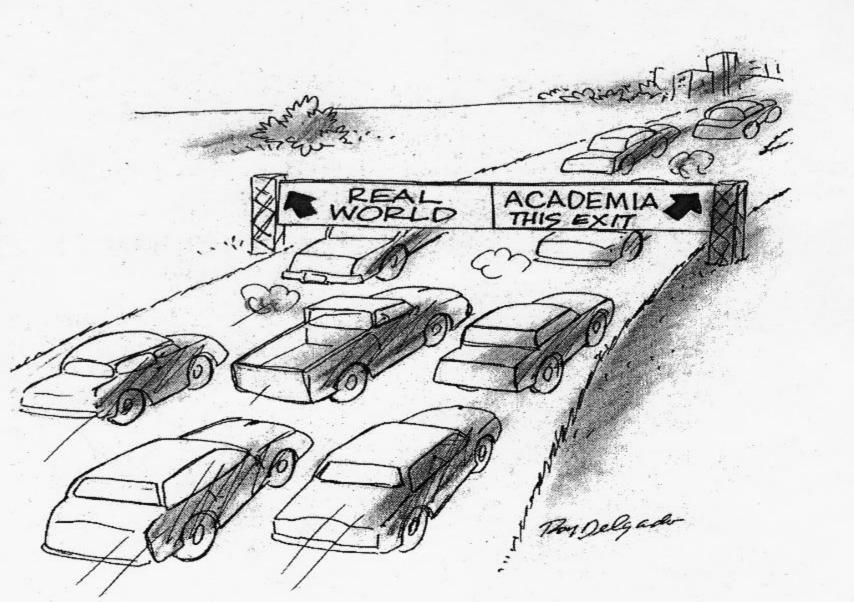


Influencing Housing Services and Policies for People Living with HIV: Some Lessons Learned, Success Stories and Challenges from Positive Spaces, Healthy Places

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The housing and health policy-making environment and process is complex

- Decisions about the amount and location of housing stock and services involve different levels of government
- The policy guiding housing and health services can involve multiple provincial ministries: Health and Municipal Affairs
- The planning and funding for community-based HIV services may be on ministry responsibility, while the planning and funding for supportive housing programs may be in another
- There are a small number of HIV-specific supportive housing programs and most people with HIV rely on general housing programs for services.

The housing and health policy-making environment and process is complex

- For HIV focused programs, housing is a priority but they have few resources to devote to housing. For housing programs, people with HIV are only one population in need of better access to stable, appropriate housing.
- The "problem" can vary from region to region. Some parts of the province lack housing stock, or rent-geared-to-income options, while others do not offer supportive housing services. These regional variations mean that a "one size fits all" policy will likely not be effective. The system may need a menu of policy options.
- The policy process is particularly challenging during times of fiscal constraint, when all public service sectors are being asked to do more with existing resources.

• In 2002, at the Ontario AIDS Network (OAN) annual retreat for Executive Directors of AIDS Service Organizations participants overwhelmingly identified "housing issues" as a significant problem for people with HIV across the province - But no Canadian data available to inform how to act

• <u>In 2003</u>:

- Ontario AIDS Network receives CIHR funding for a Research Technical Assistant
- Fife House develops new strategic plan that identifies
 CBR as a priority for the agency
- The Ontario AIDS Bureau Strategy identifies "housing as a key unmet need of people with HIV"



- the OHTN decides that in order to have more impact, research portfolio needs to be more prominent and competitive, and embarks in a new direction - hires an academic who could lead as both an Executive and as a Scientific Director
- Board Chair and ED lead Board to redesign the OHTN with 5-year Strategic Plan to become competitive and recognized nationally / internationally for research / KTE
- CBR was identified to be a priority (and this was not without controversy) but we sold it that it would be the type or research that would be recognized and funded by CIHR



- Key literature reviews indicate no information regarding this issue within the Canadian context
- Housing Connections, the agency the maintains the central wait list for social housing in Toronto, depriorizes HIV from the medical priority list
- People with HIV must now get a Doctor to check a box that states the person has less than 2 years to live
- Ruthann Tucker (ED at Fife House) makes convincing case to the OHTN at CBR retreat that housing research needs more attention and investment
- OHTN creates CBR fund and Fife House receives support to do a small needs assessment and qualitative housing study

In 2004

- NHRDP moves HIV funding to CIHR CBR program live
- OHTN offers to assist Ruthann Tucker and colleagues to develop a proposal for submission to the CIHR for a grant to expand needs assessment study to a more comprehensive 3-year study which includes both quantitative and qualitative methodologies

• In 2005

 CIHR funds study – "A prospective study to explore the impact of housing support and homelessness on health outcomes of people with HIV" – PSHP is created





Community-Academic Investigator Team



Principal Investigators - Phase IV

Dr. Sean B. Rourke, OHTN, University of Toronto, St. Michael's Hospital Ruthann Tucker, Senior Director, Community-Based Initiatives, OHTN Dr. Saara Greene, McMaster University, School of Social Work

Co-Investigators

Michael Sobota, Executive Director, AIDS Thunder Bay
Jay Koornstra, Executive Director, Bruce House
Steve Byers, Executive Director, AIDS Niagara
LaVerne Monette, Executive Director, Ontario Aboriginal AIDS Strategy
Dr. Steven Hwang, St. Michael's Hospital, University of Toronto
Dr. James Dunn, St. Michael's Hospital, University of Toronto
Frank McGee, AIDS Bureau, Ministry of Health and Long-Term Care

Project Coordinator

J. Watson

Peer Research Assistants

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Partners



Community-Based AIDS Service **Organizations**







AIDS Niagara AIDS Thunder Bay **Bruce House**









Ontario AIDS Network

Ontario Aboriginal HIV/AIDS Strategy

Universities Hospitals & Research Centres



McMaster University







Funders











Getting PSHP Off the Ground

- Building the team and developing PSHP identity (academics – new kids on the block - needed to earn credibility which did not happen overnight)
- Leveling the playing field equal voice on team
- Commitment of time, energy and expertise
- Decisions were made by consensus
- Community more conservative in implementation
 - All funding needed to be secured and workplan needed to be well planned and organized before study could get underway
- How we defined / implemented OCAP

Early Factors of Success

- Community leaders appreciated the need for rigorous data and methods that would bring the necessary credibility to study results – academics could make sure this was taken care of
- Community leaders took responsibility for engaging their communities for recruitment and implementation of study
- Everyone found time in their busy schedules to be involved and contribute
- Data analyses completed within one month that cohort was established – Solid powerpoint presentations developed – results shared

The Middle Years: Hitting the Ground Running

- Held key meeting with John Lavis CRC in KTE discussed key pieces of data, processes and outcomes we would need to engage policy-makers. <u>This included</u>: (1) systematic / rigorous data on issue (PSHP), (2) real stories of people, (3) systematic review of the literature, (4) housing system and solutions in Ontario; (5) knowledge products; (6) KTE strategy
- Held 1st Think tank on HIV, housing and health Brought plan to the Ontario community (with academics and policy-makers) to review and get support for this action plan
- OHTN Commissioned: (i) systematic review of HIV, housing and health Leaver et al., 2007 (AIDS and Behavior special issue); and (ii) CAMH Housing solutions report

The Middle Years: Hitting the Ground Running

- Completed over 10 slides decks of baseline findings (in scientific format but with main messages and in user-friendly formats) and worked with team to teach them about how to present academic results and how to couch results
- Built website and promoted study findings and main messages across all community-based agencies
- Started to work on peer-reviewed publications
- Began work to develop fact sheets



Integrating Research into Practice: Case Example





HIV, housing & health

Welcome to the Fife House website

Fife House is an innovative, client-focused provider of secure and affordable supportive housing and support services for persons living with HIV/AIDS.

Fife House is recognized as a North American leader in its delivery of services, which are focused on enhancing quality of life, building on individual strengths and promoting independence - recognizing that access to secure and affordable housing is a key determinant for the health and well-being of people living with HIV/AIDS.

Upcoming Events

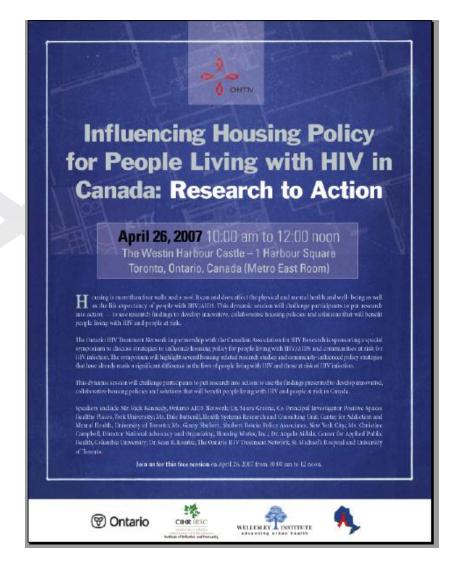
Mark your calendars!



The Middle Years: Hitting the Ground Running

- Submitted 2 abstracts to the US National AIDS
 Housing Coalition-Housing Works-John Hopkins led
 HIV, Housing and Health Research Summit both
 accepted team made conscious decision to send
 community leaders to present
- Submitted 5 abstracts to CAHR (and worked with CAHR executive) to get 1st oral CBR session dedicated to PSHP housing findings
- Held Satellite meeting at CAHR (CIHR funded) with US leaders in housing (academic and community) that initiated Ontario Research to Action strategy

Research to Action Forum: Special Symposium CAHR 2007 – 1st of its kind





The Last 2-3 Years: Stepping it up a notch in Ontario and nationally

- First PSHP peer-reviewed paper accepted
- Held 1st National HIV, Housing and Health meeting in Canada (CIHR funded) – developing national network
- Built new bridges and partnerships with community and policy groups
- OHTN (and eventually the CIHR Centre for REACH) became hub and offered expertise and support to CIHR Catalyst grant submissions to build housing and health work in other provinces
- PSHP receives CIHR funding for another 3 years this is the 1st CIHR CBR study to be refunded
- Submit 1st Research to Action grant to CIHR

Why it all Worked? What were the Key Ingredients? Any misplaced Steps?



The Beginning of Our KTE Approach and Research to Action Strategy

- Community identified the problem
- Held Think Tank researchers,
 policy makers, front-line workers
 - Included experts outside HIV mental health, housing, homelessness
- Learned that evidence to support new policy did not exist in Canada
- Conducted research
 - Policy makers part of research team





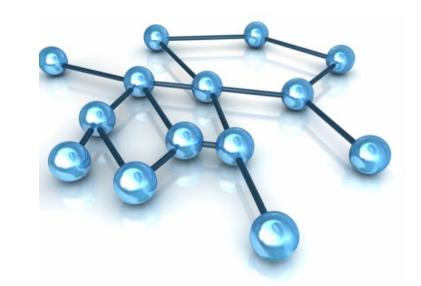
Thought about who was our target audienceFigured out that strategies differ

Provincial government

AIDS Bureau

Ministry decision makers

Federal government



Regional health authorities

Community-based HIV/AIDS organizations



We used Jonathan Lomas' Approach to KTE (which we believe applies very well to CBR)

There are 5 Key Principles:

- 1. KTE (and CBR) is a contact sport
- 2. Written materials (or saying you have a best practice) are not enough to consistently transfer knowledge



- 3. KT and (CBR) is about coordinating three "teams": those who create the knowledge, those who can disseminate it, and those who can use it
- 4. The best form of KTE is co-production of the research
- 5. It is as important to equip decision-makers or community members with the tools to find and use research as it is to help researchers (and others) to communicate it.

Jonathan Lomas, former CEO, CHSRF

Our Approach to Integrated KTE

Conducting a longitudinal study takes time but we did not wait until the end ... what were key factors

- Began sharing findings early
- Provided regional breakdowns
- Held Summit invited non-profit housing sector as well as HIV, addictions and mental health
- Ontario-based study but shared findings nationally to help others
- Met with key policy makers to discuss findings, implications and opportunities





Our Integrated Approach to CBR and KTE

Identified Community Champions

- Armed them with local data
- Organized town hall meetings
- Met with/lobby municipality and Local Health Integration Network (LHIN) CEOs and health managers
- The ownership and control of the data was by the community – this has built trust

Our Integrated Approach to CBR

Closed the Gap Between Knowledge & Action

- Knowledge exchange is about people and partnerships – identifying champions
- KTE is a culture, not an activity
- Knowledge exchange is about solving problems
- Knowledge exchange is about the interface between evidence-based practice (academics) and practice-based evidence (front-line experts)
- Knowledge exchange is a moral imperative



The Last 2 Years: Stepping it up a notch in Ontario, nationally and internationally

- Buillt collaboration with CAAN to develop and submit Aboriginal grants to CIHR – 1st
- 3 other manuscripts submitted for publication
- Launch renewal of PSHP follow cohort for 5 years
- Become co-convening partner with NAHC / Housing Works and Johns Hopkins to host 1st North American HIV, Housing and Health Research Summit
- Submit 2nd Research to Action grant to CIHR
- CIHR Centre for REACH funded housing a priority



The Last 2 Years: Stepping it up a notch in Ontario, nationally and internationally

- 4 PSHP papers now published, 2 under review, 2 in progress
- Over 20 community presentations given across the province and in Alberta, Nova Scotia and BC
- Over 25 scientific presentations given in Canada and the US
- Alberta housing study (Sharp Foundation) funded by CIHR
- BC Catalyst funded CIHR
- National network meeting grant received from CIHR to bring together and connect housing initiatives across Canada
- 1st Health Policy Forum (Deliberative Dialogue) on housing and health funded by CIHR









EVIDENCE >> INSIGHT >> ACTION

The Impact of Our Work with PSHP To Date...

- Our findings are cited in the Ontario Human Rights Commission report
 Right at Home: Report on the consultation on rental housing and human rights
- In 2006, Fife House secured \$19 million in government funding for new supportive housing for people with HIV in Toronto, 35% increase
- In 2008, \$200,000 in new funding for supportive housing for people with HIV in southwestern Ontario (AIDS Niagara) – through the LHINs
- Through our collaboration with Ontario Ministry of Health (Mental Health and Addictions branch), people with HIV and substance use issues now eligible for new supportive housing developed for people with addictions in Ontario
- In 2010, Fife House in Toronto receives \$224,300 in annualized funding for clients with HIV and substance use problems
- In 2010, Loft Community Services receives \$275,000 in annualized funding to support 32 new housing units with support services for clients with HIV and substance use problems

The Impact of Our Work with PSHP To Date...

- Key leading partner in the development in the International Declaration on Poverty, Homelessness and HIV/AIDS presented and accepted by the International AIDS Society in 2006
- Co-convenors of the North American Research Summit on HIV, Housing and Health with NAHC, Housing Works and Johns Hopkins University School of Public Health (1st in June 2009 in Washington, DC; 2nd in Toronto in June 2010; 3rd in New Orleans in September 2011)
- Raised awareness and profile of CBR approach and utility in Canada – recognized in CIHR-III 10-year review as innovative research and KTE approach that is having impact
- PSHP approach is model for other CBR initiatives across Canada and the US – through NAHC and Housing Works
- Our work featured in the 1st CIHR Partnership Casebook



HEALTHIER TOGETHER:

The CIHR Partnerships Casebook





Canada

POSITIVE SPACES, HEALTHY PLACES: AN INNOVATIVE COMMUNITY-ACADEMIC-POLICY PARTNERSHIP MOVES RESEARCH INTO ACTION

Dr. Sean B. Rourke, Scientific and Executive Director, OHTN Scientist, Centre of Inner City Health in the Keenan Research Centre of the Li Ka Shing Knowledge Institute, St. Michael's Hospital Associate Professor, University of Toronto Adjunct Professor, University of Windsor Jean Bacon Director, Policy and Knowledge Transfer and Exchange, OHTN

Ruthann Tucker Senior Director, Community-based Research Initiatives, OHTN

Housing and housing supports play a critical role in HIV prevention, and they are also powerful determinants of health for people living with HIV. Stable and appropriate housing, however, continues to be one of the greatest unmet needs of people living with HIV. The Positive Spaces, Healthy Places (PSHP) study – jointly funded by CIHR, the Ontario HIV Treatment Network (OHTN), the AIDS Bureau of the Ontario Ministry of Health and Long-Term Care and the Ontario AIDS Network – is the first longitudinal community-based initiative in Canada to examine housing stability and housing outcomes among people living with HIV. This comprehensive three-year study, which began in 2005, has also been the catalyst for capacity development in the area and for local, national and international partnerships that are leading to better housing and other supports for people with HIV.

Putting the pieces together

The HIV community identified the lack of stable, affordable housing as an urgent issue in 2002. At a meeting of Executive Directors of community-based HIV/AIDS organizations, participants noted that housing was the greatest unmet need among people living with HIV/AIDS and that access to housing supports, which ensure safety, health and dignity, varied across the province. The lack of research on the housing status of people with HIV, particularly in Canada, was a barrier to understanding their needs and planning for the future. The community needed rigorous data to make the case for investments in housing and support services.

The issue: The HIV community identified the lack of stable, affordable housing as an urgent issue and the greatest unmet need among people living with HIV/AIDS.

As part of its Strategic Plan to 2010, the OHTN began working directly with community champions, policy makers (in the areas of HIV, addictions, mental health, and regional planning), housing providers and researchers (with expertise in homelessness and mental health) to solve problems and to fill this gap. In 2004, a multidisciplinary, multi-sector partnership was formed; since then, all of the partners have been involved in every stage of the peoject, including identifying the research questions, analyzing results, identifying solutions and best practices, and sharing knowledge.





Mobilizing Knowledge: Housing is HIV Prevention and Care

June 3-5, 2009 Doubletree Hotel Crystal City, Washington, DC

The National AIDS Housing Coalition (NAHC) and the Ontario HIV Treatment Network (OHTN), in collaboration with the Johns Hopkins Bloomberg School of Public Health, are pleased to convene the fourth Housing and HIV/AIDS Research Summit.

As the premiere venue for informing HIV/AIDS housing policy, the 2009 Summit— Mobilizing Knowledge: Housing is HIV Prevention and Care—will bring together researchers, policy experts, and consumers and providers of HIV/AIDS housing from across North America to present and discuss research findings and policy initiatives focused on the relationship between housing status and HIV prevention and care.

Important Deadlines:

- Early-Bird Summit Registration Cut-Off Date: April 24, 2009
- Hotel Cut-Off Date: May 3, 2009









"60 Canadians with HIV barred from entering US"



The National AIDS Housing Coalition

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For immediate release Friday, Mary 29, 2009 Contact: Katie Stuart nahc@nationalaidshousing.org (202) 347-0333

NATIONAL AIDS HOUSING COALITION DECRIES U.S. DENIAL OF ENTRY FOR CANADIANS LIVING WITH HIV TO ATTEND NORTH AMERICAN HOUSING AND HIV/AIDS RESEARCH SUMMIT

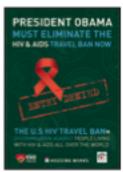
Appeals to State Department to Reverse Course.

The National AIDS Housing Coalition (NAHC) and the Ontario HIV Treatment Network (OHTN) decry the US government's denial of entry to Canadians living with HIV to attend the North American Housing and HIV/AIDS Research Summit next week, contrary to stated U.S. policy that foreigners living with HIV would no longer be barred from entering the country. The groups are calling on Secretary of State Clinton to resolve the matter and on President Obama to eliminate Department of Health and Human Services (DHHS) regulations that are effectively enforcing the HIV travel ban.

Despite enactment in July 2008 of a law authorizing the Department of Health and Human Services to lift the decades-long ban on foreigners living with HIV entering the United States, the US remains one of a handful of countries* in the world barring entry to persons with HIV though widely disapproved by domestic and international human rights organizations. The Department of Homeland Security has instituted a "streamline" process for entry into the US for people living with HIV which, in fact, is characterized by an invasive, onerous and unconscionable processes. This is ultimately equivalent to a complete ban on people living with HIV coming into the United States.

"The imposition of onerous new so-called streamline procedures on people with HIV/AIDS seeking entry to the US is unconscionable", said NAHC Executive Director Nancy Bernstine. "NAHC timely applied for a 'designated event' waiver of the ban for the Summit, but was advised verbally only days ago that such waivers will no longer be granted. Aside from the discriminatory nature of the ban, the indefensible delay on the part of the U.S. government in informing NAHC and the OHTN effectively bars Canadian citizens with HIV/AIDS from attending this important meeting."





Placard at the Housing and HIV Research Summit



DHHS Federal Register Docket



Ruthann Tucker and Sean B. Rourke were two members of a delegation from the first North American Housing and HIV Research Summit to attend a meeting at the White House about the travel ban.

Progress in Ending the US Travel Ban for People with HIV

When the OHTN was making arrangements for members of the Canadian HIV/AIDS community to attend the First North American Housing and HIV Research Summit in Washington, DC in June 2009, it ran into problems with US travel restrictions.

Although the U.S. Congress repealed the 20-year legislation banning people with HIV from travelling to the United States in July 2008 – a year ago – the regulations were still in place. Summit organizers were told that a waiver would be issued, allowing people with HIV to attend the conference. Two weeks before the Summit, they were informed that the waiver system was no longer in effect and that Canadians with HIV who wanted to attend the Summit would have to apply for a special visa, which would require them to disclose their HIV status.

In response, the OHTN and the National AIDS Housing Coalition (NAHC), co-sponsor of the Summit, wrote letters to senior U.S. government officials. The OHTN also consulted with people with HIV across the country to determine whether to continue to support the Summit. The HIV/AIDS community overwhelming advised the OHTN to support the event, and use it to highlight the need to end the travel ban. The Department of Health and Human Services is accepting public feedback on the proposed changes to the Federal Register until August 17, 2009. Visit their website to submit a comment.

As a result of that effort, the U.S. government issued a special event designation allowing people with HIV to enter the U.S. to participate in the Summit – although this did not happen in time for people to organize their travel. Jeff Crowley, Special Advisor to the White House on HIV/AIDS, attended the Summit to listen to Canadians and their U.S. colleagues talk about the impact the travel ban has on them and to explain the process underway to end the travel ban. He also invited organizers of the North American Housing and HIV Research Summit, including the OHTN, National AIDS Housing Coalition, Housing Works, Johns Hopkins University, Bloomberg School of Public Health and Human Rights Watch, to attend a meeting at the White House with officials from departments responsible for revising the regulations to discuss the effect of the travel ban on presenters and delegates attending the Summit.

Less than a month later – July 5, 2009 – the Department of Health and Human Services posted proposed changes to the regulations on the Federal Register. Members of the public have until August 17, 2009, to provide feedback on the proposed changes. NAHC is organizing a response on behalf of organizations in the U.S. involved in housing and HIV.

None of the Canadian participants attending the Summit were turned away from the U.S. border; however, three individuals chose not to attend the event either for health reasons or to protest the travel ban. Although the travel ban was not enforced, it is still crucial that the laws be changed. Said Dr. Sean B. Rourke, Scientific and Executive Director of the OHTN, "People living with HIV must be able to cross the border with dignity, like all other Canadians."

The end of the travel ban will also make it possible – once again – for organizations like UNAIDS to hold meetings in the United States.



Closing the Gap: Next Steps

- Developing a national HIV, Housing and Health task group to influence national/provincial policy
- Gather more data about other regions in Canada about the housing status of people living with HIV to support national housing strategy
- Continue to support CIHR grant submissions in housing, health and HIV in other regions across Canada to build more capacity and momentum to influence changes in housing programs and policies

Closing the Gap: Next Steps

- Build more partnerships and strategic alliances with other sectors such as mental health and addictions
- Work with regional/local planners to allocate and provide, appropriate, supportive housing for people with HIV/AIDS
- Secure endorsement of the International Declaration on Poverty, Homelessness and HIV/AIDS by multiple sectors including: housing, primary healthcare providers, etc.
- Do housing interventions improve access to health care, health and wellbeing, is a good prevention strategy and is good health policy

Key Benefits of CBR

- Questions relevant to the HIV/AIDS community but as well for policy-makers
- Facilitates research engagement and uptake
- Values the lived experience (GIPA)
- Community members more likely to contribute as active participants and agents of change – real partnerships and increased power
- Mutual ownership of results and directions
- Increases accuracy of interpretation of observed findings (evidence more contextualized)
- More likely that research evidence will result in change – academic-community-policy sectors working together

How Can CBR be Enhanced to Affect Change – The Needs

- Build more critical mass in the field (particularly in academic area and in the Aboriginal sector)
- More mentorship and collaborative networks
- Support bridges and links between HIV/AIDS and public health and other sectors – cross institutes
- Build RFAs for intervention work in particular adapt and apply existing proven interventions – DEBIs (diffusion of evidence-based interventions) in Canadian context – US is interested
- Support integrated CBR and KTE work
- Have clear and defined targets for what CBRo program can achieve

Thank you!

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