DRIVING IN DEMENTIA

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RGP Spring 2017

DISCLOSURES

CIHR

Canadian Consortium on Neurodegeneration and Aging

Ministry of Transportation of Ontario

Transport Canada

ACKNOWLEDGMENTS

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LEARNING OBJECTIVES

To understand dementia-related driving risks.

To appreciate limitations of research in this area.

To move beyond knowledge to action, while balancing the risks.

BACKGROUND

BEWARE OF SHARED DELUSION

"The one thing that unites all human beings, regardless of age, gender, religion, economic status or ethnic background, is that, deep inside, we ALL believe that we are above average drivers."

Dave Barry

Older drivers

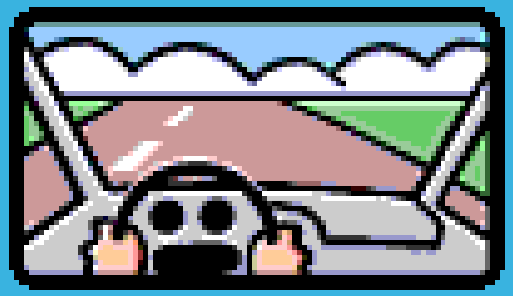
- Fastest growing segment of licensed population
- Vast majority continue to be safe to drive
- Often unfairly characterized by the media

DRIVING

THE ULTIMATE IADL

Older drivers

- high crash rate per miles driven (though not the highest)
- crash for different reasons than younger persons
- involved in different types of crashes
- once involved in a crash - highest mortality and morbidity of any age group



DRIVING AND MEDICAL CONDITIONS

Numerous medical conditions associated with crashes:

- Sensory and Motor Conditions
  - Vision
  - Movement (e.g. arthritis, pain)
- Mental Functioning
  - Abrupt changes (e.g. seizure, cardiac, cerebro-vascular)
  - Fluctuating (e.g. diabetes, psychiatric conditions)
  - Progressive (e.g. dementia, respiratory)

Prevalence of these conditions increases with age

DRIVING CESSATION

Psychosocial consequences

- Depression
- Social isolation
- Loss of self esteem
- Many report “worse than death”
- Impact on patient/physician relationship

CANDRIVE: DRIVING IN OLDER ADULTS

CIHR (PI: SHAWN MARSHALL)

CIHR TEAM ON OLDER PERSON DRIVING (CANDRIVE II) RESEARCH PROGRAM

Main goal is to determine tests that could be used by physicians to address medical fitness to drive questions

- In most Canadian provinces physicians are mandated by law to report who is not medically fit to drive
- What tests will predict who has at-fault crashes?
  - Need to examine driving exposure

WHAT DO WE HOPE TO FIND?

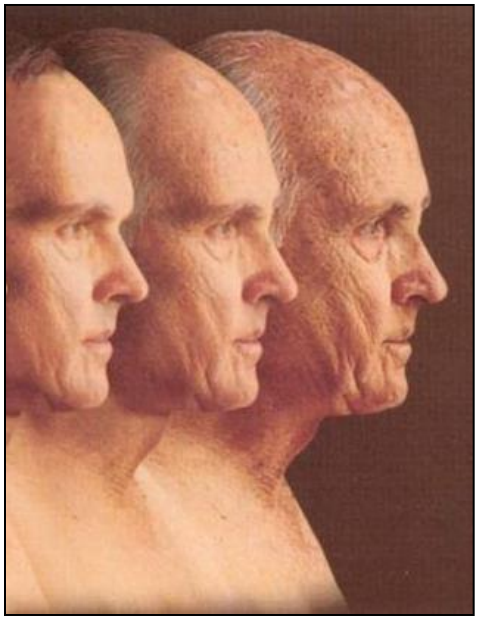
Are there tests that can be used by physicians in a specific way (not indiscriminately) to screen older drivers who are not medically fit to drive?

- Must not send a high proportion of older drivers on for further testing

Learn more about actual driving patterns, and how these patterns change over time with changes in medical conditions and function

What leads to driving cessation

Candrive /Ozcandrive:Study Description



Prospective Cohort Study

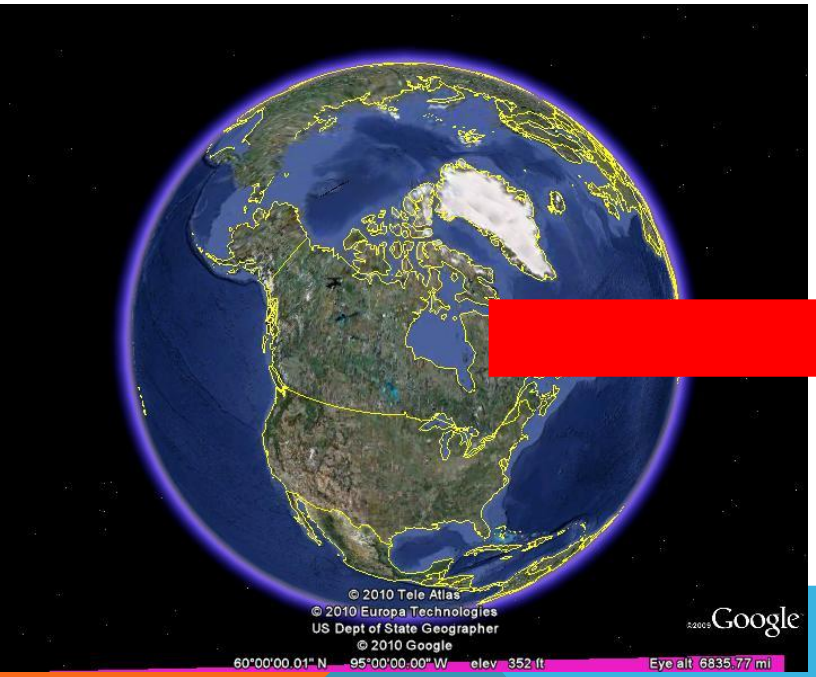
Candrive – age 70+ drivers

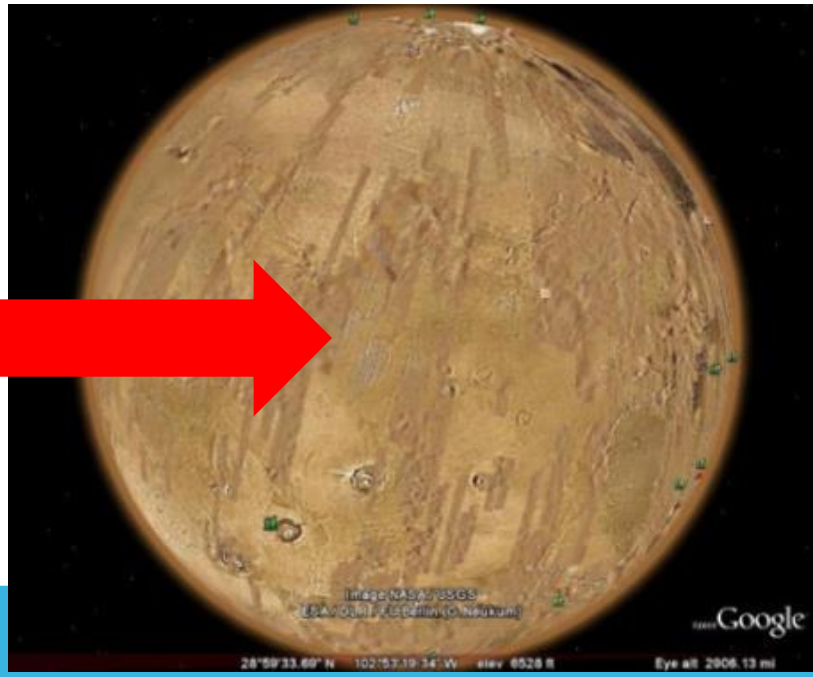
7 Canadian Sites

928 Drivers

- Comprehensive annual assessment
- 8 inter-related projects; common overall theme of knowledge translation

GPS PARTICIPANT DRIVING DATA: TO DATE OVER 37 MILLION KM OF DATA





Earth

Venus

RFID AND KEY FOB

GUIDELINES & LITERATURE REVIEW

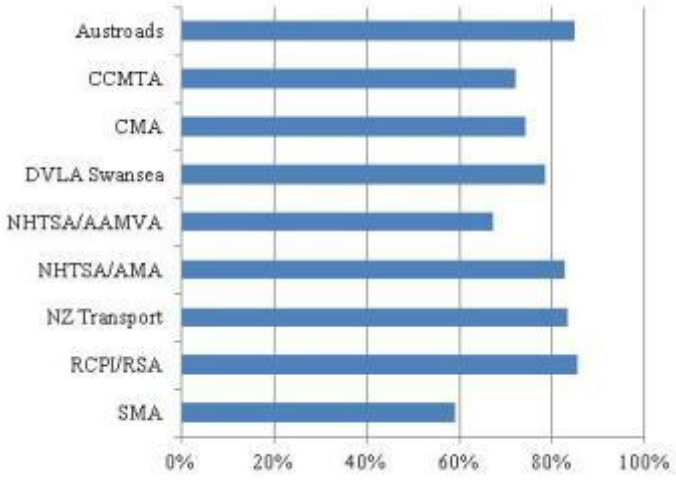
CIHR, MTO, CO-PIS: M RAPOPORT, DAVID CARR

Overall quality scores of guidelines on driving with medical illness and recommendations in descending order of overall quality

Clinical Practice Guideline	Overall Quality	Overall Recommendation (%)		
		Recommend	Recommend with Modifications	Do Not Recommend
1. NHTSA/AMA (America)	5.00/7	25	75	0
2. Austroads (Australia)	4.88/7	62.5	37.5	0
3. NHTSA/AAMVA (America)	4.88/7	12.5	75	12.5
4. CMA (Canada)	4.13/7	12.5	75	12.5
5. DVLA Swansea (UK)	3.88/7	12.5	50	37.5
6. CCMTA (Canada)	3.63/7	0	87.5	12.5
7. RCPI/RSA (Ireland)	3.50/7	0	75	25
8. NZ Transport (New Zealand)	3.13/7	0	50	50
9. SMA (Singapore)	2.25/7	0	12.5	87.5

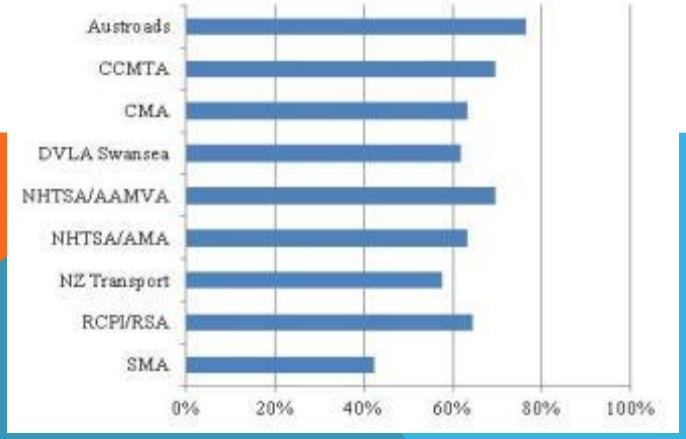
Rapoport et al, QJM 2015; 108:859-869.

Scope and purpose



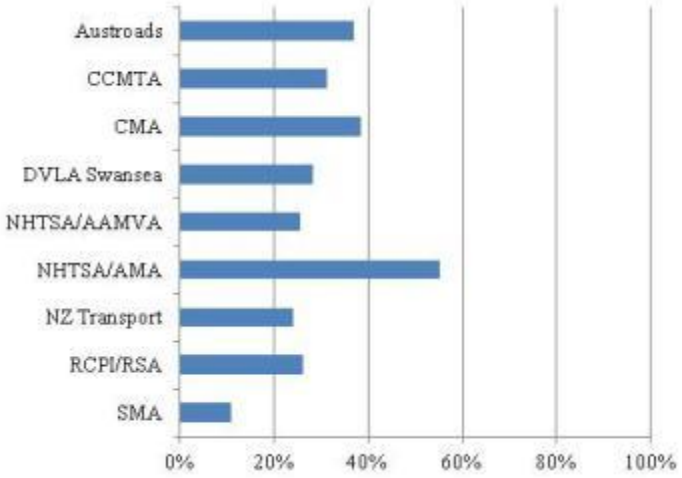
Stakeholder involvement

Clarity of presentation

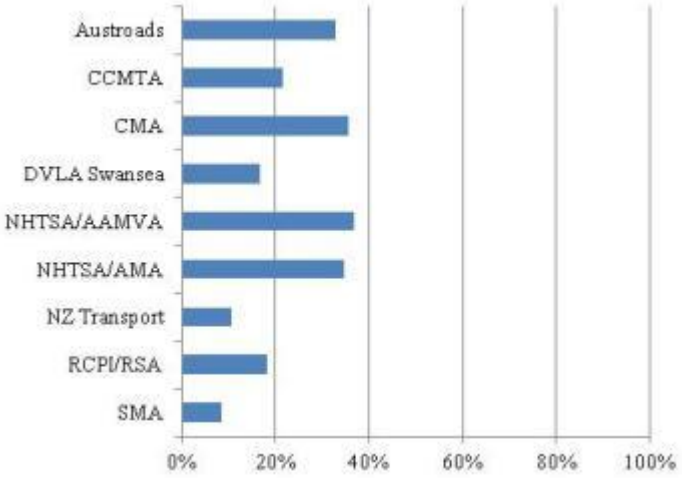


Rapoport et al, QJM 2015; 108:859-869

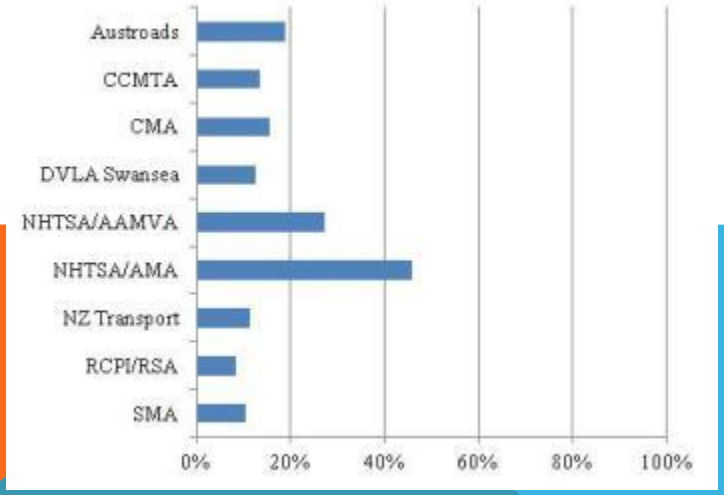
Applicability

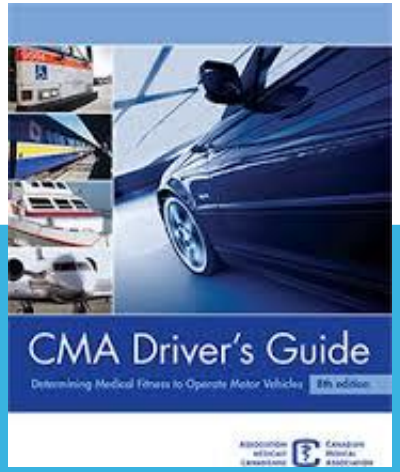


Rigour of development



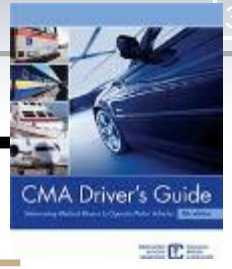
Editorial independence





Rapoport et al, QJM 2015; 108: 859-869

TEAM STRUCTURE: MEMBERSH



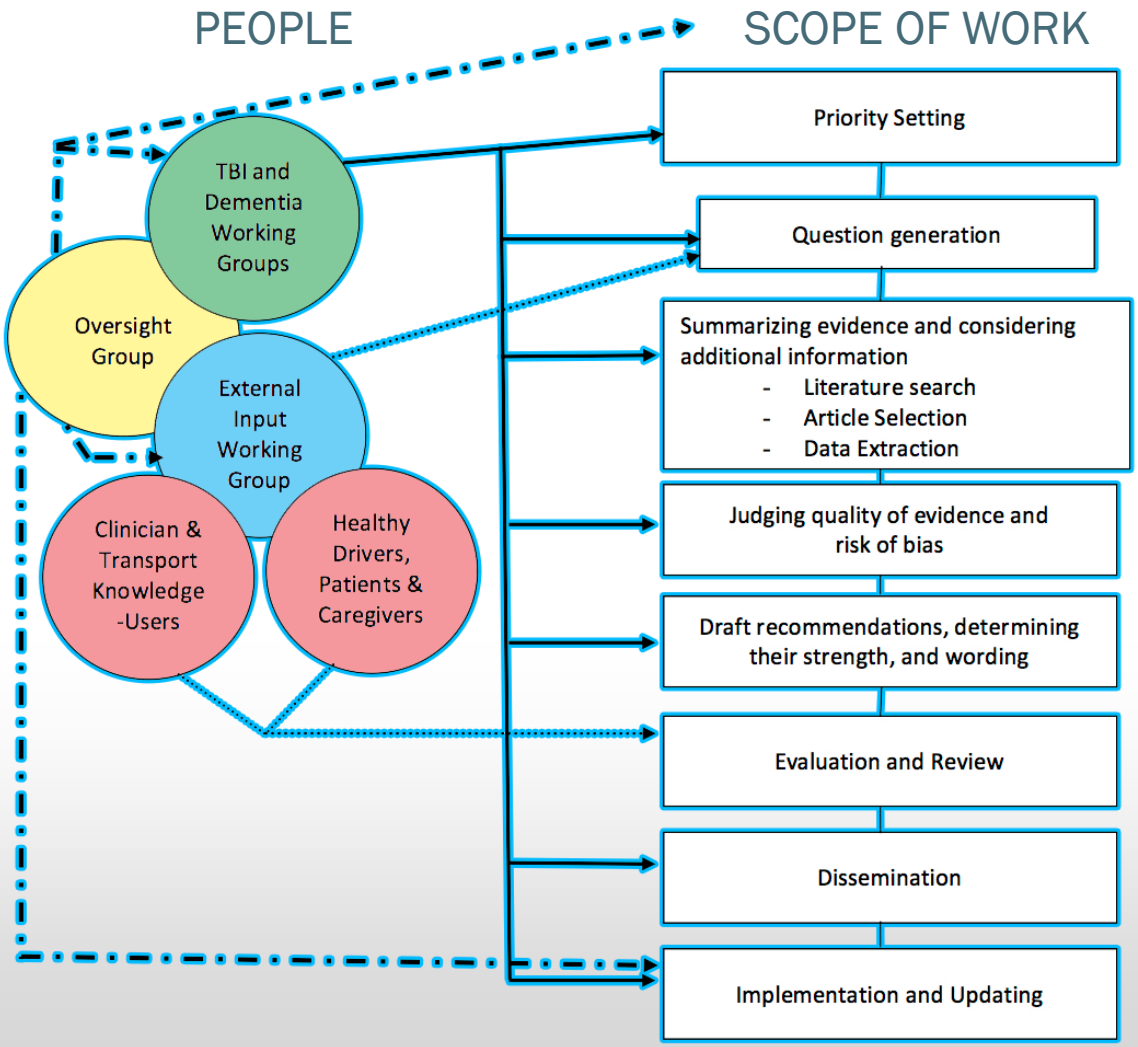
- An international team of experts followed the ADAPTE guideline adaptation process to: a) perform a knowledge synthesis on driving with dementia; and b) update existing clinical recommendations.

COUNTRY	CITIES	# MEMBERS
Canada	Toronto, Ottawa, Hamilton, London, Kingston, Quebec City, Victoria	16
Australia	Clayton	2
Belgium	Brussels	1
Ireland	Dublin	2
UK	Coventry	2
USA	St. Louis, MO, New Haven, CT	2

TRAINING	SPECIALTY	# MEMBERS
MD	Geriatric Psychiatrist, Geriatrician, Physiatrist, Psychiatrist, Neurologist, Family Physician	13
PhD	Pharmacologist, Psychologist, Occupational Therapist	9
Medical Librarian		1
Transportation Knowledge User		2

TEAM STRUCTURE: WORKING GROUPS AND PROJECT SCOPE

Adapted from Guidelines 2.0: systematic development of a comprehensive checklist for a successful guideline enterprise.



SYNTHESIS

What is the absolute and relative risk of motor vehicle collision or driving impairment, as measured by on-road testing, associated with different severities of dementia (mild, moderate, or severe) and different diagnoses (e.g. common non-AD neurodegenerative dementias, including Frontotemporal Dementia, Vascular Dementia, Lewy body disease, etc.)?

DEMENTIA AND DRIVING

- Crash rates in dementia are increased 2-8 times relative to age-matched controls.
- Between 22% and 64% of patients with dementia continue to drive.
- Many physicians do not report patients with Mild Cognitive Impairment or mild dementia because the existing guidelines are unclear and physicians are uncomfortable with them.
- No consensus previously on which patients to report.

STUDIES OF CRASH RISK IN DEMENTIA

Systematic review 2007

6 studies, 2 of highest quality(8/9 on Ottawa-Newcastle)

- BC: Cooper et al, 1993
  - Drivers with at least one collision 43 (26.1%) dementia vs 19 (11.5%) comparison.
- Michegan: Trobe et al, 1996;
  - Event Rate/ Driver years 0.08 crashes/driver years in dementia AND comparison

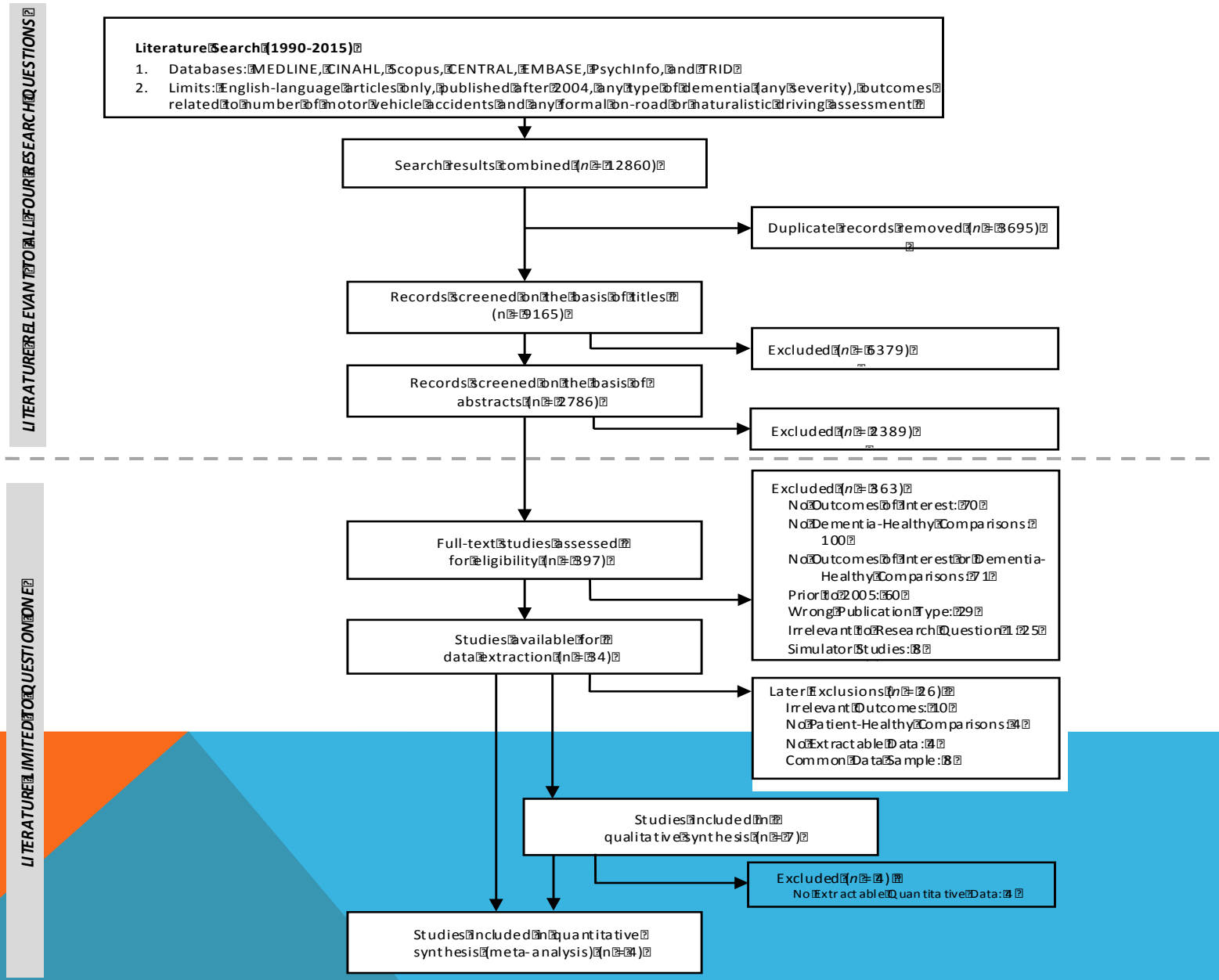
Man-Son-Hing et al, J Am Geriatr Soc 55:878–884, 2007
Cooper et al Journal of Safety Research Vol. 24, 9-17, 1993
Trobe et al, Arch Neurol. 1996;53:411-416, 1996

ABSOLUTE AND RELATIVE RISK SUMMARY

	Rates	Absolute Difference	Relative difference
Ontario 2011 Collisions Sex	4.3% M 2.4% F	1.9%	57%
Ontario 2011 Collisions Age	4.2%, 21-24 2.3%, 75+	1.9%	59%
US 2003 Fatalities M vs F (age 20-24)	43/100k, M 14/100k, F	0.029%	102%
US 2003 Fatalities Age	29/100k, 20-24 16/100k, 75-79	0.013%	58%
BC 1993 Dementia	26.1% dem 11.5% comp	14.6%	78%
Michegan 1996 Dementia	0.08 mvc/driv yr Dem and comp	0	0

2011 Ontario Road Safety Annual Report, MTO
Williams et al, J Safety Research (2003); 34: 527-531
Cooper et al Journal of Safety Research Vol. 24, 9-17, 1993
Trobe et al, Arch Neurol. 1996;53:411-416, 1996

PRISMA


LITERATURE RELEVANT TO ALL FOUR RESEARCH QUESTIONS
Literature Search (1990-2015)
1. Databases: MEDLINE, CINAHL, Scopus, CENTRAL, EMBASE, PsychInfo, and TRID
2. Limits: English-language articles only, published after 2004, any type of dementia (any severity), outcomes related to number of motor vehicle accidents and any formal on-road or naturalistic driving assessment
Search results combined (n = 12860)
Duplicate records removed (n = 3695)
Records screened on the basis of titles (n = 9165)
Excluded (n = 6379)
Records screened on the basis of abstracts (n = 2786)
Excluded (n = 2389)
LITERATURE LIMITED TO QUESTION ONE
Full-text studies assessed for eligibility (n = 397)
Excluded (n = 363)
No Outcomes of Interest: 70
No Dementia-Healthy Comparisons: 100
No Outcomes of Interest or Dementia-Healthy Comparisons: 71
Prior to 2005: 60
Wrong Publication Type: 29
Irrelevant to Research Question: 125
Simulator Studies: 8
Studies available for data extraction (n = 34)
Later Exclusions (n = 26)
Irrelevant Outcomes: 10
No Patient-Healthy Comparisons: 4
No Extractable Data: 4
Common Data Sample: 8
Studies included in qualitative synthesis (n = 7)
Excluded (n = 4)
No Extractable Quantitative Data: 4
Studies included in quantitative synthesis (meta-analysis) (n = 4)

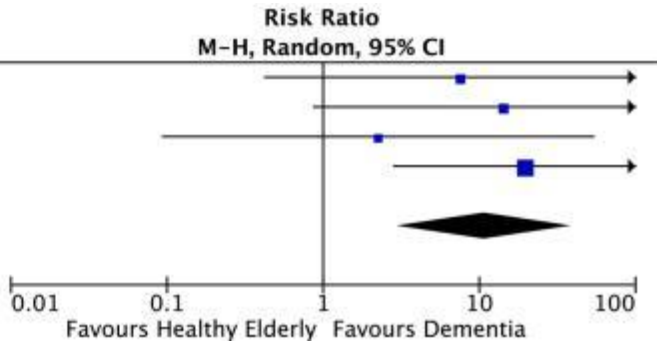
CRASH RISK OUTCOMES					
Author (Year)	Crash Risk Variable	Comparison Group: Baseline Result	Dementia Group: Baseline Result	Comparison Group: Longitudinal Result	Dementia Group: Longitudinal Result
Davis et al.[32] (2012)	Percentage of persons with MVCs	13.6% *(Past 1 Year)*	8.5% *(Past 1 Year)*	*Not assessed*	*Not assessed*
	Number of MVCs per year/10,000 miles driven	0.02 (0.04) *(Unclear: Past 1-3 Years)*	1.4 (7.5) *(Unclear: Past 1-3 Years)*	*Not assessed*	*Not assessed*
Ott et al.[33] (2008)	Percentage of persons with MVCs	11% *(Past 3 Years)*	18% *(Past 3 Years)*	**11%** *(Next 1.5 Years)*	**1%*[a]** *(Next 1.5 Years)*
	Number MVCs per 1000 miles driven per week	**1.86** *(Past 3 Years)*	**8.78 **** *(Past 3 Years)*	5.63 *(Next 1.5 Years)*	1.85[a] *(Next 1.5 Years)*
	MVC rate per driver per year	0.04 *(Past 3 Years)*	0.06 *(Past 3 Years)*	0.06 *(Past 3 Years)*	0.01[a] *(Past 3 Years)*
	Total number of MVCs	5 *(Past 3 Years)*	17 *(Past 3 Years)*	5 *(Past 3 Years)*	2[a] *(Past 3 Years)*

Meta-Analysis of the Risk of Road Test Failure Associated with Dementia

Study or Subgroup	Dementia Events	Dementia Total	Healthy Elderly Events	Healthy Elderly Total	Weight	Risk Ratio M-H, Random, 95% CI	Year
Lincoln 2006 (1)	4	37	0	31	19.6%	7.58 [0.42, 135.51]	2006
Ott 2008 (2)	13	84	0	44	20.8%	14.29 [0.87, 234.93]	2008
Davis 2012 (3)	1	59	0	44	16.2%	2.25 [0.09, 53.95]	2012
Barco 2015 (4)	37	60	1	32	43.4%	19.73 [2.84, 137.23]	2015
Total (95% CI)		**240**		**151**	**100.0%**	**10.77 [3.00, 38.62]**	
Total events	55		1				

Heterogeneity: $Tau^2 = 0.00$; $Chi^2 = 1.50$, df = 3 (P = 0.68); $I^2 = 0\%$

Test for overall effect: Z = 3.65 (P = 0.0003)



DRIVING PERFORMANCE OUTCOMES

Large Effects:

Aksan et al (2015) – Secondary Driving Task Performance, Landmark identification, Route-following

Barco et al (2015) – Driving Situation Errors

Davis et al (2012) – Road Test Error Scores

Eby et al (2012) – Lost trips, miles belted, miles driven with short headway, miles driven 10mph or more slower than surrounding traffic.

Whehilan et al (2005) – Road Test Error Scores

Medium Effects

Aksan et al (2015) Safety errors, lane observance, tursn

Barco (2015) Errors turning right or driving straight

DRAFT GUIDELINES (MAY 3, 2016)

1. Dementia often has a direct effect upon fitness to drive, and clinicians must not neglect any indications of possible cognitive compromises of fitness to drive. (Level C)

2. Diagnosis of dementia alone is not sufficient to withdraw driving privileges. (Level A)

3. Severe dementia is an absolute contraindication to driving. (Level C)

4. It unlikely that safe driving can be maintained in the presence of moderate dementia (ie any basic ADL impairments) due to cognition, and driving is to be strongly discouraged. If patients wish to continue to drive, they should be formally assessed and monitored very carefully for delirium or any progressive loss of cognition and function that would mandate holding off driving until reassessment can occur. When in doubt it is recommended to err on the side of public safety . (Level C)

OTHER TOPICS OF DRAFT GUIDELINES

DRAFT GUIDELINES (MAY 3, 2016)

- ADL/IADL loss
- Screening
- Re-evaluation
- On-road testing
- Dementia not in isolation
- Behavioral Changes
- Language impairment
- Planning cessation
- Burdens of cessation
- Caregiver report

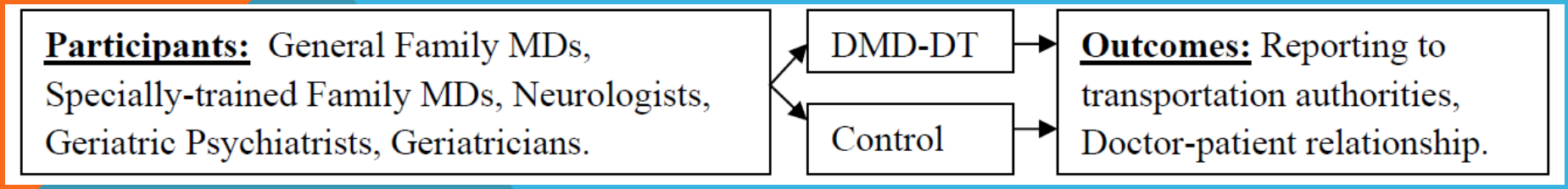
CLINICAL DECISION TOOL

CIHR, PI: M RAPOPORT

Tool Development

- Literature review
- Guideline search
- Caregiver team
- Qualitative interviews

Driving in Mild Dementia Decision Tool (DMD-DT) Intervention		
Computerized Clinical Decision Support System (CCDSS)	Educational Package	Specialized Reporting Form



PRELIMINARY ANALYSIS

Per-protocol reporting rate was 43% in the control group and 49% in the intervention group.

The base rate was much higher than we anticipated (43% instead of 13%) and the difference between groups was smaller (6% instead of 10%).

Group was not a significant predictor of per-protocol reporting.

PRELIMINARY ANALYSIS CONT'D

In a multivariate analysis, caregiver concern (OR 6.2, 95% CI 2.7-14.3) and abnormal clock drawing (OR 10.6, 95% CI 5.0-22.5) were predictors of per-protocol reporting.

- Of course, caregiver concern and abn clock are included in the algorithm of the intervention, but the multivariable analysis controls for group membership.

Interpretation: The intervention doesn't increase reporting but rather caregiver concern and clock drawing abnormalities are strong predictors of reporting patients with mild dementia/MCI.

A Driving Cessation Decision-Making and Coping Framework and Toolkit for People with Dementia

CCNA Team 16: Driving and Dementia
Team Leaders: G. Naglie & M. Rapoport
Research Associate: S. Sanford

www.ccna-ccnv.ca

STUDY OBJECTIVES

1. To develop a multi-component, evidence-based intervention that supports decision-making about driving, as well as emotional, transportation and other needs following driving cessation
2. To build upon existing driving cessation research by including the perspectives of key stakeholders

SYSTEMATIC AND SCOPING REVIEWS

1. Driving cessation interventions for individuals with dementia and older adults
2. Strategies to facilitate driving cessation for persons with dementia
3. Sex differences in driving cessation in dementia
4. Alternative transportation options for individuals with dementia
5. Intervention approaches to major life transitions in older adulthood
6. Psychotherapeutic interventions for older adults with cognitive impairment

QUALITATIVE STUDY

- **In-depth, semi-structured interviews and focus group sessions to explore the perspectives and experiences of key stakeholders (n=31) on strategies to support decision-making and the transition to non-driving**
  - **Healthcare providers (n=10)**
  - **Representatives from organizations (n=6)**
  - **Family caregivers (n=13)**
  - **Former drivers with dementia (n=2)**

OTHER RESEARCH ACTIVITIES

- Informal consultation with other stakeholders
- Semi-structured website searches for relevant tools and resources
- Review of publically available tools and resources in different formats
- Resources assessed for relevance, feasibility and accessibility

CHALLENGES IDENTIFIED

- Relative gap in intervention research on driving cessation and dementia
- Evidence to support existing interventions is relatively weak
- Lack of education and resources to support advanced planning and decision-making about driving cessation and the transition to non-driving

CHALLENGES IDENTIFIED (CONT'D)

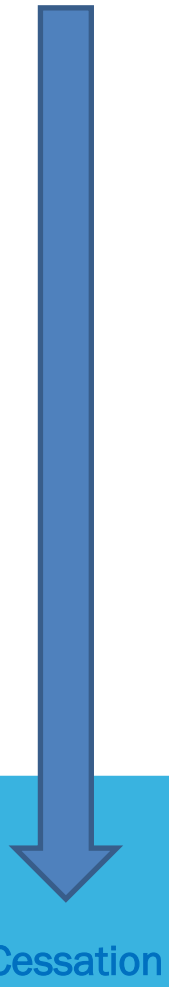
- **Healthcare providers and caregivers experience difficulty determining which resources are trustworthy**
- **Supportive approaches to emotional responses are often overlooked due to narrow focus on practical approaches (e.g., transportation planning)**
- **Following driving cessation, caregivers often assume the "burden" to maintain purpose, roles and social participation of person with dementia**

META-SYNTHESIS OF RESEARCH FINDINGS

- **Framework for cessation interventions for persons with dementia and their caregivers with a toolkit of approaches and resources**
- **Draws from Transtheoretical Model of Behaviour Change - concept of decision stages from pre-contemplative to post-cessation**
- **Themes represent distinct, but overlapping, content areas that depict various needs of drivers and former drivers with dementia, as well as those of their caregivers**

FRAMEWORK CONTENT AREAS

1. Driving and Dementia Education and Awareness
2. Communication Support
3. Crisis Support
4. Practical Planning
5. Skills Building
6. Coping with Loss and Grief
7. Interpersonal Elements and Role Transitions
8. Identity and Preservation of Meaning
9. Mobility Support
10. Community Access and Social Participation
11. Adjustment and Adaptation to Change
12. Advocacy and Political Action



IMPLICATIONS

- **Address a range of needs by offering individualized approaches with supportive tools and resources**
- **Increase accessibility of available resources**
- **Facilitate driving cessation decisions and improve safety for persons with dementia and the public**
- **Improve quality of life by maintaining social inclusion**

NEXT STEPS

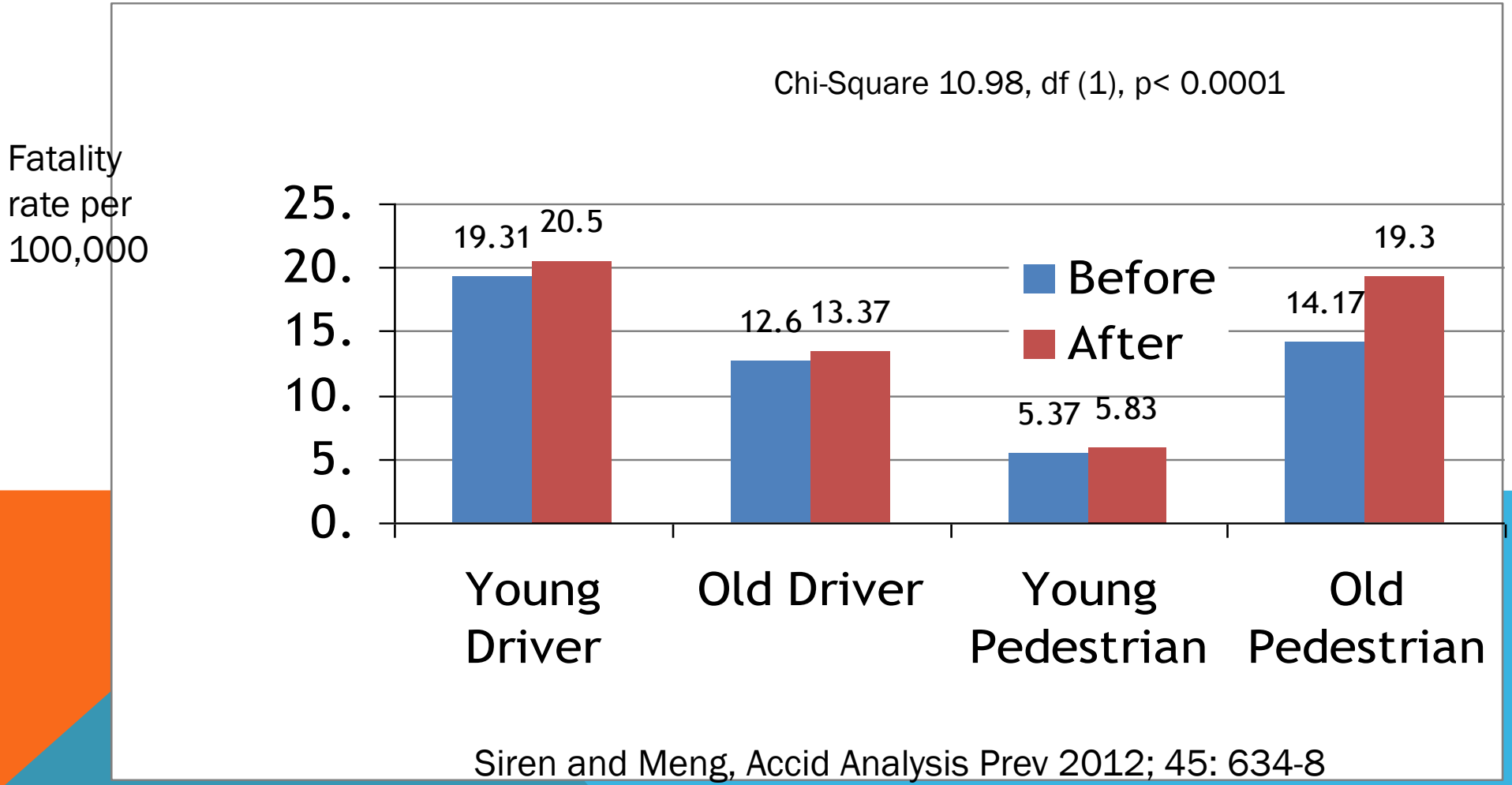
- Implement framework and accompanying toolkit in local settings
- Evaluate toolkit – content, experience of delivery, use and early effects
- Refine toolkit and approaches to implementation in different contexts
- National implementation and evaluation of outcomes

FUTURE OBJECTIVES

1. Develop and evaluate a unique group-based intervention for persons with dementia and their caregivers based on the intervention framework and toolkit
2. Establish the unique driving intervention needs of rural drivers with dementia and their caregivers
3. Identify and evaluate a GPS-based outcome measure of life space for persons with dementia that can be used as an outcome measure of interventions for driving cessation

Nowadays

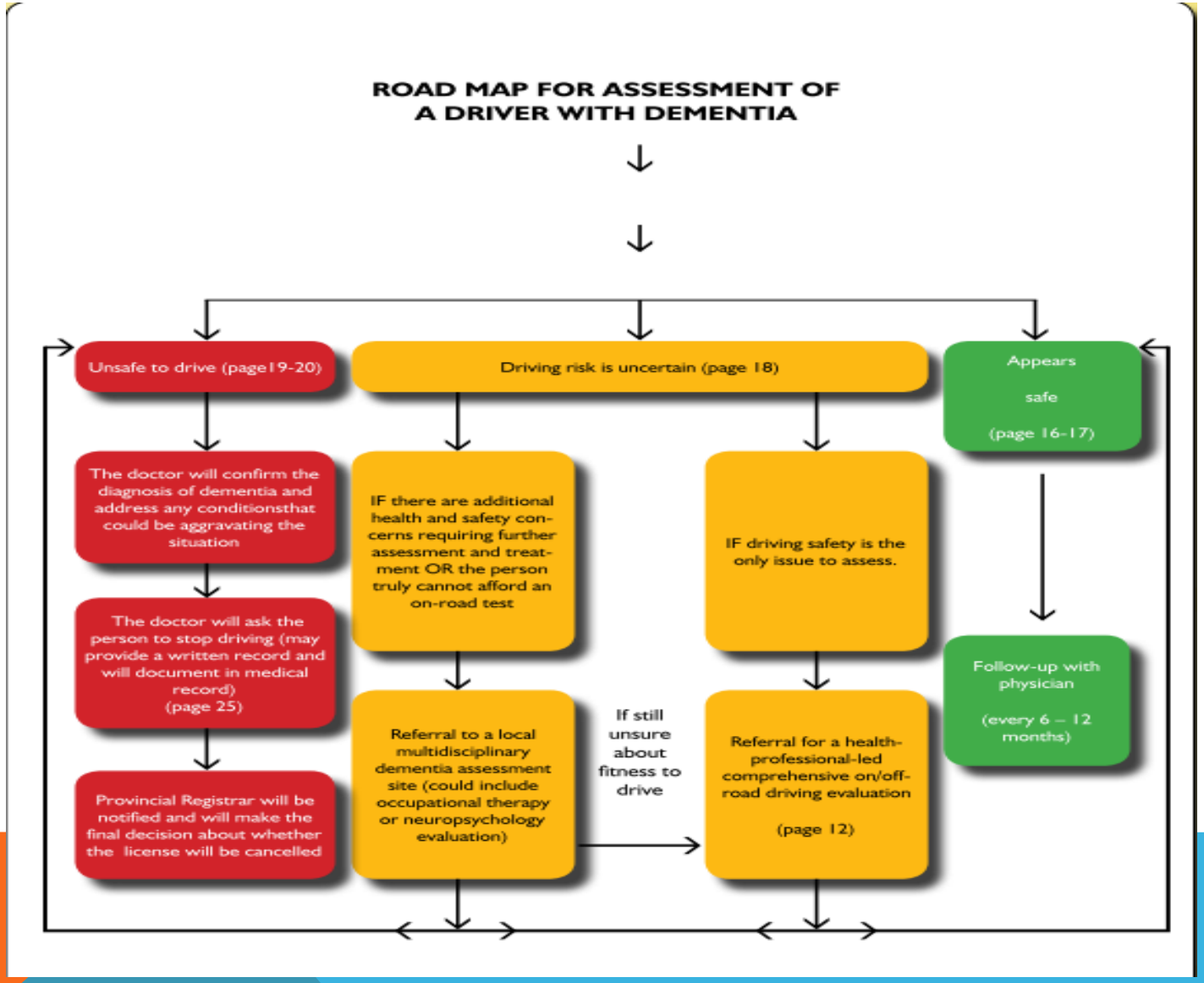
SCREENING AT THE GOVERNMENT LEVEL



Siren and Meng, Accid Analysis Prev 2012; 45: 634-8

DEMENTIA & DRIVING

- The diagnosis of dementia does *not* automatically mean *no driving (some people with mild dementia can drive albeit for a limited period of time before they must hang up the keys)*
- The diagnosis of dementia *does mean*:
  - You must ask if the person is still driving
  - You must assess and document driving safety and follow your provincial reporting requirements
  - If safe to drive, you must reassess fitness-to-drive every 6 months
  - You should start to counsel regarding eventual '*driving retirement*' as early as possible to allow the patient to process, adjust and prepare



Byszewski, Dementia and Driving Toolkit (online resource. www.Rgpeo.com)

RATIONAL USE OF COGNITIVE TESTING

Are the test results consistent with other clinical evidence?

What are we really measuring?

What is the trajectory?

What is my duty?

Common sense

Qualitative and dynamic aspects of testing.

Trichotomization

Molnar, F.J., Rapoport, M.J., Roy, M. (2012) CGS CME.

HOW TO

Document re: Driving

Ask Family.

Review cognition, behavior, function, hearing, motor, and sensory function.

Rule out significant dangerous medical conditions (eg. Seizure disorder, sleep apnea, stroke, PD), medications (esp anticholinergic) and substances.

Decide on referral for specialized testing.

Give feedback.

SUMMARY

Not the same as driving in the elderly.

Many cognitive skills required.

Dementia increases crash risk, but also decreases exposure. Not enough info.

Drivers with dementia are persistent.

Many patients in the early stages may be safe to drive.

Cognitive testing limited predictive ability. We need better tools.

Individualized assessment needed. We need to make this practical and affordable.

Behavioral changes play a significant role, especially psychosis, apathy and depression.

Legislation - Safety outweighs autonomy, very challenging to balance, and doctors are not reporting.

RESEARCH TEAM

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Stephanie Yamin (Saint-Paul University)

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- **Alex Mihailidis** (University of Toronto), **Lead, Team 15: Gerontechnology and Dementia**
- **Joel Sadavoy and Mary Chiu** (Mount Sinai Hospital, University of Toronto), **Leads, Team 18: Effectiveness of Caregiver Intervention**
- **Debra Morgan** (University of Saskatchewan), **Lead, Team 20: Issues in dementia care for rural and indigenous populations**

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Candrive

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Questions?