THE UNIVERSITY OF BRITISH COLUMBIA

Learning Exchange

Plain Language Summaries: Lessons Learned from the Making Research Accessible in the DTES Initiative (MRAi)

BACKGROUND

The MRAi is a campus-community collaboration led by the UBC Learning Exchange that seeks to improve access to academic research and community-generated materials with a focus on Vancouver's Downtown Eastside (DTES). The need to access high-quality research and information was brought to the attention of the Learning Exchange by people living and working in the DTES. These groups voiced their concern with research projects that extracted information and findings that were subsequently published in journals that were locked behind publisher paywalls. Members of community organizations also identified the need to preserve community-generated materials.

The MRAi's goals are to:

1. Increase the accessibility and impact of research by facilitating: open-access to research materials, the development of plain-language summaries, and opportunities to share information and learn from one another (i.e. knowledge mobilization), and

2. Increase the recognition and availability of community-generated materials such as program reports, research and evaluation documents, and organizational histories

Housed at the Learning Exchange, the MRAi is a partnership with UBC Library, the Public Scholars Initiative (PSI) and various stakeholders in the DTES. The MRAi is pursuing several avenues for disseminating research focused on the DTES, including an online and open access information repository that contains academic research and community-generated materials. An online repository will contribute to knowledge transfer initiatives by making these resources available to agencies and individuals in and beyond the DTES. The MRAi also works to facilitate opportunities for faculty members, community organizations, students, community members, and other stakeholders to learn from and collaborate with each another. Through developing a wider platform to share the findings from research and community-generated materials, and facilitating the uptake of this information in the context of the DTES, we hope to broaden the positive impact of evidence-based information in people's lives.

GOALS OF THIS WORKSHOP
- o Have the tools to develop a plain language summary with a specific audience in mind
- o Identify key design elements of a strong plain language summary

- o Have tools to evaluate the use and usefulness of plain-language summaries and other research outputs to the potential audiences/communities you wish to communicate the findings to
- o Recognize the importance of data linkage and be able to map out a plan within your own organization for consistent deliverables associated with research
- o Expand knowledge of Open Access and Open Access Resources

KEY TERMS & RESOURCES

Article Processing Charges (APCs): charges required by publishers to provide immediate Open Access to full-text academic journal articles they host online (e.g. full-text article in "Health & Place" hosted by publisher Elsevier has a $2200(USD) APC)

cIRcle: UBC's Institutional Repository (IR) that provides Open Access to digital materials including pictures, reports and academic materials http://circle.ubc.ca/ .

Community Scholars Program: (http://www.lib.sfu.ca/about/overview/services-you/community-scholars) an initiative of SFU library that provides people working in non-profit organizations across BC with access to a select set (as identified by agreement between SFU and publisher) of journals and resources available through SFU's library.

Downtown Eastside (DTES): considered by many the "heart of the city"(1), Vancouver's Downtown Eastside is situated east of Vancouver's Downtown Core on unceded Coast Salish territory. It continues to be home to many Indigenous people as well as many other communities. The neighbourhood has been especially impacted by gentrification as poverty, and the criminalization of drug use and sex work contribute to community member's vulnerability. However, the area is also one of incredible resilience and strength.

Knowledge Exchange: "is a collaborative problem-solving between researchers and decision makers that happens through linkage and exchange. Effective knowledge exchange involves interaction between decision makers and researchers and results in mutual learning through the process of planning, producing, disseminating, and applying existing or new research in decision making (2)."

Knowledge Mobilization (KMb): moving research into action or practice to make it useful to society (3). The act of connecting academic stakeholders to non-academic stakeholders to bring research findings into practice.

Knowledge Translation: "the exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system(2)."

Open Access (OA): "Open Access (OA) literature is digital, online, free of charge, and free of most copyright and licensing restrictions(4)."

Plain Language Summaries (PLS): involve the "translation" of academic research outputs (e.g. scholarly articles, reports) into language that is free of academic jargon and easier to understand by people of diverse backgrounds (5,6).

BY THE NUBERS:

- As of August 29, 2017 we have identified **700 research articles with a focus on the** DTES, the majority of which have been published since 2010
- As of June 2017 there were **74 studies** that had received ethics approval from UBC to take place in the DTES
- In 2016, **60** articles were identified, of which 77% had a UBC affiliation and **67 % of these (31 full-text journal articles) were behind publisher pay-walls (**i.e. not available for public access)

AUDIENCE

One of the key problems that we identified during the 'Making Research Accessible' initiative was the findings from research that was taking place in the DTES were not getting back to participants. This was despite a large number of studies and research papers with a focus on the DTES (7). We identified two key problems in early consultations:

1. People living and working in the DTES had to pay to access research articles
2. Disciplinary jargon made it difficult for non-expert audiences to read and interpret academic research articles

Plain language summaries (PLS) were available for some of these articles, however, language continued to be a problem within PLS. Many of the PLS that we identify seemed to have been produced with health care practitioners and policy makers in mind[1]. While these are important audiences for PLS to speak to, the MRAi is interested in how to do a better job of bringing research findings to a non-expert audience that had participated in research in the DTES. This audience is referred to as "community members" in the rest of this

> 3 Assumptions to make about PLS audiences (11):
> 1. They are not familiar with the research method
> 2. They are not familiar with the problem/intervention
> 3. They may not have English as a first language

document while keeping in mind that there are many different communities that call the DTES home. **The focus of this workshop is on creating PLS that do a better job of sharing research findings with community members.** For a more in-depth discussion of considerations to take into account when sharing and exchanging information Jacobson et al. (8) provide a good summary of questions to ask to better understand user context, and Phipps et al.(3) provide a table of the role that PLS can play in translating research findings to different audiences (See Appendix A).

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[1] *Multiple research outputs may be needed to help share research effectively! Relevant information for one audience may not be relevant to another audience and PLS should reflect this.*

PLS KEY DESIGN ELEMENTS

There are a number of different ways to structure a PLS, however, this list of 'must haves' should help identify key elements that need to be included. Using a template with consistent headings and branding will also help community members pick out information that is relevant to them and know where information is coming from.

Length – A Canadian study of PLS that was informed by a steering committee of serviced providers identified 2 pages as an ideal length for summaries(9), this is consistent with Cochrane review suggestions of a word count between 400-700(10).

Font – Use a standard font (Arial/Times New Roman) and size (12 point) consistent with clear language design principles(9).

Design - Using a template with consistent headings and branding will also help community members pick out information that is relevant to them and know where information is coming from. Bold and consider using underlining to highlight headings and break information into palatable pieces. Bullet points are also a good way to highlight key points and ideas. While having a recognizable template is important having too many text boxes, distracting highlighted areas may be a drawback to community members being able to read the information and take in the research context.

Table 1: Plain Language Summary Checklist

PLS headings	What you should check	Guidance
Title	Is the title easy to understand?	Consider revising the title if it uses terms that might be unfamiliar to community members Keep in mind that the connection between the PLS and the full-text article may not be apparent to the reader if the title is changed significantly. If an alternative title is chosen, ensure that the full-text title is included and clearly labelled underneath
Keywords	Are the words identified by the publisher easy to understand? Are there words/terms/short forms related to the key words that may be helpful to include (e.g. HCV and Hep C)	Include a list of keywords as identified by the publisher that can be used to help search for the article and help community members identify whether the information in a PLS is relevant to them/their interests. When possible provide hyperlinks to a definitions and a list of other associated summaries/articles/resources.

PLS headings	What you should check	Guidance
"Research Team" **(=Authors)**	The full name of researchers are listed	Community members will find articles that have a name they recognize more appealing/reputable. If the information is presented online, hyperlinks to a researcher bio and other publications should be included. Information about the authors should not be included in the PLS
"What is the aim of this study?" **"What is this research about?"** **"Why was the study conducted?"** **(= Background)**	Is there a clear 'purpose' statement? Consider language such as "The purpose of this study was to..."	This section should not include any recommendations or key findings
"Key Messages"	Is there a short summary of the main results with reference to quality/certainty?	This section should include only the main results and reference to the quality/certainty of the information plus important research gaps if applicable
"What did the researchers do?" **(=Methods)**	Is there a clear summary of the number of people in the study and their characteristics (inclusion criteria), when the study was conducted (timeline), and how information was collected (qualitative/quantitative)?	Including a table with key group characteristics may be a helpful way to summarize information in a clear manner. Including a clear **who, when, where** in this section can help community members place the information in context.

PLS headings	What you should check	Guidance
"What are the main results" **"What can be learned from this study?"** **(=Results)**	Here is where you want to describe the effect of the intervention, the key findings or outcome. Is there a clear findings statement? Community members involved in grant writing want statements that they can use directly with a citation (e.g. This study found that…)	"When presenting the main results of the review, the PLS authors should have followed these principles: 1. Only present results for the most important outcomes, and try to present no more than seven outcomes. 2. Present the quality or certainty of the evidence for each outcome 3. Present the results consistently, using similar words and expressions for similar levels of effect. (See [Cochrane Standardized Statements Appendix A](#)) 4. If your assessment of the quality / certainty of the evidence are anything other than high, then you should avoid strong statements such as "[intervention] leads to ["outcome"]. You should rather indicate to the reader that there is some degree of uncertainty by adding modifying terms such as "probably", "may" (see [Appendix A](#)). 5. Ensure that the results are reported consistently between the plain language summary and the main text 6. Do not present recommendations"(11) Consider including a table that clearly summarizes the findings if there are multiple outcomes reported.

PLS headings	What you should check	Guidance
"Policy Implications" "Recommendations" (=Discussion)	Are there specific recommendations around treatment options, care or access to resources that could be helpful to the audience you're hoping to reach?	While Cochrane reviews specifically state not to include recommendations based on the research findings there may be a key message that is important to communicate to the target audience.
"Source Article" (=Citation)	Provide a complete citation for the full-text article using a consistent citation style. If available a digital object identifier (doi) should also be included as these are a stable way to search specific information and won't change, unlike web links that may not be available or may change after a specific period of time.	When a PLS is presented online there should also be the option to follow the citation to the full-text article.
"Created by"	Provide the name of the person who authored the PLS and the date the document was complete/made publicly available. Contact information for the 'creator' should also be included.	It should be clear to the reader that the PLS is a research summary and not a stand-alone piece of information. Community members may be more comfortable contacting the creator of the PLS with questions.

This table has been modified from the Checklist created for Cochrane review PLS (11)

TIPS FOR CREATING PLS FOR COMMUNITY MEMBERS

- Avoid jargon – have someone from outside of your organization, group, etc. read over the PLS to help identify terms that may not be widely used outside a specific discipline or research area
- Limit the use of acronyms
- Don't cut and paste information from the full-text article or use in-text citations
- Make it clear that information is being summarized and coming from a full-text academic article
- Provide direct links to the full-text article if possible
- Context(8)! The **"why?"** of the research may not be apparent from the purpose statement. Think of a broad statement that may help contextualize the work.
- KISS: keep it short and simple (ok maybe it's not so simple)
- Key consideration; how are community members going to cite PLS in grant applications and organizational reports? One reason that more resources aren't being put into PLS, despite a general understanding of their importance to knowledge translation and mobilization is that they are not recognized research outputs that most academics can add to their CVs. By being able to cite a PLS specifically rather than the full-text article there is an opportunity to track the use of PLS outside of academic circles.

EXAMPLES:

Simplify Title: Benzo use and Hep C infection in a group of people who use injection drugs; Journal article title: Benzodiazepine use and Hepatitis C seroconversion in a cohort of persons who inject drugs

Focus group participants weren't familiar with the term Benzodiazepines but were familiar with the term 'Benzos'. 'Seroconversion' and 'cohort' were also confusing. Most participants in the focus group didn't get past the title of this PLS.

This 'quick fact' was out of context for most people and the use of acronyms made it difficult to understand.

There are 3 acronyms in the first bullet point alone. Avoid using acronyms for PLS developed for community members whenever possible.

The definition for 'Benzodiazepines' provided at the bottom of the summary was not noticed by any of the participants in the focus group

It wasn't apparent to participants that the information could be found using the citation. Label "Source Article" can help community members make the connection.

Focus group participants recognized the names of BCCSUs partners (cut off in image of this summary) including St. Paul's and associated these organizations with the strength of the information.

While the list of affiliated organizations added credibility to the information being presented, participants were put off by the feeling of it being presented like an "advertisement."

gshi — Gender & Sexual Health INITIATIVE

The impact of construction and gentrification on an outdoor trans sex work environment

Background
Trans sex workers often face a high level of violence, often shaped by racism and economic barriers. This study aimed to investigate how road construction and gentrification impacted trans sex workers in an outdoor environment in Vancouver's Downtown Eastside.

The Question
How do environmental and structural changes to an outdoor work environment impact trans sex workers in Vancouver, Canada?

The Study
The issue of changes to the work area arose during qualitative interviews with 33 trans sex workers that were conducted between June 2012 and May 2013. In response, ethnographic walks that incorporated photography were undertaken with trans sex workers. Participants were recruited from an open prospective cohort of sex workers (An Evaluation of Sex Workers Health Access) and three open prospective cohorts of individuals who use drugs (The At Risk Youth Study, Vancouver Injection Drug Users Study, and AIDS Care Cohort to Evaluate Access to Survival Services).

The Results
Changes to the work environment were found to increase vulnerabilities in three areas:
- **Violence** – Disrupting traffic patterns increased sex worker vulnerability to violence by exacerbating unsafe working conditions and decreasing client traffic.
- **Displacement** – Gentrification resulted in a loss of work space and increase in resident complaints about sex work being conducted in the area.
- **Policing** - Within a criminalized context, construction and gentrification contributed to harassment from police and residents.

"Scarlett discussed how she has complaints from the café on that block because they don't like that traffic comes down to the area for sex work and not for their business. She felt frustrated by this response since she has been working there for over 15 years and is a business owner herself in her line of work."

The Policy Implications
- This study cautions against environmental and structural changes that disrupt trans sex work settings, foster displacement, and enhance structural vulnerabilities. Such gentrification promotes middle-class lifestyles and deems sex work as inappropriate, further marginalizing trans sex workers who are already impacted by colonial practices that construct racialized, trans, and sex workers' bodies as 'disposable.'
- Trans sex workers must be meaningfully included in community consultations and urban planning discussions.
- This study supports structural interventions that address cis- and heteronormativity and the effects of colonization to improve the health, safety, and economic security of trans sex workers. This study also supports the decriminalization of sex work as a method of increasing the safety and protecting the rights of trans sex workers.

Lyons,T., Krüsi, A., Pierre, L., Small, W., and Shannon, K. The impact of construction and gentrification on an outdoor trans sex work environment: Violence, displacement, and policing. *Sexualities*, 2016.

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Callout boxes:

KISS: *"Trans sex workers often face a high level of violence, often shaped by racism and economic barriers. This study aimed to investigate how road construction and gentrification impacted trans sex workers in an outdoor environment in Vancouver's Downtown Eastside."* Simplify! -> *"Trans sex workers often face high levels of violence. This study looked at how road construction and gentrification impact trans sex workers safety on the streets in Vancouver's Downtown Eastside."*

Watch for jargon! As one participant noted after reading 'The Study' section, "They use big words here too. Instead of just walks they have to put ethnographic in there, no one knows what that means."

Participants liked the use of bolding and bullet points in the results section and reported that this section was easy to read and understand.

Participants in the focus group found the highlighting of information in this PLS distracting. Most people reported that they read 'Scarlett's' anecdote in the box highlighted in red first and didn't know how to interpret it.

It was unclear to participants that the Gender and Sexual Health Initiative had been responsible for putting together this PLS and could be contacted with further questions. "For more information about this study" could help signal this link to community members.

CONNECTING INFORMATION

A strength of presenting information online is that information can be embedded in the PLS to connect community members to related information they may be interested in, including key definitions, authors information and related articles. Restricting the PLS to key findings is essential to providing the information in a meaningful way, however, whenever possible there should be clear links to where the information is coming from and how to find related information.

Information to consider connecting (providing hyperlinks to further information):
- **Key words** – are there other resources or PLS that have the same key words? Can the community member link to these resources if they click on the keyword?

- **Authors** - If a community member recognizes an author's name they will see the information as more reputable. If they find the information relevant or related to their initial query they may also want to be connected to more information by the same author.
- **Full text or other related materials** – provide a link to the full-text article whenever possible. In some cases there may be more than one output (e.g. report, infographic, poster, presentation) so multiple links to the related materials may provide different depths of information relevant to the community member's needs.

OPEN ACCESS

When thinking about the best way to connect information online, the importance of having access to full-text materials that PLS can be linked to whenever possible becomes of the utmost importance. There has been a movement within academia to move towards Open Access publishing and this is supported by the [Tri-Agency Open Access Policy on Publication.](#) This policy states that all research funded by the Tri-Agencies (Social Sciences and Humanities Council (SSHRC), Canadian Institute of Health Research (CIHR) and National Sciences and Engineering Research Council of Canada (NSERC)) must be accessible 1 year after publication. There are two options that researchers and research institutes (e.g. [BCCSU](#), [CHEOS](#), [BCCFE](#)) funded by the tri-agencies have to provide Open Access. Researchers can archive their full-text journal articles after the embargo period (period during which the publisher holder sole rights to the information within the journal article) has expired. This is referred to as "green" Open Access and uses institutional repositories such as UBC's [cIRcle](#). The other option is for researchers to pay an [Article Processing Charge](#) to the journal when their paper is accepted that will allow for immediate free public access and consumption. This is referred to "gold" Open Access. Article Processing Charges are an eligible budget item to include within any grant to the Tri-Agencies.

Gold Open Access should be the first approach whenever possible for two reasons; 1. It provides immediate access to the journal article once they are published online, allowing for timely access to the full-text by community members, and 2. Even if there is 'green' Open Access' to a journal article most search results will bring people to the publisher's page and ultimately a pay-wall. Most people will not know to continue their search, or how to use search terms that will help them access the article that has been archived within an Institutional Repository. While Open Access may not seem to be directly relevant to PLS, the ultimate goal of PLS is to improve access to research findings and exchange of knowledge with the goal to initiate change, either at the individual level, community level, organizational level or institutional level. Being able to connect people not only to research through PLS but also, to the full-text journal articles, provides an opportunity to move beyond a surface level understanding of information that is often necessary to constitute change.

BEYOND PLS: THOUGHTS ON KNOWLEDGE MOBILIZATION

PLS are only a tool to help make research findings more accessible. As a stand-alone item out of context they will play a limited role in actually helping people understand research findings, or put research findings into practice within their own lives or within their organizations. It is the personal relationships and work with community members that has the potential to lead to meaningful

interactions with research and potential change (3,12,13). Furthermore, sharing research summaries with community can be an important opportunity for the exchange of information and ultimately learning from one another and mobilize change (12,13).

One of the key lessons that we have learned by working on the "Making Research Accessible" in the DTES initiative is that providing access to academic journal articles through providing Open Access only scratches the surface of knowledge translation and mobilization. Knowledge translation requires time and resources to be done well and is best suited to an environment where there is an enduring connection to community and consultation and exchange can occur throughout the process. It is also essential that community capacity and time be recognized with financial compensation. The expectation that communities should volunteer their time to projects and partnerships where benefits to researchers and research organizations largely outweigh those to community is outdated and paternalistic. When programs are embedded in the community (and meet the needs of various communities) meaningful engagement can occur, however, without sustained interactions and dedicated staff it is difficult to implement meaningful change.

One final caution is that traditional research outputs (academic journal articles, conference presentations etc.) are largely unsuited to the needs of community members. Taking the time to tailor key messages to a specific audience takes time and energy, but is necessary in order for information to be understood and exchanged. Tables and graphs that are the staple of many academic presentations and play an important role in quickly summarizing information for academic audiences are largely ineffective as communication tools for community members. Rather communities should be worked **with** whenever possible to identify the ways that they prefer to learn and contribute to translating information so that it is meaningful and within context.

ACKNOWLEDGMENT

RESOURCES

[Research Impact](http://researchimpact.ca/) (http://researchimpact.ca/) has a repository of research summaries and some guidelines for effective knowledge mobilization and partnership.

[Tri-Agency Open Access Policy on Publication](http://www.science.gc.ca/eic/site/063.nsf/eng/h_F6765465.html?OpenDocument) (http://www.science.gc.ca/eic/site/063.nsf/eng/h_F6765465.html?OpenDocument) this policy was put in place to increase the availability of research findings to the public. Grant recipients are required to make sure that their research is publically accessible within 12 months of publication.

[Cochrane Review Checklist](#): this checklist provides guidelines to review before and after putting together a PLS.

(http://www.cochrane.no/sites/cochrane.no/files/public/uploads/checklist_for_cochrane_pls_28th_feb_2017_0.pdf) [BCCSU research summaries](https://www.bccsu.ca/research-summaries/) (https://www.bccsu.ca/research-summaries/) further examples of BCCSU PLS.

[GSHI research summaries](http://gshi.cfenet.ubc.ca/research-summaries) (http://gshi.cfenet.ubc.ca/research-summaries) further examples of GSHIs research summaries.

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APPENDIX A

TABLE 2: RECOMMENDATIONS ON HOW DIFFERENT STAKEHOLDERS CAN USE CLEAR LANGUAGE AND CLEAR LANGUAGE RESEARCH SUMMARIES (3)

Universities and Research Institutions	- Clear language research summaries can be used as communication vehicles to clearly communicate the results of research to non-academic research audiences. - Clear language research summaries serve as introductions to research expertise that may lead to future research collaborations. - Teaching students to write according to clear language writing and design principles provides a unique skill set valuable for many non-academic careers.
Research Funding Organizations	- Clear language research summaries can be used as communication vehicles to clearly communicate the outcomes of investments in research to parliamentarians, donors, and other funders. - Clear language research summary frameworks can be used to solicit end of grant research reports from grant recipients.
Knowledge Transfer and Exchange Organizations	Organizations such as the Social Care Institute for Excellence or the Arthritis Society can use clear language research summaries to present research to a variety of decision-makers and stakeholders.
Knowledge Brokers	Clear language summaries can be used to communicate research findings from research projects to mobilize knowledge and attract interest in the research of your project/unit/institution.
Community Based Researchers	As opposed to university-based research, community-based research is inherently change-oriented. Clear language research summaries are one tool to communicate research to decision-makers. Working outside of an academic paradigm of research, community-based researchers could learn clear language writing and design principles to make their research accessible.
Community and Government Decision-makers	Seek out clear language research summaries to connect to research and research expertise to inform decision making.

TABLE 3: COCHRANE STANDARDIZED STATEMENTS (11)

	Important benefit/harm	Less important benefit/harm	No important benefit/harm
High quality / certainty[1] evidence	[*Intervention*] improves/reduces [*outcome*] (high quality / certainty evidence)	[*Intervention*] slightly improves/reduces [*outcome*] (high quality / certainty evidence)	[*Intervention*] makes little or no difference to [*outcome*] (high quality / certainty evidence)
Moderate quality / certainty[1] evidence	[*Intervention*] probably improves/reduces [*outcome*] (moderate quality / certainty evidence)	[*Intervention*] probably slightly improves/reduces / probably leads to slightly better/worse [*outcome*] (moderate quality / certainty evidence)	[*Intervention*] probably makes little or no difference to [*outcome*] (moderate quality / certainty evidence)
Low quality / certainty[1] evidence	[*Intervention*] may improve/reduce [*outcome*] (low quality / certainty evidence)	[*Intervention*] may slightly improve/reduce [*outcome*] (low quality / certainty evidence)	[*Intervention*] may make little or no difference to [*outcome*] (low quality / certainty evidence
Very low quality / certainty[1] evidence	We / The review authors are uncertain whether [*intervention*] improves/reduces [*outcome*] as the quality / certainty of the evidence has been assessed as very low		
No studies	No studies were found that looked at [*outcome*]		

Created August 2017
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