



# Pushing past platitudes – from co-design to holding leaders to account for achieving real system transformation felt by everyday people in everyday life

February 8, 2024

# Today's speakers

## In order of appearance

- Hosts
  - Maureen Smith, Co-chair, Citizen Leadership Group, Evidence Commission (Canada)
  - Richard Morley, Consumer Engagement Officer, Cochrane and Cochrane Consumers Network (United Kingdom)
- Speakers:
  - In Brazil, **Danilo Castro**, currently the journalist at Instituto Veredas, was General Coordinator of Communication and Digital Participation for the Brazilian federal government. He worked on the Brasil Participativo platform, which collects online proposals from citizens in the country, in an experience of techno-civic innovation
  - In Colombia, **Daniel Patiño** has dedicated his team's work to exploring citizen panels, including citizen panels with children and youth
  - In Cameroon, eBASE Africa's **Patrick Okwen** has developed an evidence storytelling methodology with relevance for the evidence synthesis environment
  - In South Africa, **Bulelwa Maphela**'s work on end-of-life services (for the proper handling of human remains) offers insights on the implementation of public health and environmental policies
  - In Canada, **Bernice Downey**'s work supporting Indigenous research policy initiatives, as a member of the Canadian Institute of Health Research, Institute of Aboriginal Peoples Health, Institute Advisory Board, and including her work as one of the Indigenous leads for the WHO Commission on the Social Determinants of Health, Canadian Reference Group. Notably, Bernice's presentation will also premise our fifth session in the global webinar series

# Putting evidence at the centre of everyday life:

A global webinar series for citizen leaders and citizen-serving NGOs



Webinar series:

## 2023

- [Session I](#). The big picture – Putting evidence at the centre of everyday life (**June 2023** – [recording available](#))
- [Session II](#). Citizen-backed evidence – Engaging citizens in providing evidence synthesis and support (including for evidence-informed policy-making) (**Aug 2023** – [recording available](#))
- [Session III](#). Battling the bunk – Bringing evidence and citizen engagement to bear in addressing misinformation (**Nov 2023** – [recording available](#))

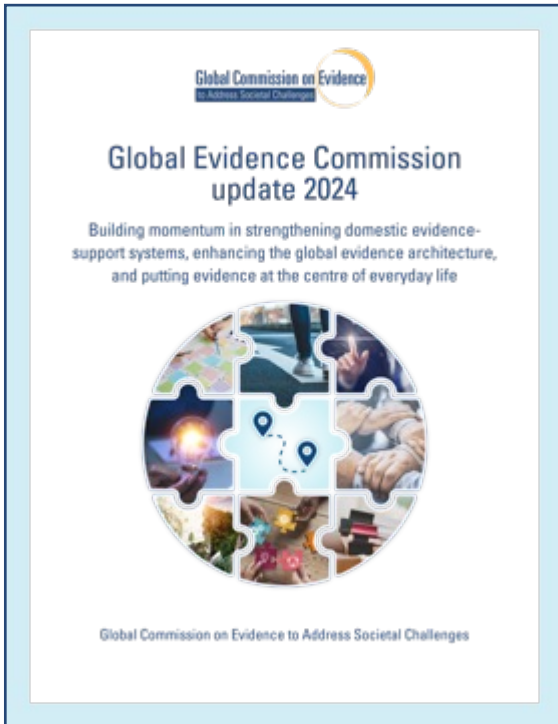
## 2024

- [Session IV](#). Pushing past platitudes – from co-design to holding leaders to account for achieving real system transformation felt by everyday people in everyday life (**Feb 8, 2024** – **today**)
- [Session V](#) – **details coming soon!**

Hosted by three groups working together to ‘put evidence at the centre of everyday life,’ including:

- [Cochrane](#) (the world’s largest producer of evidence syntheses and home to the [Cochrane Consumer Network](#))
- the [Global Commission on Evidence to Address Societal Challenges](#) (with one of its three implementation priorities being ‘putting evidence at the centre of everyday life,’ which is being overseen by the [Citizen Leadership Group](#))
- the World Health Organization’s [Evidence-informed Policy Network \(EVIPNet\)](#) with its new work on [Citizen Engagement in Evidence-informed Policymaking](#).

# Putting evidence at the centre of everyday life: Signs of building momentum



a

Partners are coming together to **learn from one another** (e.g., Cochrane-Global Evidence Commission-WHO EVIPNet webinar series; space is being co-created for discussions about Indigenous rights and ways of knowing)

b

Greater acknowledgement that citizens are inundated with information, misinformation and disinformation, and more commitment to finding effective ways to **counter mis/disinformation**

c

More appreciation for the **strong headwinds** and for the **need to 'lock arms'** to make progress against these headwinds

d

Greater recognition that we need to use a **collective-impact orientation**

# Ways to put evidence at the centre of everyday life



Help citizens judge what others are claiming



Make evidence available to citizens when they are making general choices



Engage citizens in asking questions and answering them



Make evidence-based choices the default or easy option



Give citizens a bigger role in system transformations

Developing trust relationships among citizens, evidence producers, and evidence intermediaries  
Addressing equity, diversity, and inclusion



# Danilo Castro

# BRASIL PARTICIPATIVO

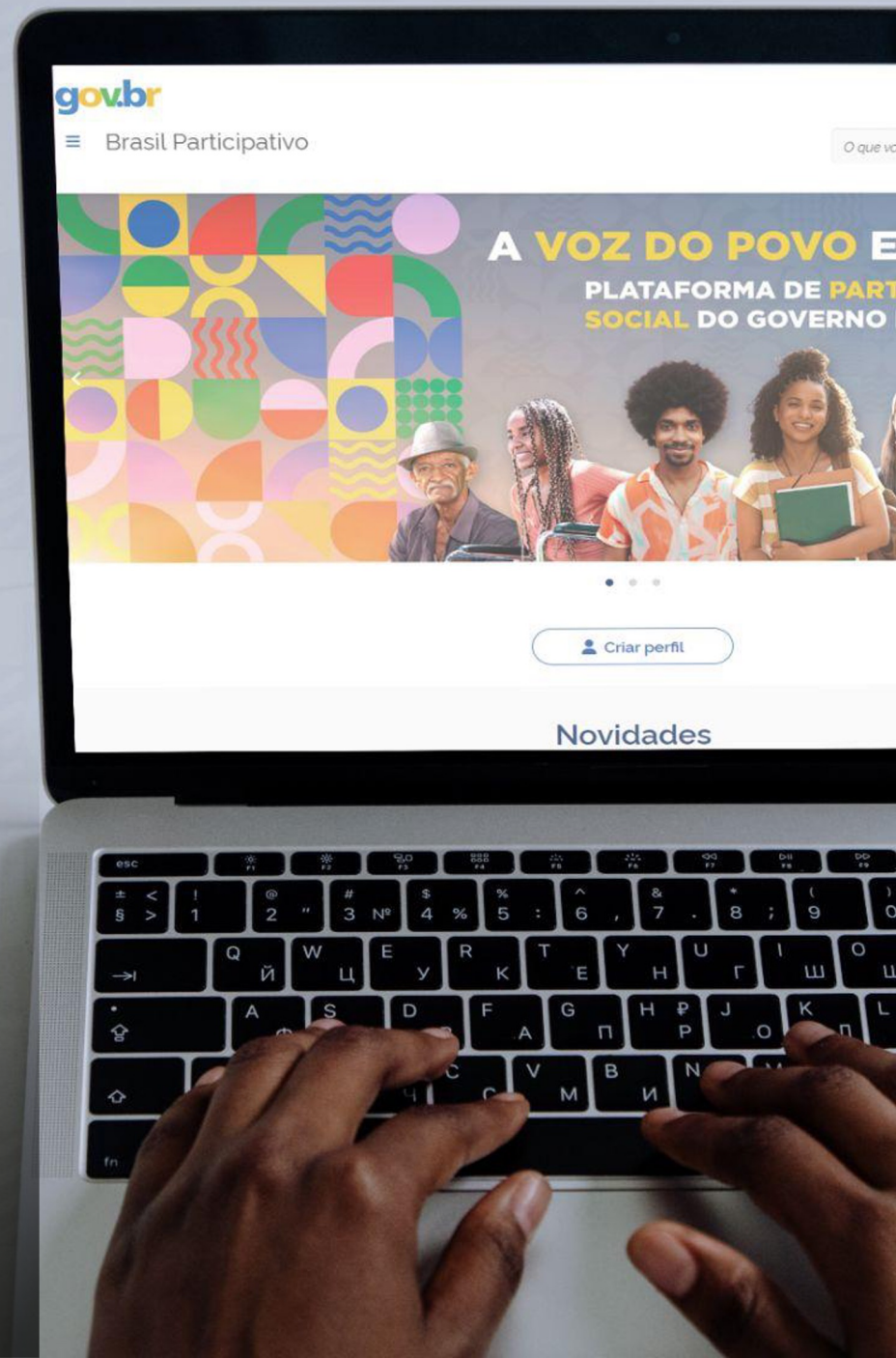
UM PAÍS COM A CARA DO SEU POVO



**Webinar - Pushing past Platitudes**  
Global Commission on Evidence - Mc Master University

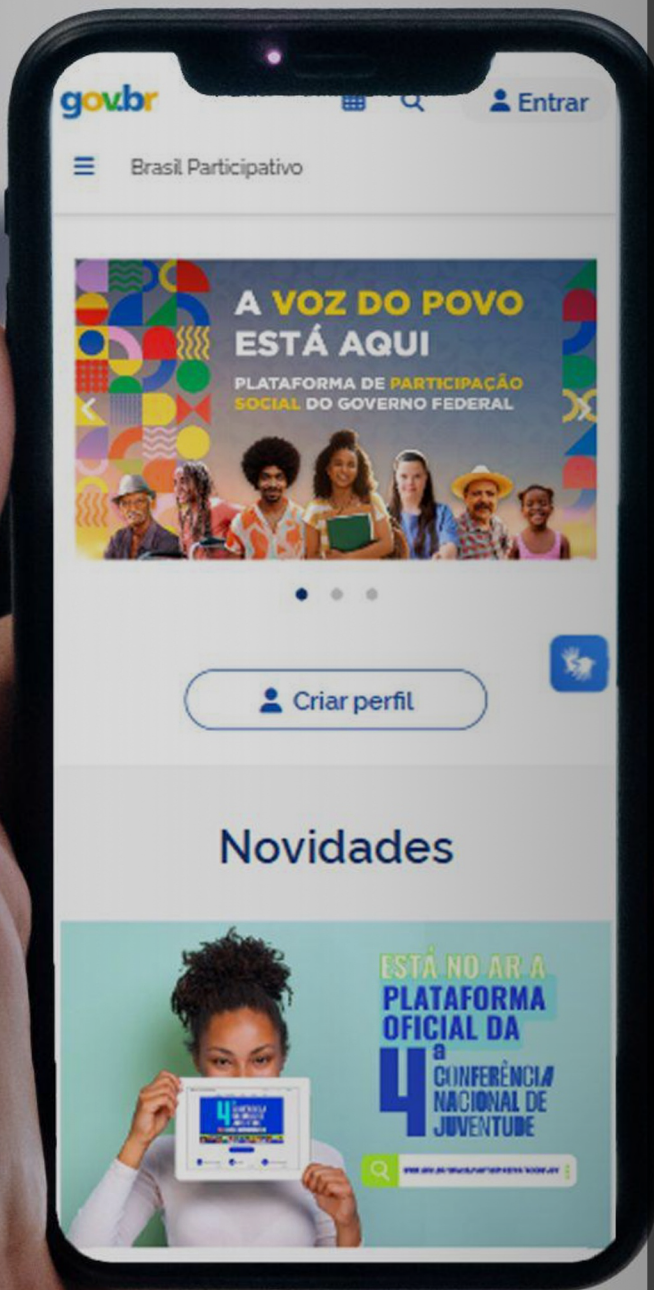
Danilo Castro - Instituto Veredas - Brasil

8 Feb, 2024 - [comunica@veredas.org](mailto:comunica@veredas.org)



**Brasil Participativo**  
is a platform  
created by the  
Brazilian federal  
government in 2023  
to collect opinions  
and ideas for the  
Multi-Year Plan

[gov.br/brasilparticipativo](https://gov.br/brasilparticipativo)



Brasil had a well-established tradition of participation for 30 years, but so far mainly counselors, experts and participants of in-person conferences had their voice heard.

With Brasil Participativo, we opened the door of social participation to all the citizens sharing their dreams and preferences regarding policies and guidelines from the government.

The experience broke a record for digital participation in the world because we aligned a strategy with social media influencers to boost dissemination.

This was the first time that we had massive everyday citizen participation



# TIMELINE OF DIGITAL PARTICIPATION IN BRAZIL FEDERAL GOV

**1.** Public Security  
Virtual Conference  
(2009)  
**2.014**  
participants

**3.** Internet Civil  
Framework  
Consultation (2014):  
**331**  
participants  
**1.200**  
comments

**2.** Youth Participatory  
Observatory (2013):  
**11.000**  
participants

**4.** App 3rd Youth  
Conference (2015):  
**20.000**  
participants

**5.** Dialoga Brasil  
(2016):  
**23.551**  
participants

**6.** Participa.Br (2014)  
Participa + Brasil  
(2019):  
**258.000**  
participants

**7.** **BRASIL**  
**PARTICIPATIVO**  
UM PAÍS COM A CARA DO SEU POVO

more than

**1,4**

**MILLION**

**PARTICIPANTS**  
in its first open  
consultation



# PPA PARTICIPATIVO CONSULTATION FOR THE MULTI-YEAR PARTICIPATORY PLAN



- Registered Participants:

**1.419.729**

- Proposals presented:

**8.254**

- Votes:

**1.529.826**

- Accesses:

**4.087.540**

[gov.br/brasilparticipativo](https://gov.br/brasilparticipativo)

may until july of 2023



# 9° MOST VOTED PROPOSAL

## National Dog and Cat Population Control Policy

- Total votes

**39.980**

This is an example of a new topic for the Ministry of Health to think about because is important to citizens and the government didn't know.

# USABILITY AND ACCESSIBILITY

- **81%** of individuals over 10 years old are Internet users in Brasil;
- **62%** of Brazilian internet users access internet exclusively on mobile phones;

Source: Survey on the Use of Information and Communication Technologies in Brazilian Households - ICT Households 2022.

## PLUGINS TO ENHANCE EQUITY IN PARTICIPATION

- **Contrast and font** enhancement features for people with impaired vision;
- **Functionality that translates** into Brazilian Sign Language for people with hearing disabilities;
- **Automatic text** reading for people who are blind.



# OPEN SOFTWARE EXPERIENCE

1. The platform is in an open software, that is, the code is open for other countries and social projects to use it for free;
2. The users could vote in other proposals and also create campaigns to endorse them;
3. The proposals were evaluated by the Ministries;
4. After, the bill was voted by congresspeople;
5. Now, the current law with ideas from citizens will be used to guide government policies during the next 4 years.

Social media influencers who were engaged with specific advocacy agendas (i.e. human rights) were contacted to endorse and disseminate proposals of their interest, which help to improve awareness of citizens of the platform.

This experience was a **civic technology innovation** because the government guaranteed the right to social participation, which is in the Constitution, on a large scale for the first time.

# BRASIL PARTICIPATIVO

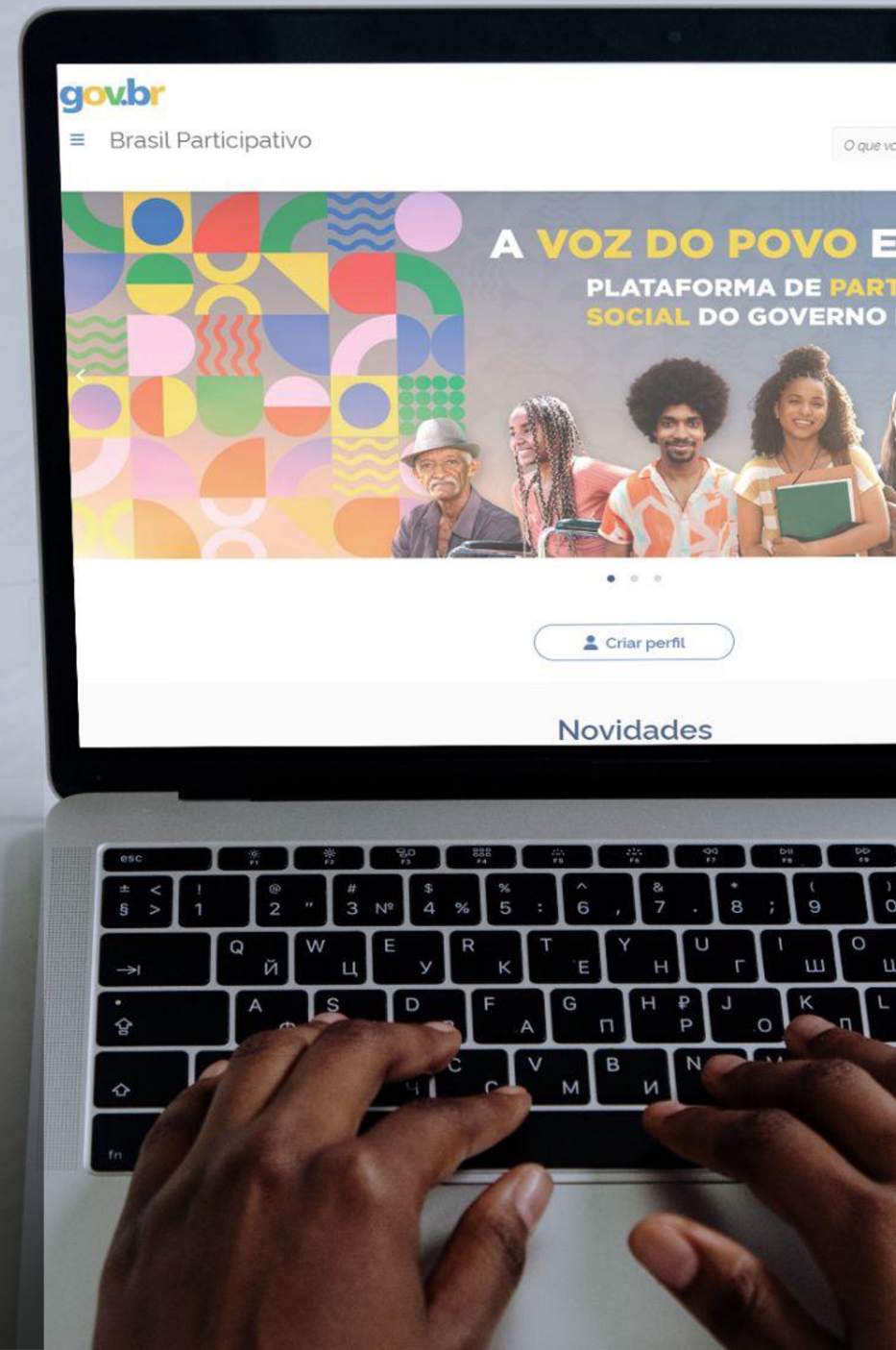
UM PAÍS COM A CARA DO SEU POVO

[gov.br/brasilparticipativo](http://gov.br/brasilparticipativo)

Thank you.

**Danilo Castro**

Communication Coordinator of Veredas Institute  
[veredas.org](http://veredas.org) - [comunica@veredas.org](mailto:comunica@veredas.org)





# Daniel Patiño



**UNIVERSIDAD  
DE ANTIOQUIA**

Facultad de Medicina

Unidad de Evidencia y Deliberación  
para la toma de decisiones

**UNED**



# Contextualizing the use of evidence in policy making: UNED citizen panels experience

Daniel Felipe Patiño MsC, PhD

Professor

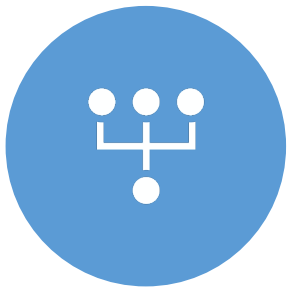
Facultad de Medicina, Universidad de Antioquia

February 2024





## Unit of evidence and deliberations for decision making: UNED



We support the **decision making** of communities, patients (citizens), (health) professionals, organizations and decision makers using the **best available evidence** and **people's values and preferences.**



Patient decisions Aids  
Rapid synthesis (10 days, 30 days or 90 days)  
Evidence Gap Maps  
**Evidence briefs for policies**  
**Citizen panels**  
**Stakeholders and policy dialogues**  
Health technology assessments  
Clinical practice guides  
Evidence search services  
Teaching, continuing education  
Research

Our purpose is to contextualize evidence



# Evidence informed policy process:

Medical Cannabis, Antimicrobial resistance and Children and adolescents' participation in policy decisions



Evidence combined with citizens preferences and stakeholder's views and experiences to inform policies in Colombia.



# Description of the process: Terms of reference



- Created a steering committee with members of UNED and policy makers.
- Developed the TOR around the policy problem, the options to address the problem and implementation considerations.

## Cannabis:

1. THC control limit.
2. Effectiveness and safety
3. Supports for patients, professionals and community.

## Antimicrobial resistance:

In human health, animal health, agriculture, and environmental sectors

## Youth participation in policy:

1. Strategies for youth participation in accountability policy process.

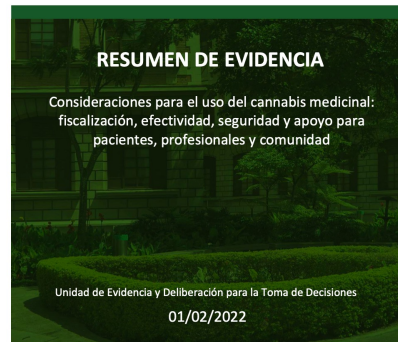
# Description of the process: Evidence brief for policy



- Systematic search
- Screening
- Data extraction
- Risk of bias assessment
- Narrative synthesis



 UNIVERSIDAD  
DE ANTIOQUIA  
Facultad de Medicina



# Description of the process: Citizen's brief



- Plain language summary of the evidence
- Involve citizens in the development.
- The objective is to inform the deliberations of the citizens' panel.



UNIVERSIDAD DE ANTIOQUIA  
Facultad de Medicina

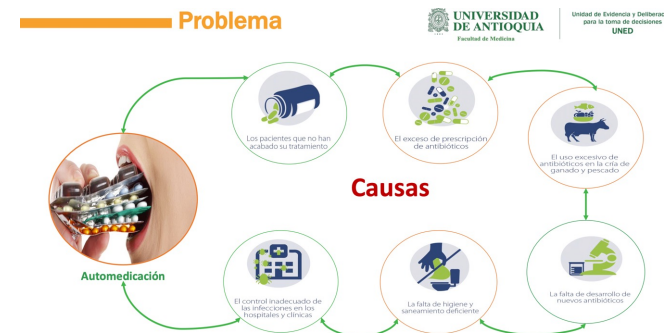


Unidad de Evidencia y Deliberación para la Toma de Decisiones - UNED

## EL CONTEXTO



Es importante fortalecer la participación de Niños, Niñas y Adolescentes en procesos de control a la implementación de las políticas públicas que les competen



# Description of the process: Citizen panel



- Seek the input of citizens on important issues.
- Participation: ideal 14-16.
- Participants discussed their ideas and experiences regarding the issue, learn from research evidence, and from the views of others.
- The panel helps to understand the values that citizens feel should inform future decisions about the issue, as well as to reveal new understandings and get ideas about how it should be addressed.



# Key challenges

1. There is a need to institutionalize efforts within governments to incorporate evidence and citizen values transparently and systematically on a routine manner.
2. Assessment of the citizens brief and citizen panel, evidence brief and stakeholder's dialogue
3. Assessment of the impact, utilization, of these mechanism in the policy cycle.



# Patrick Okwen



# Evidence Tori Dey

## *Telling Evidence Stories*

*Patrick Okwen  
Team Lead, eBASE*



[www.ebaseafrica.org](http://www.ebaseafrica.org)

 [ebase\\_africa](https://twitter.com/ebase_africa)



# Scientists Speaking to Themselves?

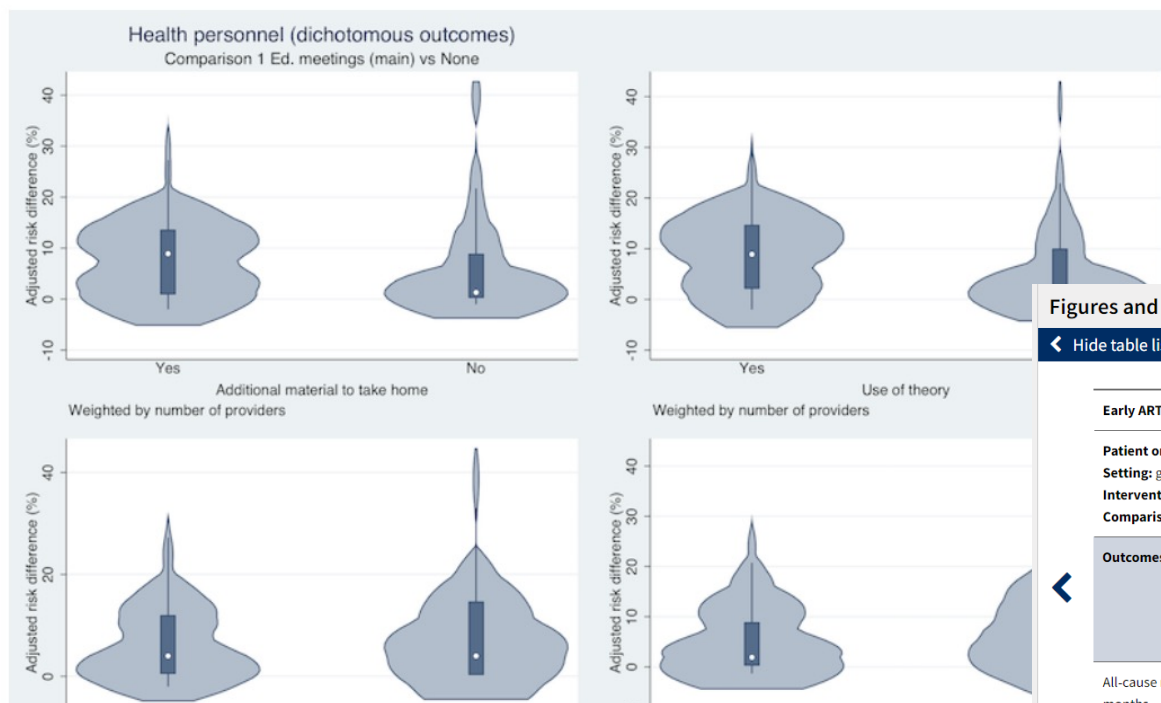


Trusted evidence.  
Informed decisions.  
Better health.

Cochrane Database of Systematic Reviews



Figure 7. Comparison 1. Educational meetings (main) vs None - Health personnel (dichotomous outcomes).



Figures and Tables - Early versus delayed antiretroviral treatment in HIV-positive people with cryptococcal meningitis

Hide table list

### Early ART compared to delayed ART initiation in HIV-positive people with cryptococcal meningitis

**Patient or population:** HIV-positive people with cryptococcal meningitis

**Setting:** global

**Intervention:** early ART initiation (less than 4 weeks after initiation of cryptococcal meningitis treatment)

**Comparison:** delayed ART initiation (more than 4 weeks after initiation of cryptococcal meningitis treatment)

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	Number of participants (trials)	Certainty of the evidence (GRADE)	Comments
	Risk with delayed ART	Risk with early ART				
All-cause mortality at 6 to 12 months	311 per 1000	442 per 1000 (317 to 613)	RR 1.42 (1.02 to 1.97)	294 (4 RCTs)	⊕⊕⊕⊖ LOW <sup>1,2,3</sup>	Early ART initiation may increase the risk of mortality at 6 to 12 months.
Cryptococcal meningitis relapse	87 per 1000	24 per 1000 (6 to 43)	RR 0.27 (0.07 to 1.04)	205 (2 RCTs)	⊕⊕⊕⊖ LOW <sup>4</sup>	Early ART initiation may reduce relapses of cryptococcal meningitis compared to delayed ART initiation.



# Storytelling

## & Global Health Equity





# What is “Evidence Tori Dey”?

- How do you say evidence in your local language?
- How do you explain “evidence” to a 5 year old?
- How easily do you understand data from research evidence?



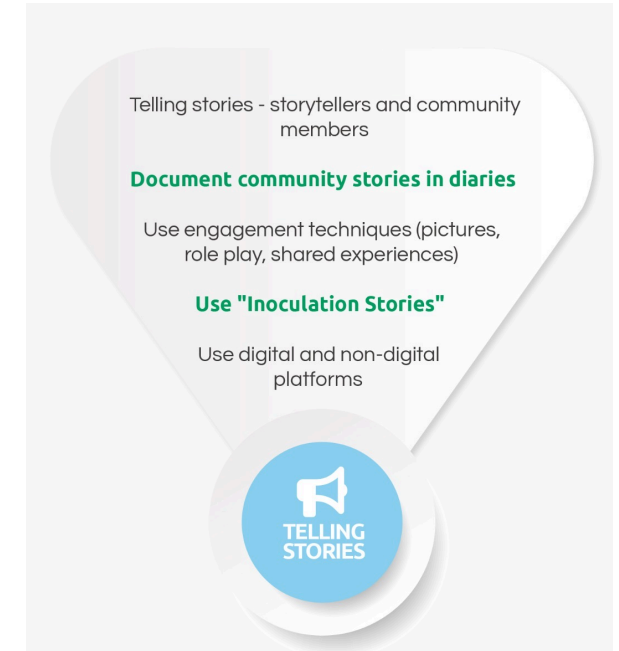
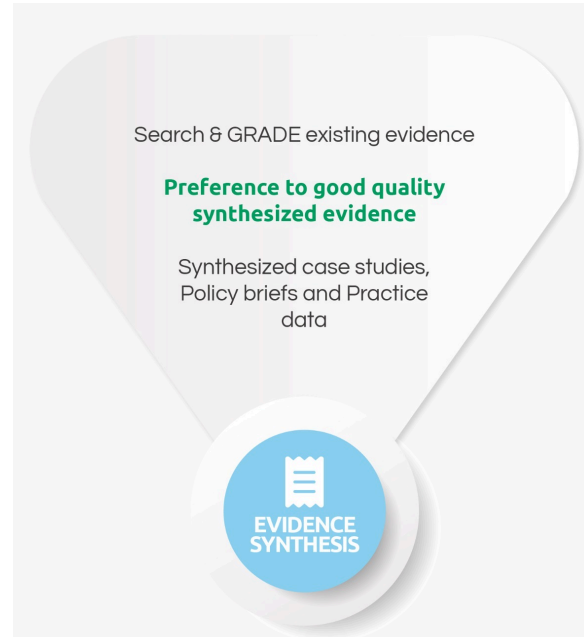
# What is “Evidence Tori Dey”?

- How do you say evidence in your local language?
- How do you explain “evidence” to a 5 year old?
- How easily do you understand data from research evidence?

**Definition:** *Evidence Tori Dey* is a systematic interactive approach of communication of data and evaluation change based on indigenous African principles of storytelling. “*Evidence Tori Dey*” is in local pidgin language spoken in Africa which means “*let’s talk evidence.*” Storytelling employs use of recounting, drama, dance, poems, mimes, and songs.



# What is “Evidence Tori Dey”?





# Knowing Your Audience



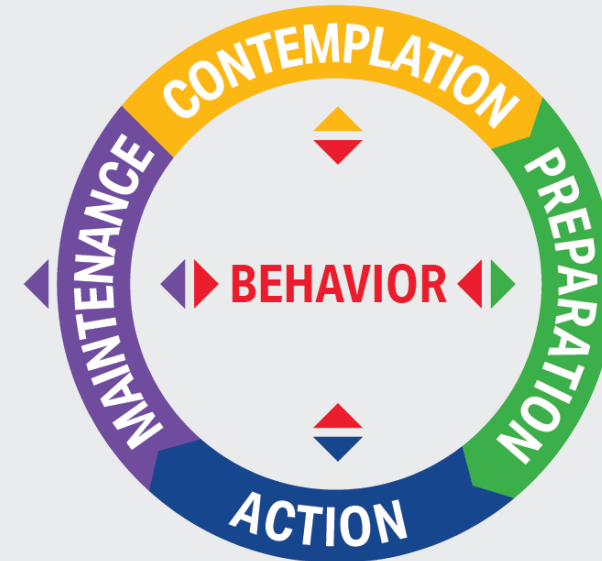
Apply the transtheoretical model of behavior change

**Collect barriers, facilitators, and coping strategies; lived experiences and real-life data; practice experiences and data; policy experiences and data; baseline stories in storytelling diaries.**



## Stages of Change

**PRECONTEMPLATION**



© 2021, R1 LLC



# The River of Science



- 🏠 Evidence ... data ... science
- 🏠 Too complex for policy, practice & public
- 🏠 Not accessible
- 🏠 Usually in English





# Evidence Statements for a 5 Year Old



Develop evidence statements from plain language summaries, recommendations, policy briefs, and meta-aggregated qualitative data.

## Plain evidence statements

Charactered evidence statements

Ask: can a 5-year-old understand?

  
EVIDENCE STATEMENTS

- Short statements for a 5 year old to understand
- Plain language summaries reduced



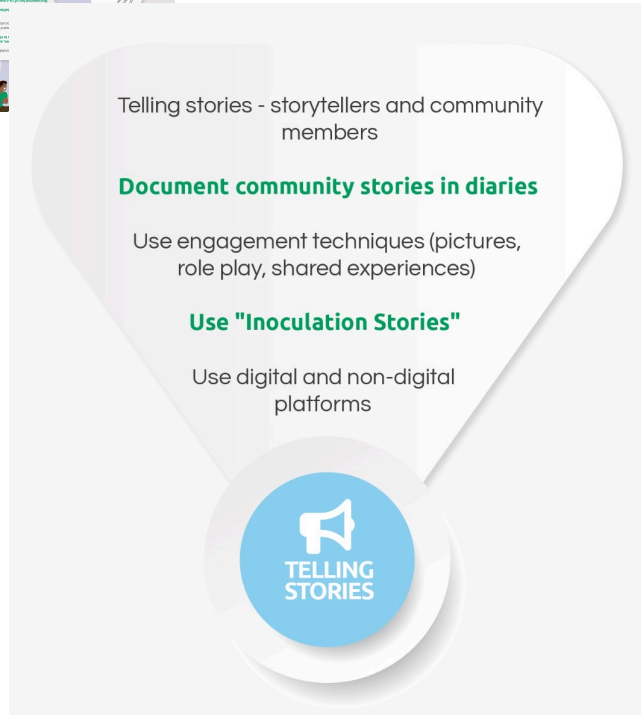
# Co-create Stories



- Co-creation values
- Ubuntu – Collective Fingers Theory
- Be sure the message in the study is the message in the story
- Consider audience and behavior change theories



# The River of Stories



- 🌀 Evidence Tori Dey
- 🌀 Gather people's experiences
- 🌀 Explore RED and GREEN Stories
- 🌀 Inoculate the community



# Assess!



Ensure research standards are met including informed consent

**Diaries evaluate RED and GREEN stories over a timed period**

Diaries could be audio or paper-based

**Use existing structures e.g. community health workers, social workers, and councilors**



 Knowledge

 Intention

 Behavior



# Intermittent Fasting for Weight Loss

Log in or Register | Subscribe to journal | Get new issue alerts | Submit your manuscript

Wolters Kluwer

## JBI EVIDENCE SYNTHESIS

Articles Search



Advanced Search

Home | Articles & Issues | Collections | Online First | Article Series | Digital Media Content | For Authors | Journal Info

History

< Previous Abstract | Next Abstract >

SYSTEMATIC REVIEWS



Cite



Share



Favorites



Permissions

## Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis

Harris, Leanne; Hamilton, Sharon; Azevedo, Liane B.; Olajide, Joan; De Brún, Caroline; Waller, Gillian; Whittaker, Vicki; Sharp, Tracey; Lean, Mike; Hankey, Catherine; Ells, Louisa

Author Information

JBI Database of Systematic Reviews and Implementation Reports 16(2):p 507-547, February 2018. | DOI: 10.11124/JBISRI-2016-003248

BUY

Metrics

### Article Level Metrics



- Tweeted by 129
- Blogged by 4
- On 16 Facebook pages
- Picked up by 39 news outlets
- On 18 videos
- 596 readers on Mendeley
- 1 readers on CiteULike

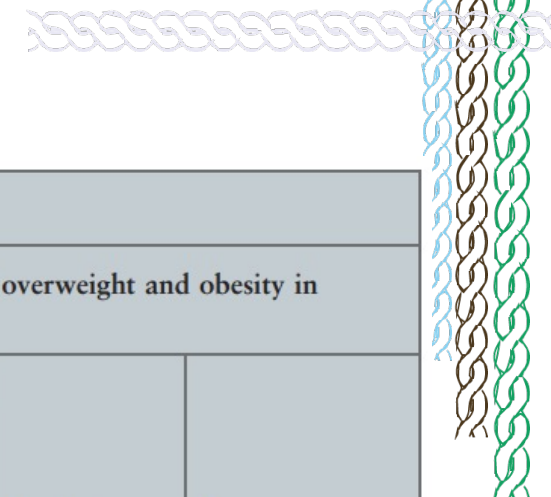
Storytold by 3

View full article metrics including social shares, article views and publishing history

... Best Evidence for Best Practice Decision Making ...



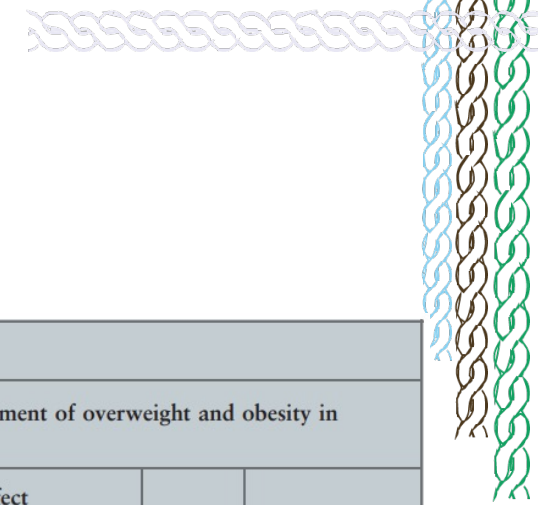
# Intermittent Fasting for Weight Loss



Intermittent energy restriction compared to usual care for treatment for overweight and obesity in adult population											
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al.</i> Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. JBI Database System Rev Implement Rep 2018; 16(2):507–547.											
Quality assessment							N <sub>e</sub> of patients		Effect	Quality	Importance
N <sub>e</sub> of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	intermittent energy restriction	usual care	Absolute (95% CI)		
Weight (kg)											
4	randomised trials	serious <sup>a</sup>	not serious	serious <sup>b</sup>	serious <sup>c</sup>	all plausible residual confounding would reduce the demonstrated effect dose response gradient	161	126	MD 1.03 lower (2.46 lower to 0.1 higher)	⊕⊕⊕○ MODERATE	IMPORTANT



# Intermittent Fasting for Weight Loss



Intermittent energy restriction compared to usual care for treatment for overweight and obesity in adult population						
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al.</i> Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. JBI Database System Rev Implement Rep 2018; 16(2):507–547.						
Quality assessment					No of patients	Effect
No of studies	Study design	Risk of bias	Inconsistency	Indirectness		
4	randomised trials	serious <sup>a</sup>	not serious	serious <sup>b</sup>	intermittent	

Intermittent energy restriction compared to no treatment control for treatment overweight or obesity in adults											
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al.</i> Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. JBI Database System Rev Implement Rep 2018; 16(2):507–547.											
Quality assessment							No of patients		Effect	Quality	Importance
No of studies	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	intermittent energy restriction	no treatment	Absolute (95% CI)		
Weight (kg)											
2	randomised trials	serious <sup>a</sup>	very serious <sup>b</sup>	serious <sup>c</sup>	serious <sup>d</sup>	strong association all plausible residual confounding would reduce the demonstrated effect dose response gradient	31	31	- MD 4.14 mean difference lower (6.30 lower to 1.99 lower)	⊕⊕○○ LOW	IMPORTANT



# Intermittent Fasting for Weight Loss

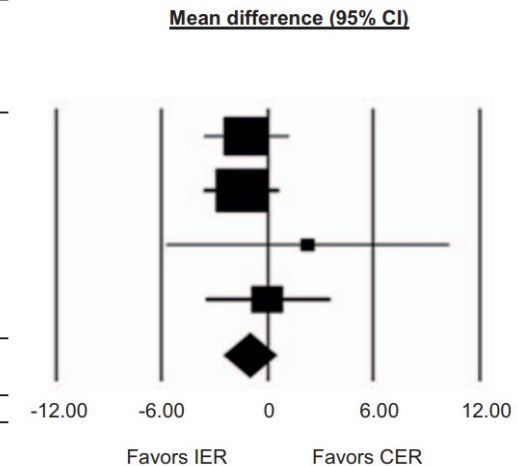
Intermittent energy restriction compared to usual care for treatment for overweight and obesity in adult population				
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al</i> . Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. <i>JBIM Database System Rev Implement Rep</i> 2018; 16(2):507-547.				
Quality assessment		No of patients	Effect	

No of studies	Study design	Risk of bias	Inconsistency	Intermittent energy restriction compared to no treatment control for treatment overweight or obesity in adults				
Weight (kg)				Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al</i> . Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. <i>JBIM Database System Rev Implement Rep</i> 2018; 16(2):507-547.				
4	randomised trials	serious <sup>a</sup>	not serious	Quality assessment				

No of studies	Study design	Risk of bias	Inconsistency	Indirectness
Weight (kg)				
2	randomised trials	serious <sup>a</sup>	very serious <sup>b</sup>	serious <sup>c</sup>

Reference	Intermittent energy restriction (IER)		Continuous energy restriction (CER)		Mean difference (95% CI)
	Mean (SD)	N	Mean (SD)	N	
Harvie <i>et al.</i> <sup>19</sup>	-5.70 (5.00)	42	-4.50 (6.40)	47	-1.20 (-3.61 to 1.21)
Harvie <i>et al.</i> <sup>20</sup>	-5.30 (5.29)	75	-3.80 (5.95)	40	-1.50 (-3.62 to 0.62)
Hill <i>et al.</i> <sup>21</sup>	-7.20 (10.10)	14	-9.50 (8.70)	9	2.30 (-5.73 to 10.33)
Viegener <i>et al.</i> <sup>25</sup>	-8.98 (6.73)	30	-8.96 (7.27)	30	-0.02 (-3.57 to 3.53)
Pooled estimate (Random effect)		161		126	-1.03 (-2.46 to 0.40)

Tests for heterogeneity:  $p = 0.76$ ,  $I^2 = 0.0\%$ ,  $T^2 = 0.0$



**Figure 2: Weighted mean difference in body weight (kg) between the intermittent energy restriction interventions and continuous energy restriction interventions (SD: standard deviation; CI: confidence interval)**





# Intermittent Fasting for Weight Loss

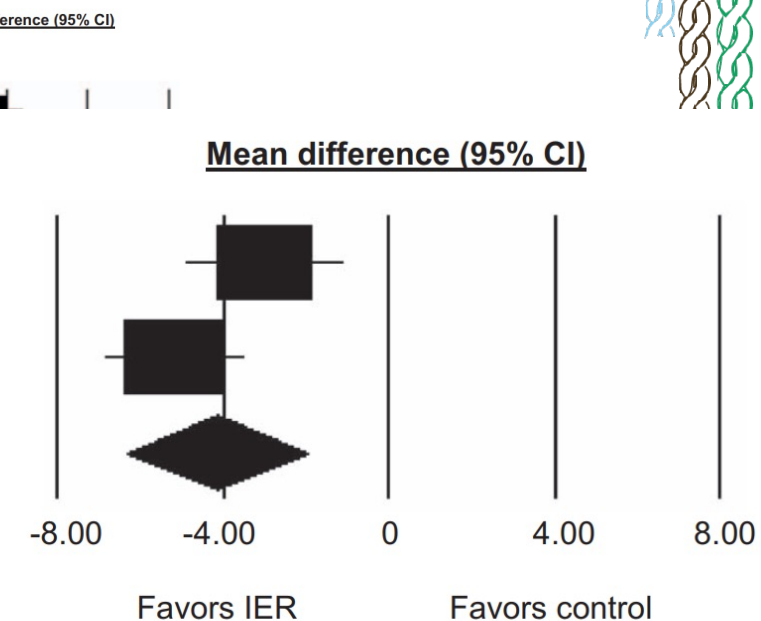
Intermittent energy restriction compared to usual care for treatment for overweight and obesity in adult population			
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al.</i> Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. JBI Database System Rev Implement Rep 2018; 16(2):507–547.			
Quality assessment		No. of patients	Effect

Intermittent energy restriction compared to no treatment control for treatment overweight or obesity in adults				
Bibliography: Harris L, Hamilton S, Azevedo LB, Olajide J, De Brún C, Waller G, <i>et al.</i> Intermittent fasting interventions for treatment of overweight and obesity in adults: a systematic review and meta-analysis. JBI Database System Rev Implement Rep 2018; 16(2):507–547.				
Quality assessment				
No. of studies	Study design	Risk of bias	Inconsistency	Indirectness
4	randomised trials	serious <sup>a</sup>	not serious	not serious

Reference	Intermittent energy restriction (IER)		Continuous energy restriction (CER)		Mean difference (95% CI)
	Mean (SD)	N	Mean (SD)	N	
Harvie <i>et al.</i> <sup>19</sup>	-5.70 (5.00)	42	-4.50 (6.40)	47	-1.20 (-3.61 to 1.21)
Harvie <i>et al.</i> <sup>20</sup>	-5.30 (5.2)				
Hill <i>et al.</i> <sup>21</sup>	-7.20 (10.				
Viegner <i>et al.</i> <sup>25</sup>	-8.98 (6.7				
Pooled estimate (Random effect)					
Tests for heterogeneity: p = 0.09, I <sup>2</sup> = 65.7%, T <sup>2</sup> = 1.6					

**Figure 2: Weighted interventions and interval)**

Reference	Mean difference (95% CI)
Bhutani <i>et al.</i> <sup>22</sup>	-3.00 (-4.88 to -1.19)
Varady <i>et al.</i> <sup>26</sup>	-5.20 (-6.88 to -3.52)
Pooled estimate (random effect)	-4.14 (-6.30 to -1.99)



**Figure 3: Weighted mean difference in body weight (kg) between the intermittent energy restriction (IER) interventions and control interventions (CI: confidence interval)**



# Intermittent Fasting for Weight Loss

## Evidence Statements

*S1: Intermittent fasting can treat overweight and obesity.*

*S2: An overweight or obese person on intermittent fasting will lose weight compared to one not on intermittent fasting.*

*S3: Zila and Phumla are both 23 years of age, weigh 77kg, and BMI of 26kg/m<sup>2</sup>. If we put Zila on IER and put Phumla on no care, Zila will lose weight faster than Phumla. However, if we put Zila on IER and Phumla on CER, they may both lose weight at a similar speed – but Zila may lose weight faster.*

*S4: Zila who is receiving IER is more likely to get more fulfilling relationships, jobs, better health outcomes, and mental and spiritual balance compared to Phumla who is not receiving any care.*

*S5: Phumla who is not receiving any care is more likely to suffer consequences of overweight or obesity for example failed relationships, fewer job opportunities, non-communicable or metabolic diseases like hypertension, diabetes etc., and may not have a stable mental and spiritual life.*



# Intermittent Fasting for Weight Loss

## Behavior Change Strategies

(Based on Abraham & Michie Taxonomy of BCT)

### Behavior Change Principles in Action (How the two Rivers Impact Behavior Change)

*Assumptions: Because in this intervention we have gone past knowledge, we assume certain BCTs eg. Social Cognitive Theory is no longer relevant.*

#### Considerations:

1. **Transtheoretical Model of Change:** We are telling a story to a community that already knows about IER. They have good knowledge and they have intentions to use IER. However, their challenge is implementing the action. Through the Transtheoretical Model, they are in the PREPARATION stage and our intention is to move them to the ACTION stage and MAINTAIN them there.
2. **Information-Motivation-Behavioral Skills Model (IMB):** The story provides information on consequences. It motivates the audience with useful research evidence that they can implement in their lives and get positive outcomes. This evidence can be found in a JBI review by Harris et al 2015. Azah's character provides information about the benefits and costs of action while Akon's character provides information on inaction. These focus on what will happen if the person does or does not perform the behavior (Intermittent fasting).
3. **Theory of Reasoned Action (TRA):** The TRA suggests that if individuals have a positive attitude towards a suggested behavior and perceive that others expect them to perform that behavior (subjective norm), this can increase their motivation and intention to perform the behavior,



**Thank  
you for  
your kind  
Attention**



# Bulelwa Maphela

**The interface of the National Health Policy and emerging funeral directors (EFDs)**

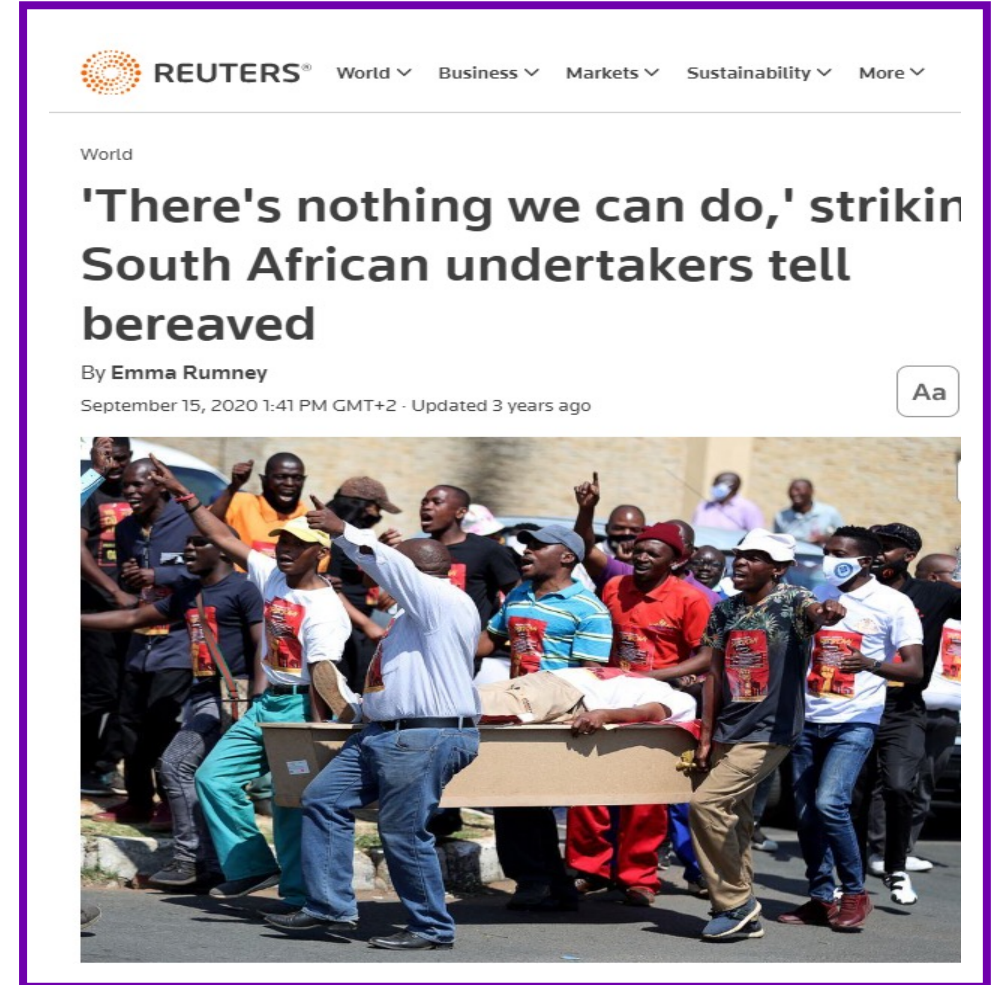
**end-of-life services (for the proper handling of human remains) and insights on the implementation of public health and environmental policies.**

**Bulelwa Maphela**  
**South Africa**

# Introduction

- The intersection of local economic development (LED) and human remains management in South Africa presents a complex and sensitive topic (Akinyoade, Dietz, & Uche, 2017).
- While seemingly disparate, these domains have potential for both conflict and collaboration. Understanding this dynamic is crucial for navigating ethical and sustainable development practices within communities (National Planning Commission, 2011) (Balfour, 2021).
- Local economic development (LED) in the realm of human remains management presents valuable opportunities; its environmental impact demands careful consideration (Bhorat, Asmal, Lilentein, & van der Zee, 2018).

Table 1. Emerging Funeral Directors (EFDs) Picketing outside Chris Hani Hospital.



Source: [Rumney, E. \(2020\)](#)



# Regulatory Precedence



The National Health Act 2003 (Act 61 of 2003) was formulated to provide a governing and regulatory framework for a structured, homogenous healthcare system within the Republic of South Africa.



Chapter 3 of the framework (herein known as Regulation 363) speaks to the management of human remains.



There is vast evidence of the work done to preserve life, but no evidence on the management of human remains (end-of-life services).



The World Health Organization (WHO, 2021, Report EB148/24 page 1) articulated that “opportunities to be healthy are closely linked to the conditions in which people grow, learn, live, work and age”. But what about death?



Thus, the Department of Health is dependent on private businesses to alleviate the burden of human remains management.



This delicate activity falls into the hands of largely emerging businesses that struggle with the running of issues of compliance.





# Local Economic Development and Human Remains Management

- LED programs can assist emerging funeral directors in formalizing their businesses, improving compliance, and accessing training to enhance their skills and professionalism (Department of Cooperative Governance and Traditional Affairs, 2023).
- From a developmental perspective, LED draws on different disciplines. Houghton (2017) concurs that it is a cross-cutting discipline that seeks to find working strategies to assist local emerging businesses within a specified jurisdiction.
- Meyer (2014) explains that development practitioners view LED as playing an important role in creating jobs, alleviating poverty, and improving the quality of life of local communities. This agenda of LED is in line with the SDGs and the SA's National Development Plan (NDP).

## Funeral Industry in South Africa records 12% annual growth.

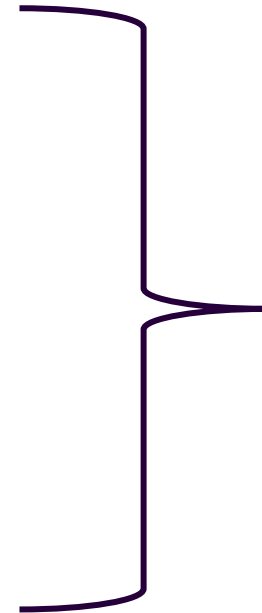
While undertakers and funeral parlours played critical roles during the pandemic, there were many challenges, especially for small funeral operators.

Source: [News24](#)



# Local Economic Development and Human Remains Management

“What is the share for EFDs”, from R10 billion per annum Funeral Services Industry in South Africa?



# Challenges and Concerns for EFDs

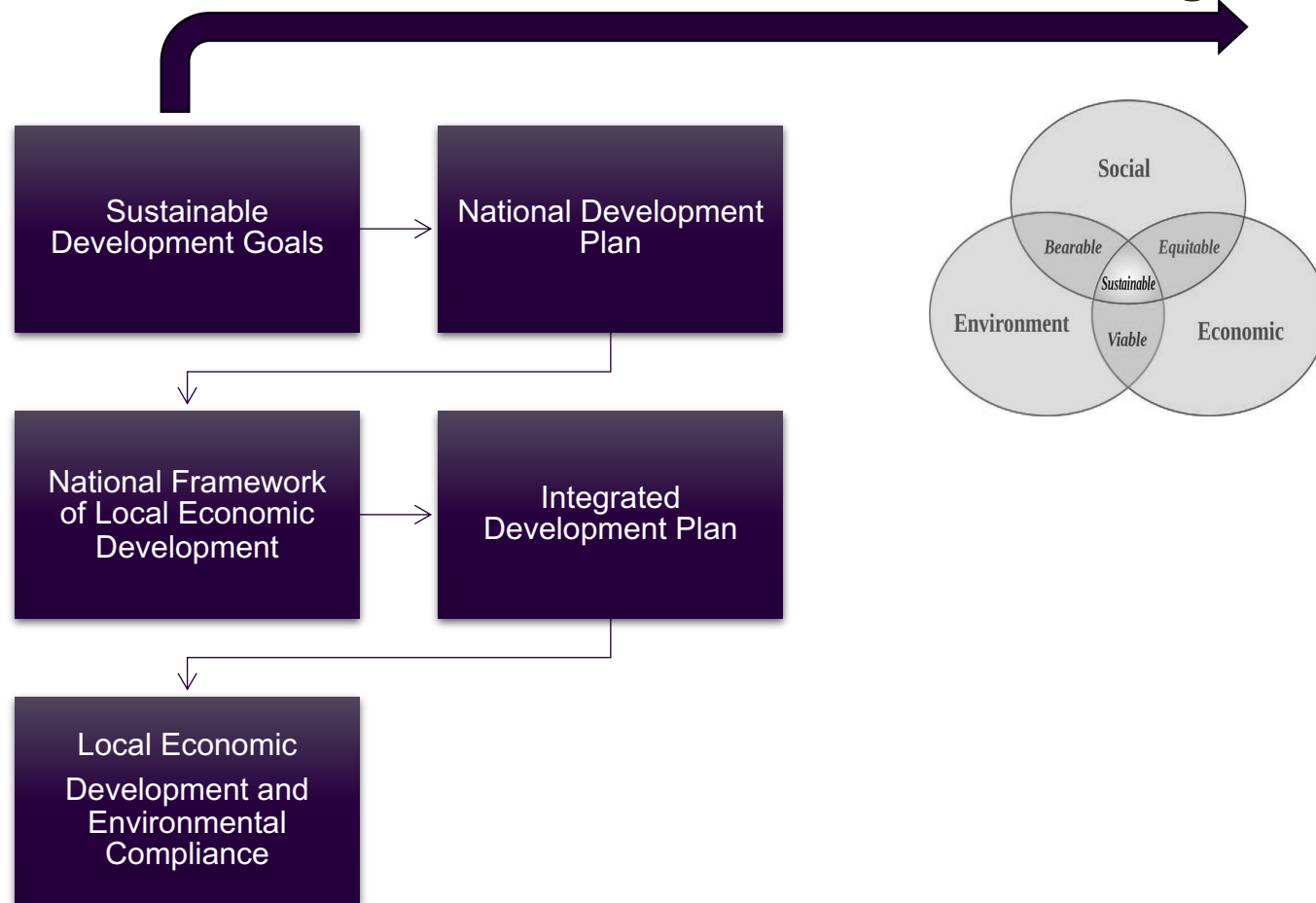
- Mathee and Wright (2021) point out that the WHO projected that 25% of the global burden of ailments or diseases emanates from modifiable environmental factors.
- The proliferation of informal funeral homes is linked to concerns about pollution and improper waste disposal of human remains (Akinyoade, Dietz, & Uche, 2017). This clashes with LED's goal of fostering environmentally sustainable development (National Planning Commission, 2011).
- Emerging funeral directors often lack knowledge of regulations and struggle to achieve compliance, hindering their formalization and potential contribution to the local economy (Balfour, 2021).
- Communication gaps exist between LED offices and funeral businesses, impeding collaborative efforts to address challenges and explore opportunities (Bojabotseha, 2011).
- Respecting cultural practices and beliefs surrounding death and burial must be paramount in any economic development initiatives related to human remains management (Bhorat, Asmal, Lilentein, & van der Zee, 2018).



# Preview of the conceptualization of the studies done thus far

## Tracing Local Economic Development

## SDG agenda



## Key Considerations

- **Sustainability:** All development initiatives must consider long-term environmental and social sustainability, ensuring benefits for future generations (National Planning Commission, 2011).
- **Community Participation:** Inclusive and participatory planning processes are crucial for ensuring community buy-in and addressing diverse needs and concerns (Department of Cooperative Governance and Traditional Affairs, 2023).
- **Legal Frameworks:** Strict adherence to existing laws and regulations governing human remains management is essential (The National Framework for Local Economic Development, 2018).
- **Cultural Respect:** Recognising and respecting cultural sensitivities surrounding death and burial practices is paramount throughout the development process (Bhorat, Asmal, Lilentein, & van der Zee, 2018).



# Conceptualization of the research

- In 2013, with regards to section 68(1)(b) read with section 90(4)(c) of the National Health Act 2003 (Act 61 of 2003), the regulations about the management of human remains were gazetted
- The discussion only focuses on Chapter 3 of the regulations, which deals with “Funeral Undertakers’ Premises and Mortuaries”,
- Since the management of human remains is dominated by Emerging Funeral Directors (**EFDs**) who are servicing a large population that is living below the breadline.
- It was important to establish how they interface with Regulation 363 of the human remains guidelines. This inquiry was prompted by a strike that took place,
- where bodies were not collected for some days for burial, which caused strife and trauma among the grieving families.
- Various meetings were held with the emerging funeral directors, and it was evident that they were not happy with Regulation 363 on how they should manage the mortuaries.
- A probable departure on evidence synthesis was to engage with the Environmental Health Practitioners (**EHPs**) who are custodians of how businesses engage with the environment, including the funeral directors.
- Thus, in 2021 and 2022, data was collected from the **EFDs** and the **EHPs** on how they engage with Regulation 363.



# Findings and conclusion

Problem	Environmental Health Practitioner	Emerging funeral directors
<b>What is the biggest challenge facing the funeral industry today?</b>	cited non-compliance with Human Remains Management R363 legislation (Department of Health 2013).	Lack of awareness of the finer details of Reg 363 and its purpose.
<b>Can you comment on the number of new entrants in this industry?</b>	There was a sharp increase in the number of entrants.	An increasing number of survivalists who do not belong to any association
<b>Do EHPs play a role in the LED agenda?</b>	Guidance on the compliance of mortuary premises and ensuring compliance.	Both the EFDs and the LED practitioners saw no connection between each other. This relationship could alleviate the compliance challenges.
<b>Does the EHP find it difficult to get new entrants in this industry to comply with the Act that governs this sector?</b>	68.2% (15 out of 22) agreed that the EHPs find it difficult to get new entrants in this industry to comply.	The EFDs proclaimed that they learned the business ropes from fellow undertakers instead of understanding REG 363.
<b>Does the EHP consult other legislative bodies before they revoke a compliance certificate?</b>	Resounding NO	
<b>what would you prefer small businesses in this sector to consider when establishing themselves in the future?</b>	Without compliance, there should be no undertaking.	The idea of serving communities and being a survivalist surpassed the understanding of Reg 363.
<b>Are you satisfied with how the sector currently operates?</b>	NO	Aggrieved they feel the EHPs must be lenient since they are merging EFDs.
<b>Do you give EFDs a grace period?</b>	Yes, depending on the nature of non-compliance.	Still felt it was unfair.





# Bernice Downey



# Dissonance between Western models of knowledge translation and the sharing of Gikendaasowin - Indigenous knowledge.

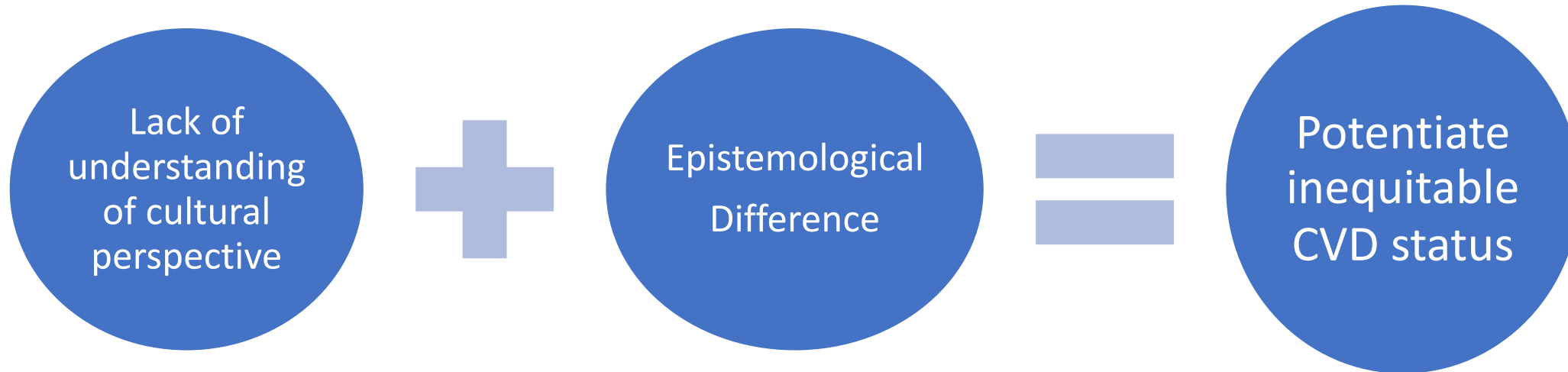
Session IV. Pushing past platitudes – from co-design to holding leaders to account for achieving real system transformation felt by real people in everyday life (Feb 2024)

Evidence Commission Webinar  
Panel Presentation by: Bernice Downey, PhD  
McMaster University  
Feb 8, 2024

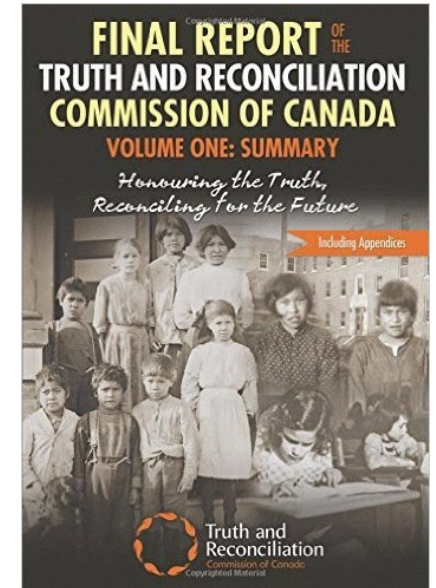




# The Challenge: Cultural Dissonance in KT



# The path forward



# KTSE for the next seven generations



KiChi – Miigwetch! Thank-you very much!  
[downebe@mcmaster.ca](mailto:downebe@mcmaster.ca)





Thank you

