

HEALTH DATA FOUNDATIONS AND EQUITABLE AI

Charlene Ronquillo | RN PhD

Assistant Professor | Lead of Health Informatics Equity Lab Co-Chair of IMIA SEP | Co-founder of NAIL Collaborative

TODAY, I AM PRIVILEGED TO JOIN YOU ON THE UNCEDED, OCCUPIED, AND TRADITIONAL TERRITORIES OF THE SYILX OKANAGAN.

I gratefully acknowledge the privilege we have gained as settlers we have benefited from the histories and structures of colonization on these lands and the institutions that have been built upon them.

May we commit to bettering ourselves by the ways we live and work towards truth and reconciliation.



TALK PURPOSE

Catalyze conversations about

data quality in health systems,

how we shape data,

downstream implications for equitable AI development

impacts on patients, communities, clinicians











INFLUENCES

migration, health and technology-related inequities, implementation science

Nursing Inquiry

Nursing Papulm 2011; 18(1): 262-275

Feature

Beyond greener pastures: exploring contexts surrounding Filipino nurse migration in Canada through oral history

Clarifone Borquilla," Georgie Bosdima," Sabrina T Wangh" and Unida Quiney:
"University of British Columbia. School of Nazing: VLBC Center for Hook Schools and Roley Research.
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- USC Debotration of Holloys Recourse Science Scien

Nursing Informatics 2014

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Access to Internet in Rural and Remote Canada

Leanne M. CURRIE, RN, PhD ^{a,1}, Charlene RONQUILLO, RN, MSN ^a and Tania DICK, MN/NP ^b

*University of British Columbia School of Nursing, Vancouver, British Columbia, Canada

^bNuu-Chah-Nulth Tribal Council, Port Alberni, British Columbia, Canada

CINR 2012, Vol. 44 No 4, 96-115

Leaving the Philippines: Oral Histories of Nurses'Transition to Canadian Nursing Practice

Charlene Ronquillo

PEN & ACCESS Freely available online PLOS MEDICI

olicy Forum

Migration and "Low-Skilled" Workers in Destination Countries

pan Benach^{1,2}*, Carles Muntaner^{1,3}, Carlos Delclos^{1,4}, María Menéndez^{1,5}, Charlene Ronquillo⁴

GERONTOLOGICAL
SOCIETY OF AMERICA®

cite as: Public Policy & Aging Report, 2018, Vol. 28, No. 4, 134-139

doi:10.1093/ppar/pry

Public Policy & Aging Report



Article

An Implementation Science Perspective on Deprescribing

Charlene Ronquillo, MSc,^{1,2} Jo Day, PhD,^{1,2} Krystal Warmoth, PhD,^{1,2} Nicky Britten, PhD,^{1,2} Ken Stein, MD,^{1,2} and Iain Lang, PhD,^{1,2,*}

¹University of Exeter Medical School, Exeter, United Kingdom. ²National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula, Exeter, United Kingdom

*Address correspondence to Iain Lang, South Cloisters, University of Exeter St Luke's Campus, Heavitree Road, Exeter EX1 2LU, United Kingdom. E-mail: LLang@exeter.ac.uk

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Keywords: Deprescribing, Implementation, De-implementation

INFLUENCES

health informatics, health services research



Vicky Bungay, PhD Canada Research Chair in Gender,

Associate Professor

School of Nursing

Associate Professor

Vancouver, BC

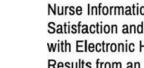
Equity and Community Engagement

University of British Columbia

Leanne M. Currie, RN. PhD

University of British Columbia





MSN, RN, [...], and Ying-Li Lee, MSN, RN

Additional article information

Nurse Informaticians Report Low Satisfaction and Multi-level Concerns with Electronic Health Records: Results from an International Survey

Maxim Topaz, PhD, MA, RN, Charlene Ronquillo,

Evidence-Based Health Informatics as the Foundation for the COVID-19 Response: A Joint Call for Action

Luis Fernandez-Luque¹ Andre W. Kushniruk² Andrew Georgiou³ Arindam Basu⁴ Carolyn Petersen⁵ Charlene Ronquillo⁶ Chris Paton^{7,8} Christian Nøhr⁹ Craig E. Kuziemsky¹⁰ Dari Alhuwail^{11,12} Diane Skiba¹³ Elaine Huesing¹⁴ Elia Gabarron¹⁵ Elizabeth M. Borycki¹⁶ Farah Magrabi³ Kerstin Denecke¹⁷ Linda W. P. Peute¹⁸ Max Topaz¹⁹ Najeeb Al-Shorbaji²⁰ Paulette Lacroix²¹ Romaric Marcilly²² Ronald Cornet¹⁸ Shashi B. Gogia²³ Shinji Kobayashi²⁴ Sriram Iyengar²⁵ Thomas M. Deserno²⁶ Tobias Mettler²⁷ Vivian Vimarlund²⁸ Xinxin Zhu²⁹

Adhera Health Inc., Palo Alto, California, United States

The Nurse LEADership for

Mobile Health Model

Charlene Ronquillo, RN, MSN

University of British Columbia

Daphne Cockwell School of Nursing

V. Susan Dahinten, RN, MSN, MBA, PhD

Assistant Professor

Ryerson University

Toronto, ON

PhD Candidate

Vancouver, BC

School of Nursing

Implementing Technologies –

(Nurse LEAD-IT – mHealth)

Address for correspondence Luis Fernandez-Luque. Adhera Health



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Artificial Intelligence -based technologies in nursing: A scoping literature review of the evidence



WILEY

Hanna von Gerich^a, Hans Moen^b, Lorraine J. Block^c, Charlene H. Chu^d, Haley DeForest^e, Mollie Hobensack^f, Martin Michalowski^g, James Mitchell^h, Raji Nibberⁱ, Mary Anne Olaliaⁱ, Lisiane Pruinellik, Charlene E. Ronquillo, Maxim Topaz (m., Laura-Maria Peltonen a.)

Artificial intelligence in nursing: Priorities and opportunities from an international invitational think-tank of the Nursing and

Charlene Esteban Ronquillo PhD, RN1.2.3 ○ ¥ | Laura-Maria Peltonen PhD, RN3.4 ○ Lisiane Pruinelli PhD, RN⁵ ♥ | Charlene H. Chu GNC(c), PhD, RN⁶ ♥ | Suzanne Bakken FAAN, PhD, RN7,8 | Ana Beduschi LLB, LLM, PhD9 9 | Kenrick Cato FAAN, PhD, RN7 9 | Nicholas Hardiker FAAN, PhD, RN¹⁰ ♥ | Alain Junger 11 | Martin Michalowski PhD⁵ | Rune Nyrup PhD¹² | Samira Rahimi Eng, PhD¹³ ○ ▼ | Donald Nigel Reed¹⁴ ○ | Tapio Salakoski PhD¹⁵ | Sanna Salanterä PhD, RN¹⁶ | Nancy Walton PhD, RN^{1,17,18} | Patrick Weber 19,20 ○ | Thomas Wiegand PhD 21,22,23 ¥ | Maxim Topaz PhD, RN 3,7 ○ ¥

Artificial Intelligence Leadership Collaborative

School of Nursing Faculty of Health and Social Development, University of British Columbia Okanagan, Kelowita, BC, Canada nternational Medical Informatics Association, Student and Emerging Professionals Special Interest Group

*Department of Nursing Science, University of Turku, Turku, Finlar

GUIDELINES AND CONSENSUS STATEMENTS

¹School of Nursing, University of Minnesota, Minneapolis, MN, USA

*Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada

chool of Nursing, Department of Biomedical Informatics, Data Science Institute, Columbia University, New York, NY, USA

*Law School, University of Exeter, Exeter, UK

⁵⁵School of Human & Health Sciences, University of Huddersfield, Huddersfield, UK Nursing Direction, Nursing Information System Unit, Centre Hospitalier Universitaire Vaudois

¹³Leverhulme Centre for the Future of Intelligence, University of Cambridge, Cambridge, UK

**Opportment of Family Medicine, McGB University Lady Davis Institute for Medical Research of Jewish General Hospital, Milo Quebec Artificial Intelligence Institute, Montreal, QC, Canada

KEY QUESTIONS

whose needs

have been considered and prioritized?

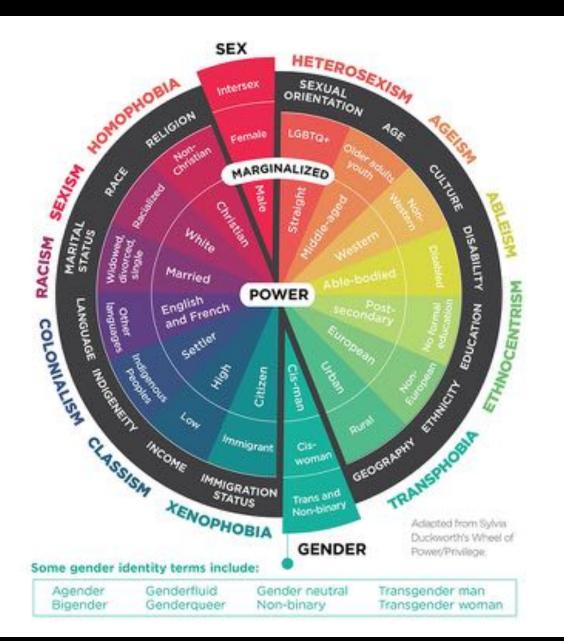
who/what is driving

the technology or project

what is missing

and who is not represented









First release papers

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HOME > SCIENCE > VOL. 366 NO. 6664 > DISSECTING RACIAL BIAS IN AN ALGORITHM USED TO MANAGE THE HEALTH OF POPULATIONS



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Dissecting racial bias in an algorithm used to manage the health of populations



Racial bias in health algorithms

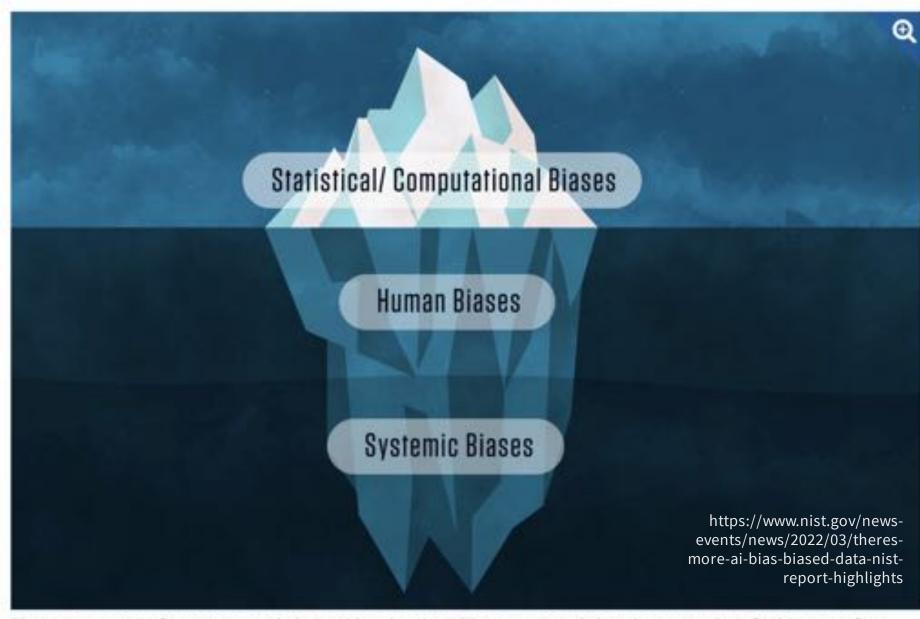
The U.S. health care system uses commercial algorithms to guide health decisions. Obermeyer et al. find evidence of racial bias in one widely used algorithm, such that Black patients assigned the same level of risk by the algorithm are sicker than White patients (see the Perspective by Benjamin). The authors estimated that this racial bias reduces the number of Black patients identified for extra care by more than half. Bias occurs because the algorithm uses health costs as a proxy for health needs. Less money is spent on Black patients who have the same level of need, and the algorithm thus falsely concludes that Black patients are healthier than equally sick White patients. Reformulating the algorithm so that it no longer uses costs as a proxy for needs eliminates the racial bias in predicting who needs extra care.

Science, this issue p. 447; see also p. 421

Inequity in technology development and implementation

DATA AS THE RAW MATERIAL





Bias in AI systems is often seen as a technical problem, but the NIST report acknowledges that a great deal of AI bias stems from human biases and systemic, institutional biases as well.

Credit: N. Hanacek/NIST

Table. US Patient Cohorts Used for Training Clinical Machine Learning Algorithms, by State^a

States	No. of studies
California	22
Massachusetts	15
New York	14
Pennsylvania	5
Maryland	4
Colorado	2
Connecticut	2
New Hampshire	2
North Carolina	2
Indiana	1
Michigan	1
Minnesota	1
Ohio	1
Texas	1
Vermont	1
Wisconsin	1

^a Fifty-six studies used 1 or more geographically identifiable US patient cohorts in the training of their clinical machine learning algorithm. Thirty-four states were not represented in geographically identifiable cohorts: Alabama, Alaska, Arizona, Arkansas, Delaware, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, Nevada, New Jersey, New Mexico, North Dakota, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Virginia, Washington, West Virginia, and Wyoming.

Geographic Distribution of US Cohorts Used to Train Deep Learning Algorithms



DATA PAUCITY ON NON-DOMINANT GROUPS IS A POVERTY THAT IS BORN OUT OF EXISTING INEQUALITIES AND COULD FOSTER FURTHER INEQUALITY

We know the most about a fairly homogeneous group

male

sex and gender

young

age and ability

healthy

physiological norms and ability

white

physiological norms and privileges

advantaged

SES and education

western

language and cultural norms



66 WE DEFINE HEALTH DATA POVERTY **AS THE INABILITY FOR** INDIVIDUALS, GROUPS, OR POPULATIONS TO BENEFIT FROM A DISCOVERY OR INNOVATION DUE TO **INSUFFICIENT DATA THAT ARE** ADEQUATELY REPRESENTATIVE,

RESEARCH Open Access

Racial equity in the fight against COVID-19: a qualitative study examining the importance of collecting race-based data in the Canadian context



Ranie Ahmed 12" Omer Jamai 12, Waleed Ishak³, Kiran Nabi 12 and Nida Mustafa¹

Abstract

Background: A failure to ensure racial equity in response to the COVID-19 pandemic has caused Black communities in Canada to disproportionately be impacted. The aim of the current study was to determine the needs and concerns of Black communities in the Greater Toronto Area (GTA) and to highlight the importance of collecting race-based COVID-19 data early on to address these needs.

Methods: Six qualitative interviews were conducted with local community health centre leaders who serve a high population of racialized communities within the GTA. Content analysis was used to extract the main themes and concerns raised during the interviews.

Results: The findings from this study provide further evidence of the disproportionate impact COMD-19 has had on Black and other racialized communities. Difficulty self-isolating due to overcrowded housing, food insecurity, and less social support for seniors were concerns identified by community health leaders. Also, enhanced financial support for front-line workers, such as Personal Support Workers (PSWs), was an important concern raised. In order to lessen the impact of the pandemic on these communities, leaders noted the need for greater accessibility of testing centres in these areas and a greater investment in tailored health promotion approaches.

Conclusions: Overall, our findings point to the importance of collecting race-based data to ensure an equitable response to the pandemic. The current "one size fits all" response is not effective for all individuals, especially Black communities. Not all populations have access to the same resources, nor do they live in the same conditions (Kantamneni, J Vocal Behav 119:103439, 2020). A deeper consideration of the social determinants of health are needed when implementing COMD-19 policies and responses. Also, a lack of attention to Black communities only continues to perpetuate the under-acknowledged issue of anti-Black racism prevalent in Canada.



Anti-Racism Data Act

On May 2, 2022, government introduced the Anti-Racism Data

The Act became law on June 2, 2022

- Breaking down barriers for people to access programs;
- Ensuring racialized people aren't disproportionately targeted;
- Improving programs and services so more people feel safe getting the help they need.

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AMIA Annu Symp Proc. 2016; 2016; 2016-2025.

Published online 2017 Feb 10.

The Untapped Potential of Nursing and Allied Health Data for Improved Representation of Social Determinants of Health and Intersectionality in Artificial Intelligence Applications: A Rapid Review

PMCID: PMC9719779

PMID: 35654435

IMIA Student and Emerging Professionals Group

Charlene Esteban Ronquillo, 1 James Mitchell, 2 Dari Ahuwall, 2 Laura-Maria Peltonen, 4 Maxim Tooaz, 5 and Lomaine J. Block 6

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Summary Go to: >

Objectives: The objective of this paper is to draw attention to the currently underused potential of clinical documentation by nursing and allied health professions to improve the representation of social determinants of health (SDoH) and intersectionality data in electronic health records (EHRs), towards the development of equitable artificial intelligence (AI) technologies.

Methods: A rapid review of the literature on the inclusion of nursing and allied health data and the nature of health equity information representation in the development and/or use of artificial intelligence approaches alongside expert perspectives from the International Medical Informatics Association (IMIA) Student and Emerging Professionals Working Group.

Results: Consideration of social determinants of health and intersectionality data are limited in both the medical AI and nursing and allied health AI literature. As a concept being newly discussed in the context of AI, the lack of discussion of intersectionality in the literature was unsurprising. However, the limited consideration of social determinants of health was surprising, given its relatively long-standing recognition and the importance of representation of the features of diverse populations as a key requirement for equitable AI.

Conclusions: Leveraging the rich contextual data collected by nursing and allied health professions has the potential to improve the capture and representation of social determinants of health and intersectionality. This will require addressing issues related to valuing AI goals (e.g., diagnostics versus supporting care delivery) and improved EHR infrastructure to facilitate documentation of data beyond medicine. Leveraging mursing and allied health data to support equitable AI development represents a current open question for further exploration and research. Nurse Informaticians Report Low Satisfaction and Multi-level Concerns with Electronic Health Records: Results from an International Survey

PMCID: PMC5333337

PMID: 28269961

Maxim Topaz, PhD, MA, RN,¹ Charlene Bonquillo, MSN, RN,² Laura-Maria Peltorien, MNSc, RN,³ Lisiane Pruinelli, MSN, RN,⁴ Baymond Francis Sarmiento, RN,⁵ Martha K, Badger, MSN, RN-BC, CPHIMS,⁶ Samira Ali, MSN, RN,⁷ Adrienne Lewis, MSc, MsN(c), RN,⁸ Mattias Georgsson, MSc, RN,⁹ Eunico Jeon, RN,¹⁰ Jude L, Tayaben, MAN, RN,¹¹ Chiu-Halang Kuo, RN,¹² Tasneem Islam, RN,¹³ Janine Sommer, RN,¹⁴ Hyunggu Jung, RN,¹⁵ Gabrielle Jacklin Eler, RN,¹⁶ Dari Alhuwail, RN,¹⁷ and Ying-Li Lee, MSN, RN¹⁸

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Abstract Go to: >

This study presents a qualitative content analysis of nurses' satisfaction and issues with current electronic health record (EHR) systems, as reflected in one of the largest international surveys of nursing informatics. Study participants from 45 countries (n=469) ranked their satisfaction with the current state of nursing functionality in EHRs as relatively low. Two-thirds of the participants (n=283) provided disconcerting comments when explaining their low satisfaction rankings. More than one half of the comments identified issues at the system level (e.g., poor system usability; non-integrated systems and poor interoperability; lack of standards; and limited functionality/missing components), followed by user-task issues (e.g., failure of systems to meet nursing clinical needs; non nursing-specific systems) and environment issues (e.g., low prevalence of EHRs; lack of user training). The study results call for the attention of international stakeholders (educators, managers, policy makers) to improve the current issues with EHRs from a nursing perspective.

dished online 2017 Feb 10.

PMCID: PMC5333337 PMID: 28269961

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> ariene Ronguillo, MSN, RN, Laura-Maria Peltonen, MNSc, RN, 3 od Francis Sarmiento, RN,5 Martha K, Badger, MSN, RN-BC, enne Lewis, MSc, MsN(c), RN,8 Mattias Georgsson, MSc, RN,9 IAN, RN,11 Chiu-Hsiang Kuo, RN,12 Tasneem Islam, RN,18 N.15 Gabrielle Jacklin Eler, RN.16 Dari Alhuwaii, RN.17 and

Go to: ▶

INADEQUACY OF CARE-RELEVANT DATA

- poor collection and underuse of nursing and allied postalmer health data

advocacy, SDoH assessment

- unable to link care interventions to outcomes

- limits possibilities of AI

CAPTURE

- missing expertise: relational care, patient

Department of Nursing Science, University of Turku, Finland School of Nursing, Columbia University, New York, USA

Diphetes Institute, Kuwgit

School of Nursing University of British Columbia Vancouver, BC, Canada

The Untapped Potential of Nursing and Allied

Health Data for Improved Representation

Intersectionality in Artificial Intelligence

of Social Determinants of Health and

IMIA Student and Emerging Professionals Group

School of Nursing, University of British Columbia Okanagan, kelowna, Canada

Charlene Esteban Ronquillo (first co-author), James Mitchell (first co-author), Dari Alhuwail¹, Laura-Maria Peltonen⁴, Maxim Topaz ⁵, Lorraine J. Block⁶

Information Science Department, Kuwait University, Kuwait and Health Informatics Unit, D.

Applications: A Rapid Review

2 School of Computing and Mathematics, Keele University, UK

Objectives: The objective of this paper is to draw attention to the currently underused potential of clinical documentation by nursing and allied health professions to improve the representation of social determinants of health (50oH) and intersectionality data in electronic health records (EHRs), towards the development of and take a still of intelligence (80) taken being

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Working within non-inclusive systems

- Tendency to value and collect data on dominant groups / concerns
- Challenge in moving beyond the status quo
- Emergent understanding of what type of data are important to which groups

Implicit bias

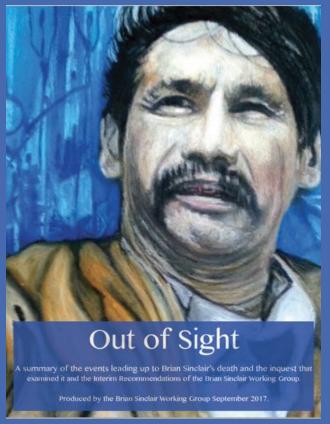
- Clinician bias can make their way into clinical documentation
- There is evidence suggesting non-random missing data among some population groups

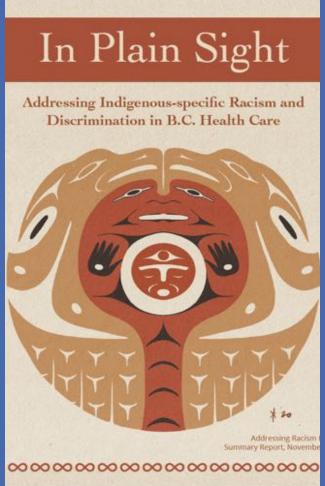
DATA WORK

Timnit Gebru Is Building a Slow AI Movement

Q Type to search

It's interesting to hear you talk about challenges with the data sets. Timnit, in your work on large language models you've called attention to problems with existing data sets, including embedded bias. The response I often hear is, essentially, "It's just too hard to make data sets better."





Capturing complex care concepts

Patient-centered?

Equitable?

Trauma-informed?

Intersectional?

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THANK YOU.

- @ charlene.ronquillo@ubc.ca
- **y** @ceronqu
- charleneronquillo.com