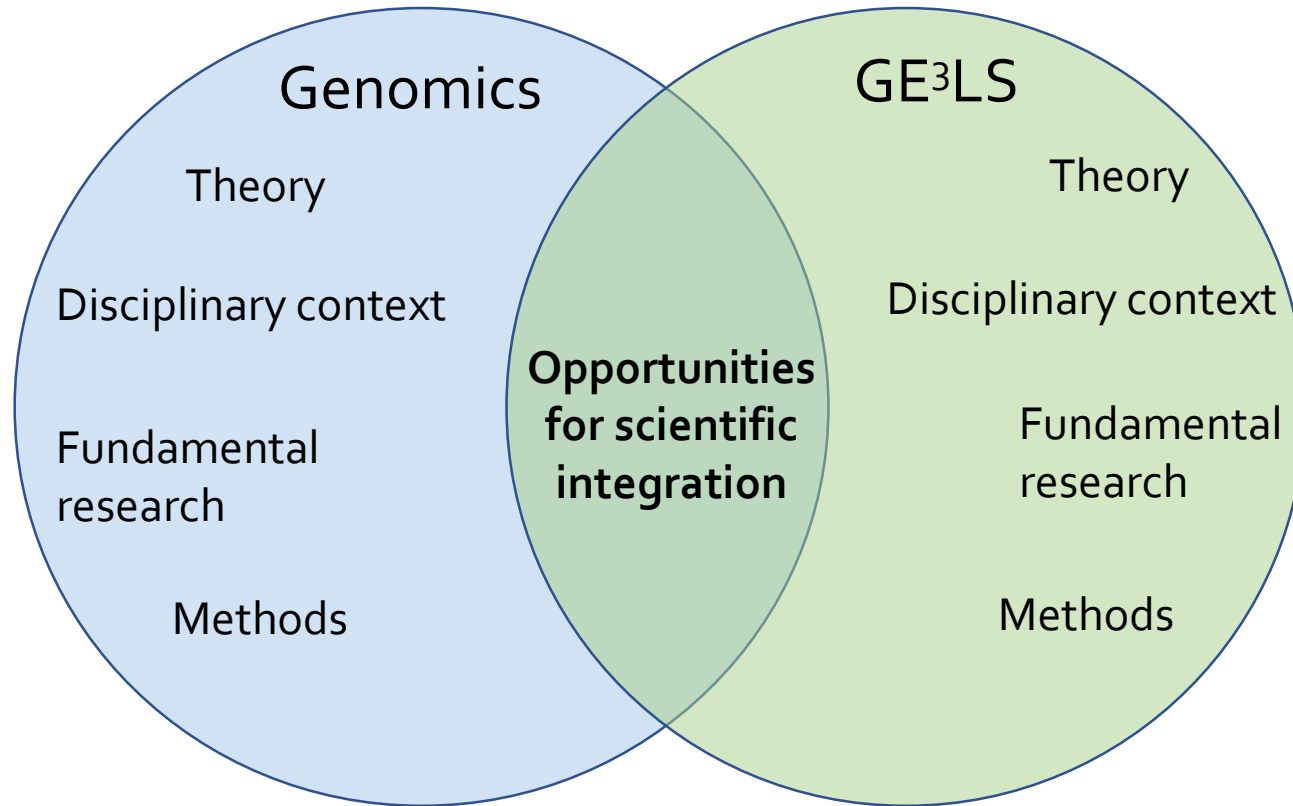


How can the social sciences help understand the application of genomics tools in forestry?

- 1) Identify risk profiles of diverse publics about assisted migration and other strategies for forestry
- 2) Identify and characterize policy barriers & opportunities
- 3) Identify socio-economic outcomes of forestry interventions



Enabling factors for scientific integration

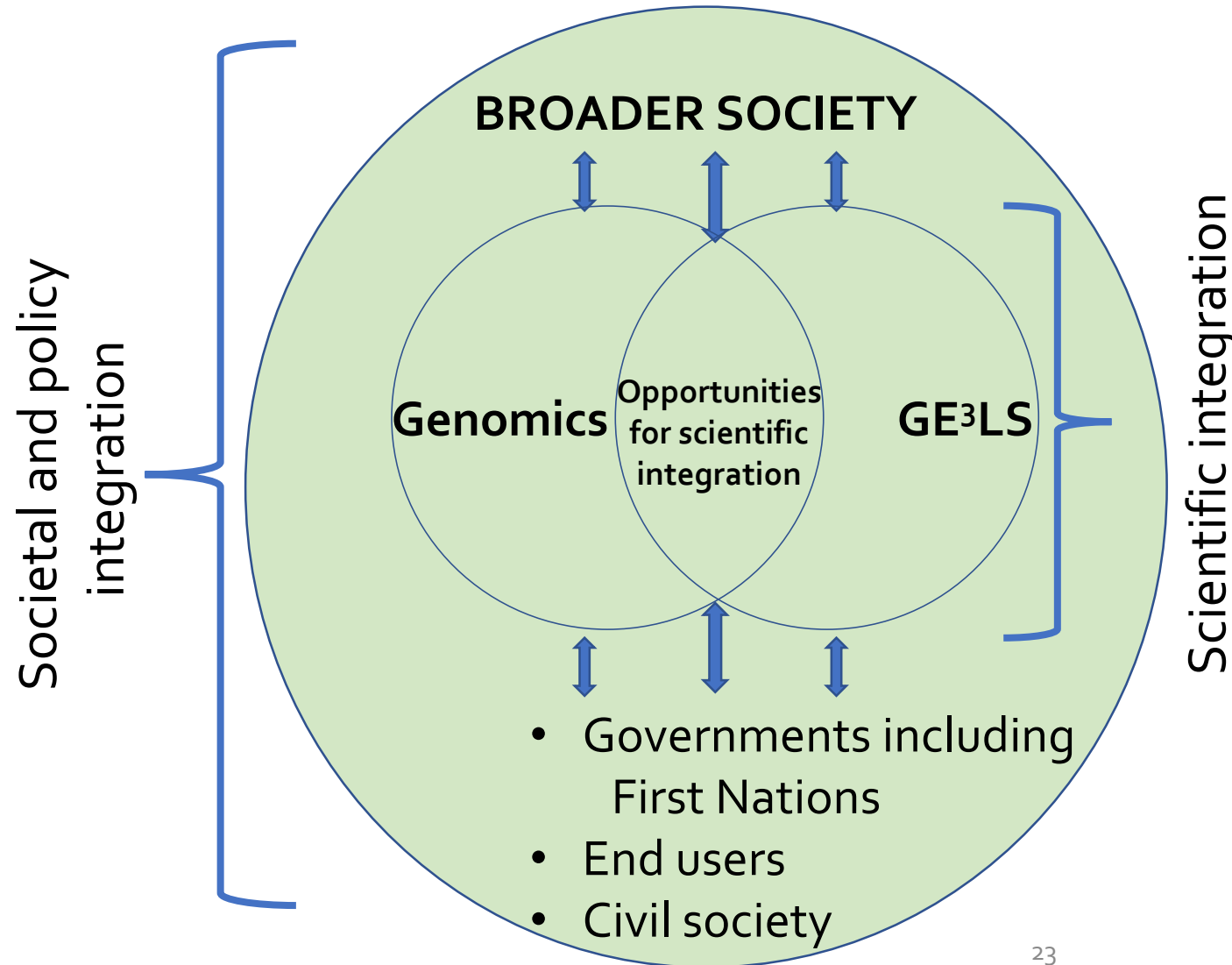


Interdisciplinary nature of forestry enables scientific integration

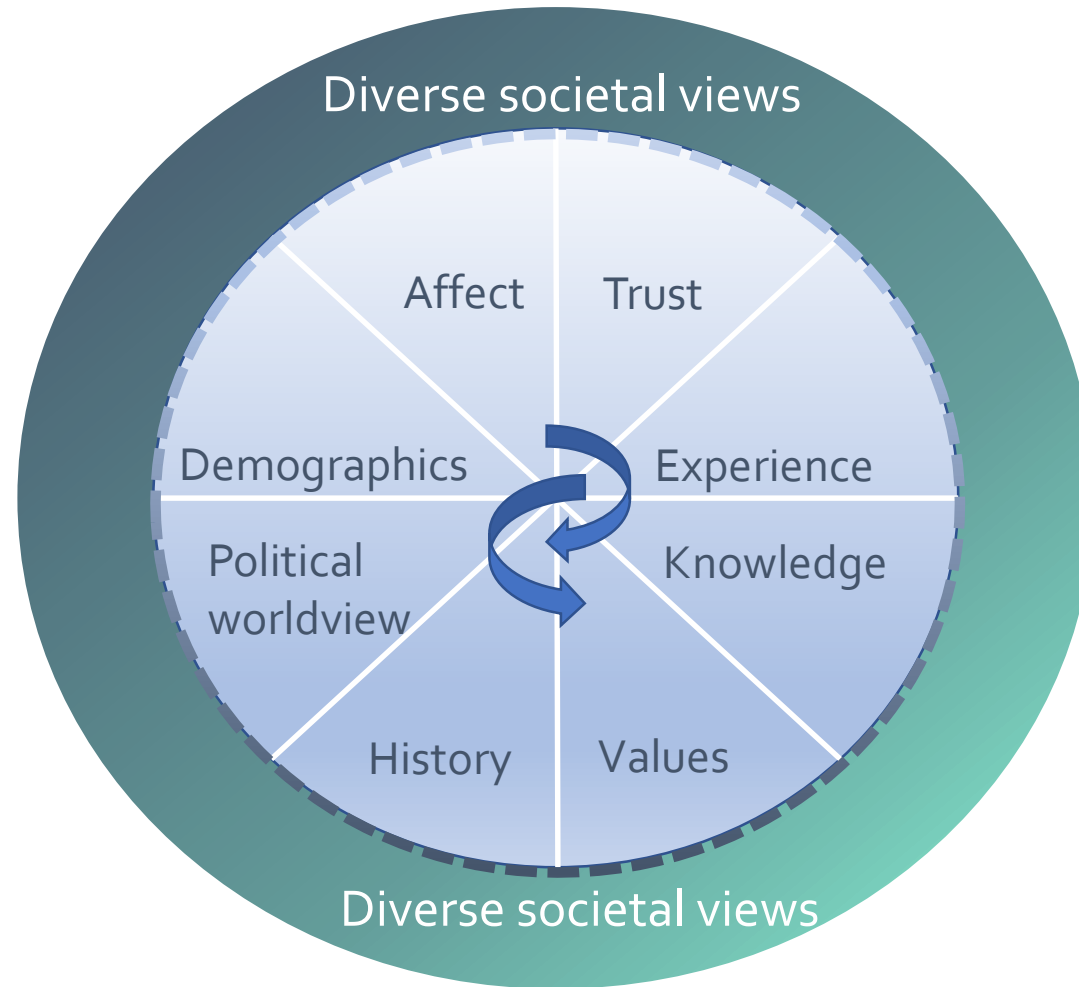
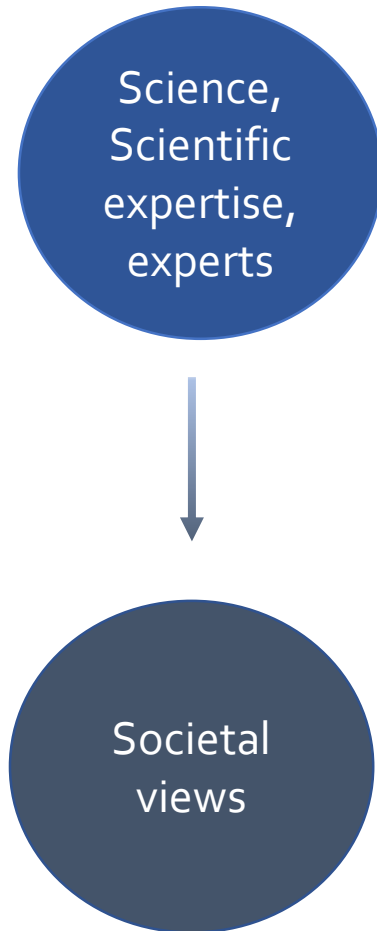
- Build collegiality, respect and trust
- Meet regularly, both formally and informally (e.g., project meetings and field trips)
- Identify strategic opportunities for integration
- Exchange social and biological perspectives while minimizing jargon
- Develop an appreciation for different research approaches



Scientific, societal and policy integration



How do people make sense of risks of emerging technologies?



Practicing integration: Three examples

- Integration of what?
- By whom?
- During what stage of the research process?
- To what end?

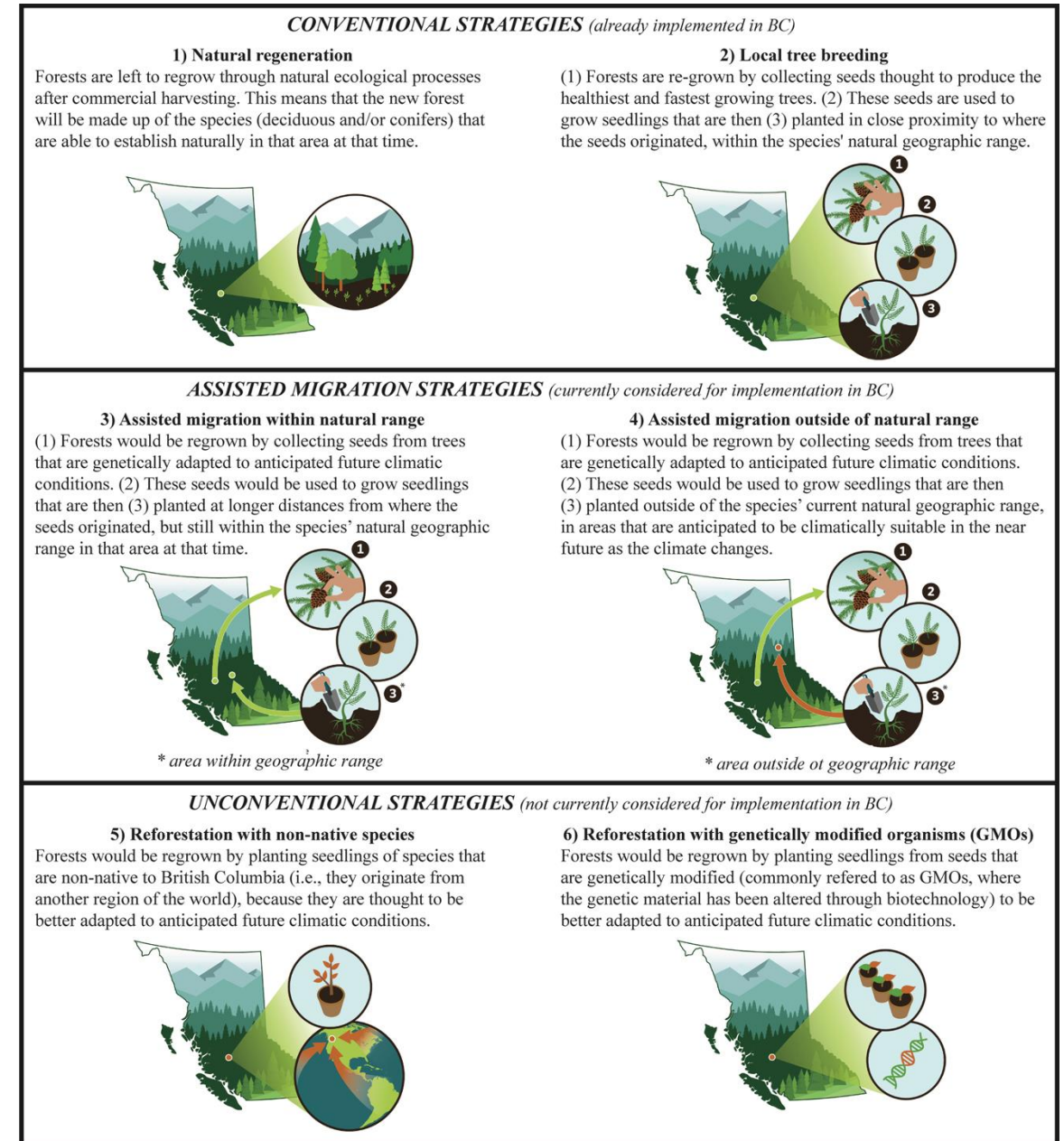


1. Integration of multiple domains of knowledge

- Co-produce an understanding of climate adaptive strategies

Outcomes:

- Accurate, image-based tutorials informed by diverse knowledge
- Mutual learning across the project team, and end users



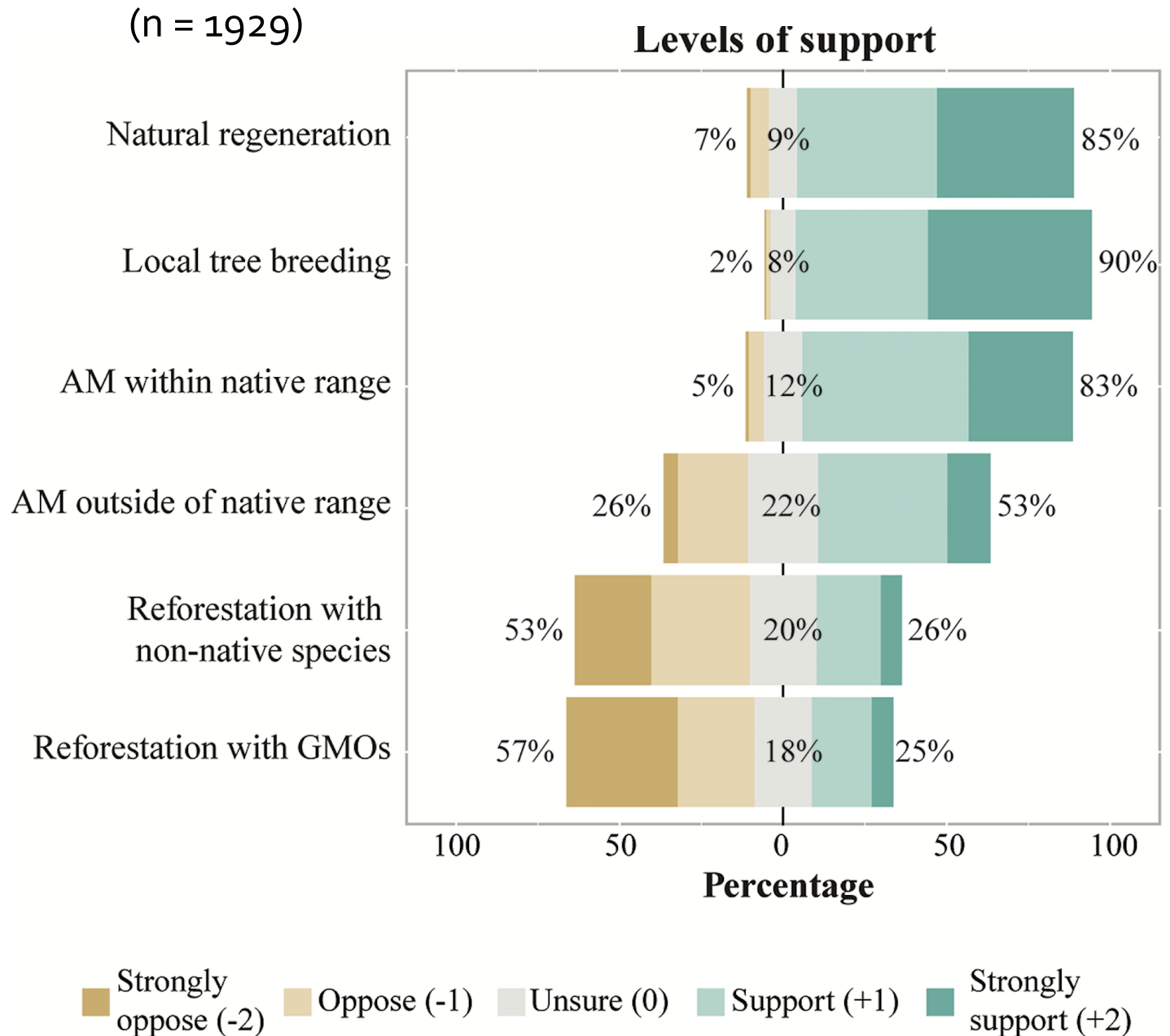
2. Integration of social science

- Address scientific question: “What is driving risk perception”?

Outcomes:

- New knowledge about the risks that publics are concerned about
- Policy insights: i) degree and conditions of public support
ii) demographic considerations

Research Implementation Phase



3. Integration of stakeholder & civil society voices

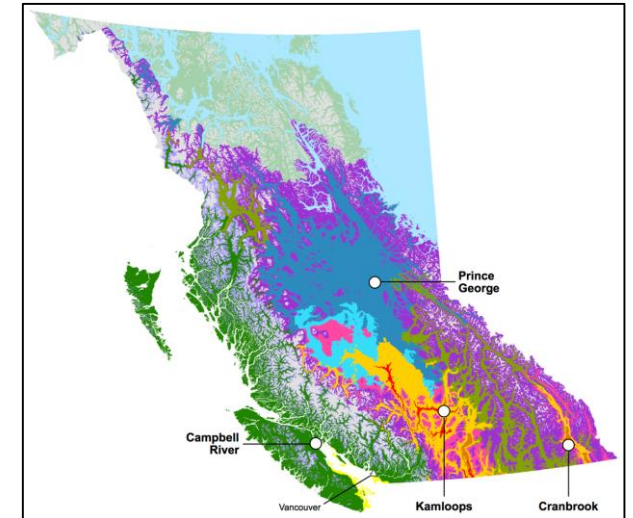
- How do stakeholders in forest-dependent communities perceive the risks/benefits?
- Engage diverse stakeholders in dialogue

Outcomes:

- Empirical confirmation of mistrust as driver of support
- Providing a voice for diverse stakeholders about decisions on public lands
- Understanding diverse views about tradeoffs that flow from new technologies



Focus groups in four forest regions, K. Findlater



Broader considerations

- End users are active participants in **knowledge co-production**
- Social research to **enrich scientific understanding**
- Integration with civil society contributes to the normative goal that **publics ought to have a say** in decisions about public lands
- Opportunities for **tri-directional learning** among stakeholders, end users and researchers
- Scientific integration can occur at all stages of a project; **distinct from translation**
- Developing trainees positioned to **address pressing societal challenges** within and outside of academia



Challenges and questions to continue to grapple with





Anatomy of a dilemma— two expressions:

1. Tendency to emphasize economic values as target for integration
2. Barriers to meaningful engagement with First Nations

- How best to foster decolonizing approaches for working with First Nations in large-scale projects?
- How best to evaluate and process evidence derived from multiple knowledge systems?
- How best to move forward with new technologies in ways that are responsive to societal concerns
- How best can funding models reward interdisciplinary, collaborative approaches?

Thank you

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- For more information about the CoAdapTree project: <http://coadapttree.forestry.ubc.ca>

