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The Bridge **Engagement Centre**

216 Murray St., Ottawa









No Disclosures

Objectives:

- 1) What do we mean by 'Patient Engagement'?
- 2) Can we achieve the REAL 'Patient Engagement' in research?
- 3) What is PROMPT and OCEAM?

PROUD Project: Participatory Research in Ottawa: Understanding Drugs

A Community-Based Participatory Research Project (CBPR) designed to:

- To understand socio-demographic risk factors of the most marginalized inner city population
- A peer-led, Community-Based Participatory Research (CBPR) project
- A cross sectional cohort study
- Conducted at our Community Research Office, 216 Murray St., near the Shepherds of Good Hope (a large homeless shelter) in downtown Ottawa.
- 856 participants:
 - Detailed socio-demographic information collected on an ipad survey

PROUD:

Tobacco Smoking rates:

Canada/US - general population - 18% Ottawa - general population - 9-12%

Ottawa PROUD population (Homeless and insecurely housed, multi-drug user) – 96%

Tobacco Inequity!!!

- Multiple ER visits & Hospitalization (\$38.2 million/yr in Ottawa)
- Tobacco costs \$1.6 billion/year in healthcare costs in Ontario
- Die <u>25 years earlier</u> than housed Canadians, mostly related to tobacco!

To address this stark tobacco inequity...

PROMPT Project:

Participatory Research in Ottawa: Management and Point-of-care of Tobacco

WHAT IS PROMPT?

A Community-Based Participatory Action Research Project (CBPAR) designed to:

- learn optimal ways to disseminate evidence-based tobacco dependence management in the hardest-to-reach inner city population.
- A peer-led, Community-Based Participatory Research (CBPR) method integrated within a Social Network approach
- A prospective cohort study
- Conducted at our Community Research Office, 216 Murray St. the Bridge Engagement Centre (the Bridge)

- Peer-led recruitment of 80 participants (target population: Homeless & Insecurely housed) completed in 6 months!
- Canadian Mental Health Association (CMHA) nurse on site twice a week
 - Nicotine Replacement Therapy (NRT), one-on-one counselling, peersupport) for 6 months
 - Participants can see the nurse as often as clinically indicated
- Peer-led, Weekly Life-skills Workshops
 - Financial Literacy, Banking,
 - Cooking, art, mindfulness
 - Access to Pet-care,
 - HIV/Hep-C education, peer-support etc.
- Peer-led monthly follow-ups for 6- months

Components of the project

The Ottawa Citizen Engagement and Action Model (OCEAM)

A ten-step model: Operationalized through PROMPT

https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0034-y

True partnership: Citizen/Peer Engagement from the beginning till the end!

1. Formulating a relevant project question

- A project question relevant to the community; and recruitment and retention of peers
 - E.g. Building the community-based participatory research team and recruiting peer researchers

- Developing a project design
- Agreed upon study method by peers and researchers
- Successful implementation of project method with peers

2. Designing project method

- Project Questionnaires and Case Report Forms
 - E.g. Culturally appropriate language and Peer training
 - Ensure successful design and selection of questionnaires and CRF that peers are satisfied with (language, cultural sensitivity etc.)

3. Designing project questionnaires and Case Report Forms (CRFs)

- Recruitment of sample
 - Peer-led Social network based recruitment to enroll genuine members of the target population
- Recruitment from March 2015-August 2015

4. Participating in recruitment

- Participant's written consent
 - Explained by peers to participants
 - \$20 as a compensation of their time/effort

5. Participating in consenting

Participant mean tobacco use

20.49 cigarettes daily 27.26 years of smoking 113.14\$ spent/month on tobacco

Participant mean lifetime illicit drug use

Crack 66.25%

Marijuana 61.25%

Heroin 23.75%

Other Opioids 26.25%

Demographics

Mental Health

- 35% diagnosed with depression
- 28% diagnosed with an anxiety disorder
- 9% diagnosed with bipolar disorder

Mean Age	44.83 years
Gender	70% M, 30% F
Primary Language	66% English / 10% French
Indigenous Representation	21%
Food Insecurity	79.5%
Anxiety/Depression	28.75% / 35%
FTND (moderate to high tobacco dependence)	72.50%
COPD on Spirometry	53.7%
Gold mild/mod/ sev/very severe MALE (n=29)	27.60% / 34.48% / 31.03%/6.90%
Gold mild/mod/ sev/very severe FEMALE (n=7)	0/71.43%/28.57%/0
Mean CAT Score	18.31%
Asthma	16.66%

COPD & Asthma

Cough

Do you usually cough when you don't have a cold?	Yes: 62.5% No: 35.0% N/A: 2.5%
If yes to above, are there months in which you cough on most days?	Yes: 50.0% No: 11.2% N/A: 38.8%
If yes, do you cough on most days as much as 3 months/year?	Yes:46.3% No: 3.7% N/A: 50.0%
How many years have you had this cough?	Less than 2 years: 8.8% 2-5 years: 11.2% More than 5 years: 30.0% N/A: 50.0%

Phlegm

Do you usually bring up phlegm from your chest, or do you usually have phlegm in your chest that is difficult to bring up when you don't have a cold?	Yes: 67.5% No: 30.0% N/A: 2.5%
If yes to above, are there months in which you have this phlegm on most days?	Yes: 45.0% No: 22.5% N/A: 32.5%
If yes, Do you bring up this phlegm on most days for as much as three months each year?	Yes: 42.5% No: 2.5% N/A: 55.0%
How many years have you had this phlegm?	Less than 2 years: 17.5% 2-5 years: 7.5% More than 5 years: 20.0% N/A: 55.0%

Baseline

Wheezing

Have you had wheezing or whistling in your chest at any time in the last 12 months?	Yes: 35.0% No: 33.8% N/A: 31.2%
If yes, In the last 12 months, have you had this wheezing or whistling only when you have a cold?	Yes: 35.0% No: 33.8% N/A: 31.2%
In the last 12 months, have you ever had an attack of wheezing or whistling that has made you feel short of breath?	Yes: 38.8% No: 30.0% N/A: 31.2%

Baseline

Shortness of breath

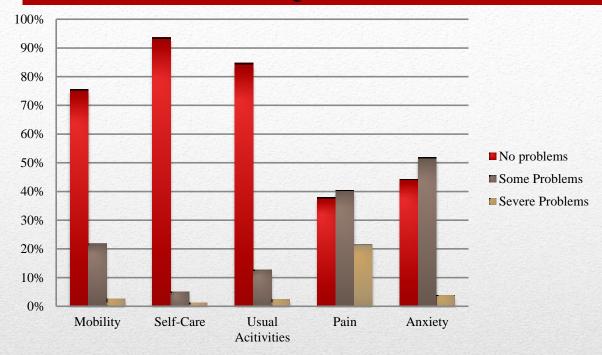
Are you unable to walk due to a condition other than shortness of breath (e.g. broken leg, arthritis, etc.)?	Yes: 32.5% No: 65.0% N/A: 2.5%
If No, Are you troubled by shortness of breath when hurrying (on level ground) or walking up a slight hill?	Yes: 18.8% No: 45.0% N/A: 36.2%
If yes, Do you have to walk slower than people of your age (on level ground) because of shortness of breath?	Yes: 1.2% No: 16.3% N/A: 82.5%
Do you ever have to stop for breath when walking at your own pace (on level ground)?	Yes: 8.7% No: 8.8% N/A: 82.5%
Do you ever have to stop for breath after walking about 100 meters [(or after a few minutes) (on level ground)]?	Yes: 3.8% No: 13.7% N/A: 82.5%
Are you too short of breath to leave the house or for other simple tasks (like dressing or undressing)?	Yes: 2.5% No: 16.3% N/A: 81.2%

Under each heading, please tick the ONE box that best describes your health TODAY. MOBILITY I have no problems in walking about I have slight problems in walking about I have moderate problems in walking about I have severe problems in walking about I am unable to walk about SELF-CARE I have no problems washing or dressing myself I have slight problems washing or dressing myself I have moderate problems washing or dressing myself I have severe problems washing or dressing myself I am unable to wash or dress myself USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities) I have no problems doing my usual activities I have slight problems doing my usual activities I have moderate problems doing my usual activities I have severe problems doing my usual activities I am unable to do my usual activities PAIN / DISCOMFORT I have no pain or discomfort I have slight pain or discomfort I have moderate pain or discomfort I have severe pain or discomfort I have extreme pain or discomfort ANXIETY / DEPRESSION I am not anxious or depressed I am slightly anxious or depressed I am moderately anxious or depressed I am severely anxious or depressed I am extremely anxious or depressed



EQ visual analogue scale (VAS)

EQ-5D



EQ Index (USA)

- Mean: 0.75
- · SD: 0.23
- Range: -0.11-1

EQ visual analogue scale:

- Mean score: 62.2
- SD: 16.96
- Range: 3-100

EQ-5D Results

Male

GOLD Categories	EQ index Mean	Range
Mild	0.78	0.24-1.0
Moderate	0.81	0.46-1.0
Severe	0.86	0.76-1.0
Very Severe	0.60	0.40-0.80

Female

GOLD Categories	EQ index Mean	Range
Mild	N/A	N/A
Moderate	0.74	0.46-0.83
Severe	0.78	0.77-0.80
Very Severe	N/A	N/A

U.S COPD population¹

GOLD Categories	EQ index Mean
Mild	0.74
Moderate	0.74
Severe	0.69
Very Severe	0.61

EQ-5D Results

- Completed Questionnaires
 - Peer involvement to avoid <u>social desirability bias</u> on the questionnaires
 - Participants more comfortable/honest with peer researchers

6. Participating in administering study questionnaires

- Testing completed
 - Handheld spirometry and oscillometry
 - Exhaled CO test

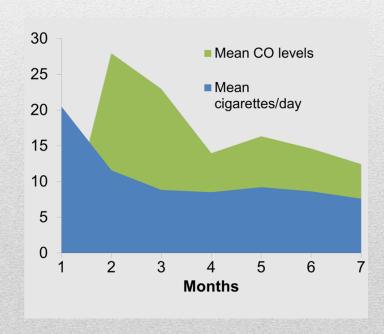
7. Participating in study related testing

8. Participating in follow-ups

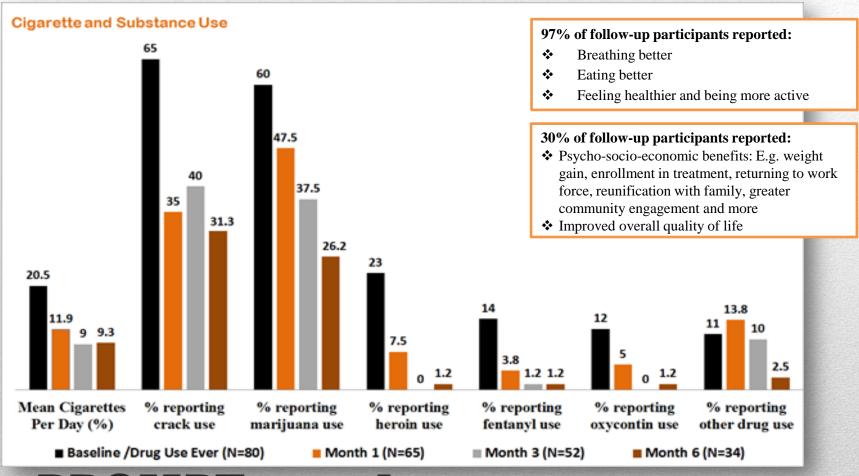
- Every participant was to be followed for 6 months:
 - E.g. \$25 as a compensation of their time/effort
 - E.g. Weekly peer-led Life Skills Workshops
- A short Survey conducted at each monthly follow-up visit by peers
- Final survey @ 6 month visit

PROMPT Results

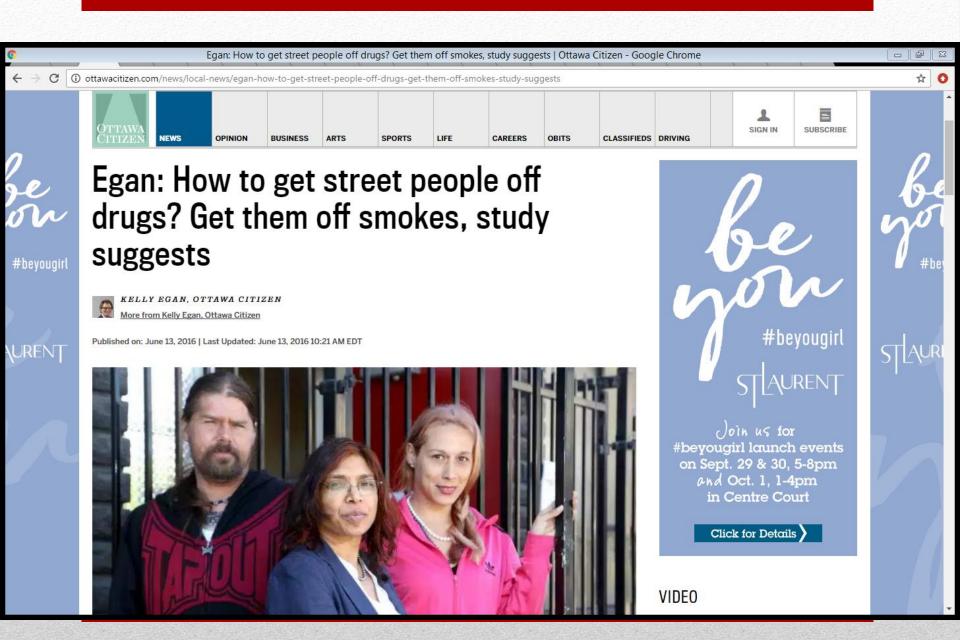
- Number of cigarettes per day
 - baseline 20.49
 - 6-month -7.6
- Exhaled CO level
 - baseline 27.94
 - 6-month 12.43
- At 6-month follow-up:
 - Stopped smoking/drugs 9%
 - Reduced Smoking/drugs 79%

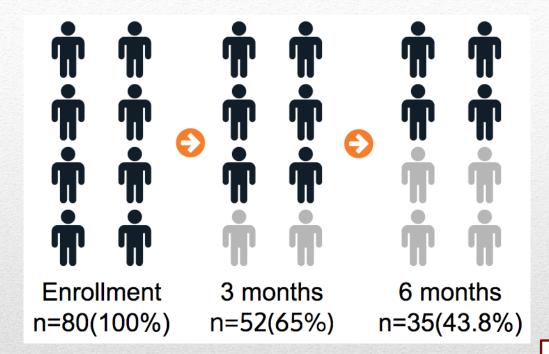


Impact of PROMPT: dramatic reductions in smoking and other drug use!



PROMPT results





Follow-up rates at 3 and 6 months

Follow-up retention

Loss to follow up:

Prison, Rehab, Hospitalization, Employment, Education, Moving and Other.

Surprises: New jobs, apartments, pets, less drugs, school admissions

What helped you reduce or quit smoking?

- "getting out and going to The Bridge every day"
- "Being busy"
- "Outreach by Tiffany and Kelly"
- "Feeling well supported"..."Women's group"
- "Exercise helps me quit smoking"
- "More quit aids"
- "the patches diminish the urge"
- "Fruit NRT gum"
- "the inhaler"
- "Being active, inline skating"
- "using my bike"
- "worrying about my health...teeth"
- "Less drinking"
- "avoiding environments where people smoke"

What stood in your way when you wanted quit?

- "The first couple cups of coffee"
- "Smoke Breaks"
- "Drinking alcohol or doing drugs"
- "Hard not to smoke after eating"
- "Hard to quit because its everywhere"
- "Smoke dealer across the hall" (living in a shelter)
- "Socially acceptable to smoke, easy to pick up"
- "Ran out of patches or inhalers before follow-up date"
- "No money for quit smoking aids"
- "Craving it, addiction", "stress"
- "free time/boredom"

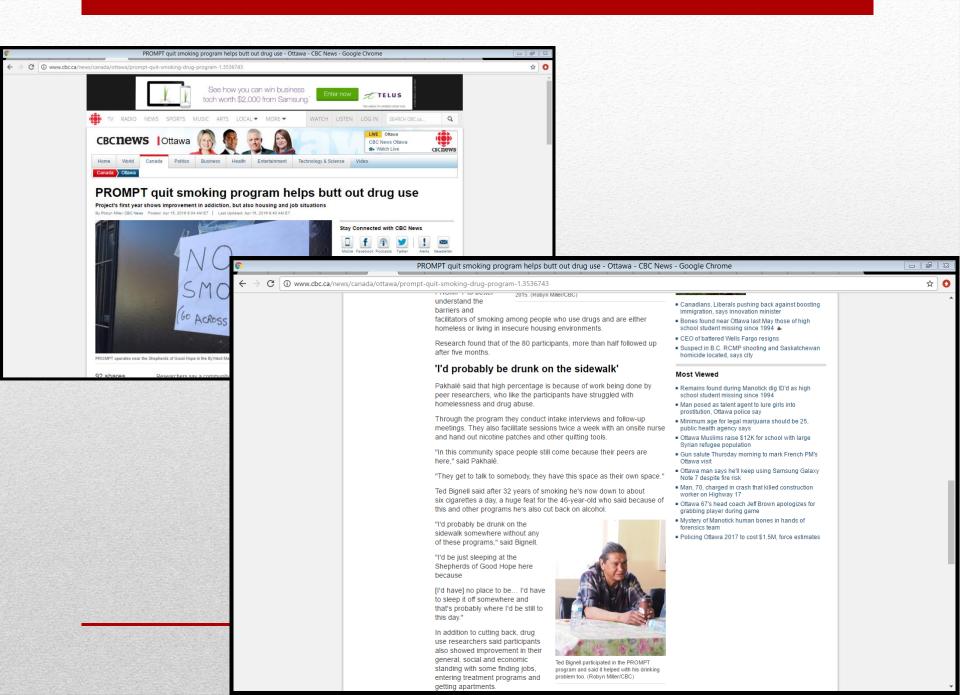
Facilitators and Barriers to quitting

9. Participating in data entry, data cleaning/analysis and interpretation

- Peer participation in data entry, data cleaning, data analysis and interpretation
 - "We are the end users of the results and hence, we must be involved in the analysis and interpretation so that the results and outcomes are relevant to us."
 - "I learnt so much, thank you for involving me!"....

10. Participating in ongoing/integrated community knowledge mobilization

- Continuos knowledge mobilization through:
 - Peer training
 - Regular project meetings with peers (at least weekly),
 - Peer-led community knowledge forums (quarterly)
 - Posters, hand-outs, news-items and manuscript writing (peers as co-authors)
 - Community capacity building activities and focus groups @ the Bridge
 - Monthly CAC meetings @ the Bridge



Community Building Activities @ the Bridge

- ONPAHR (Ottawa Network of Peers Acting for Harm Reduction)
 - Network of dedicated peers, meet weekly @ the Bridge
 - Received their first community grant!
 - Planning a weekly community building activity to be held @ the Bridge
- French Toast Fridays with DUAL
 - An open community event @ *the Bridge* on all Friday mornings
 - Ottawa Public Health nurse for harm reduction education onsite

Community Building Activities @ the Bridge

- Employment @ *The Bridge*: Peer engagement, Kitchen work, Yard work and Building maintenance
- The Bridge Community Advisory Committee (The Bridge CAC)
 - Representatives from peers and participants (voting members)
 - Representatives from local healthcare agencies (non-voting members)
 - Balanced gender, race, age, language, indigenous representation
 - Monthly CAC meetings @ the Bridge
- Peers and participants get honoraria for the time they spent on project activities

What's next? Healthy People Initiative

Alex Trebek Challenge & Innovation Fund, Univ. of Ottawa

- Empowering people to get to that 'next' level from where they are!
- Provide life-skills and build self-confidence with peer support
- Get people ready for paid small jobs or volunteering positions in the community
- Pro-actively connect them with such opportunities
- PROMPT participants told us that they want to be busy and partake in the general economy, have meaningful civic engagements and be productive!



Patient-engagement

• This practical embodiment of "by the community, for & with the community" approach will not only help reduce the tobacco use related stark disparity within our city sub-populations, but also reduce the healthcare costs and community costs.

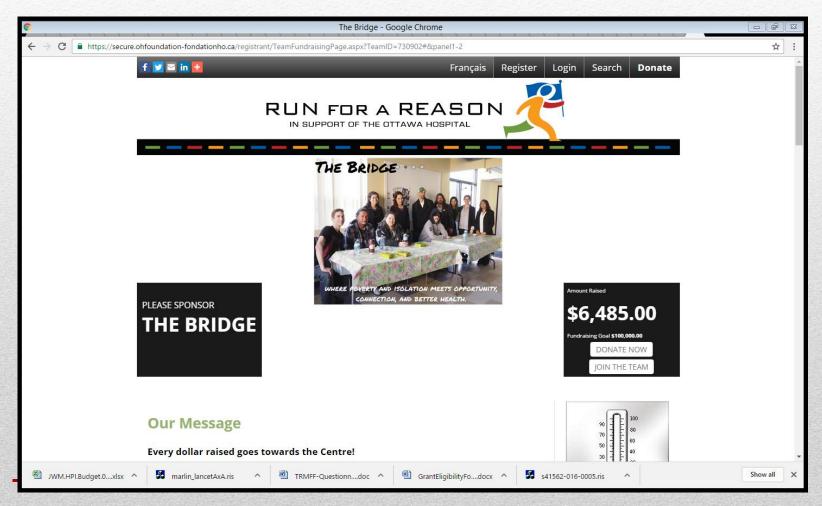


Conclusions

Thank you!

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- Kelly Florence & Tiffany Rose, Community Peer Researchers
- Community Advisory Committee
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- Wendy Muckle, Exe. Director, Ottawa Inner City Inc.
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- Dr. Mark Tyndall, Exec. Director, BC CDC, Vancouver
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- Somerset West CHC
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 - Champlain LHIN
 - Department of Medicine, TOH
 - Divisions of Respirology and Cardiology, TOH
- All participants!!!!

www.tinyurl.com/TheBridge2017



Please support the Bridge!



QUESTIONS? (spakhale@ohri.ca)