



Consumer Participation

New Tools for Old Challenges



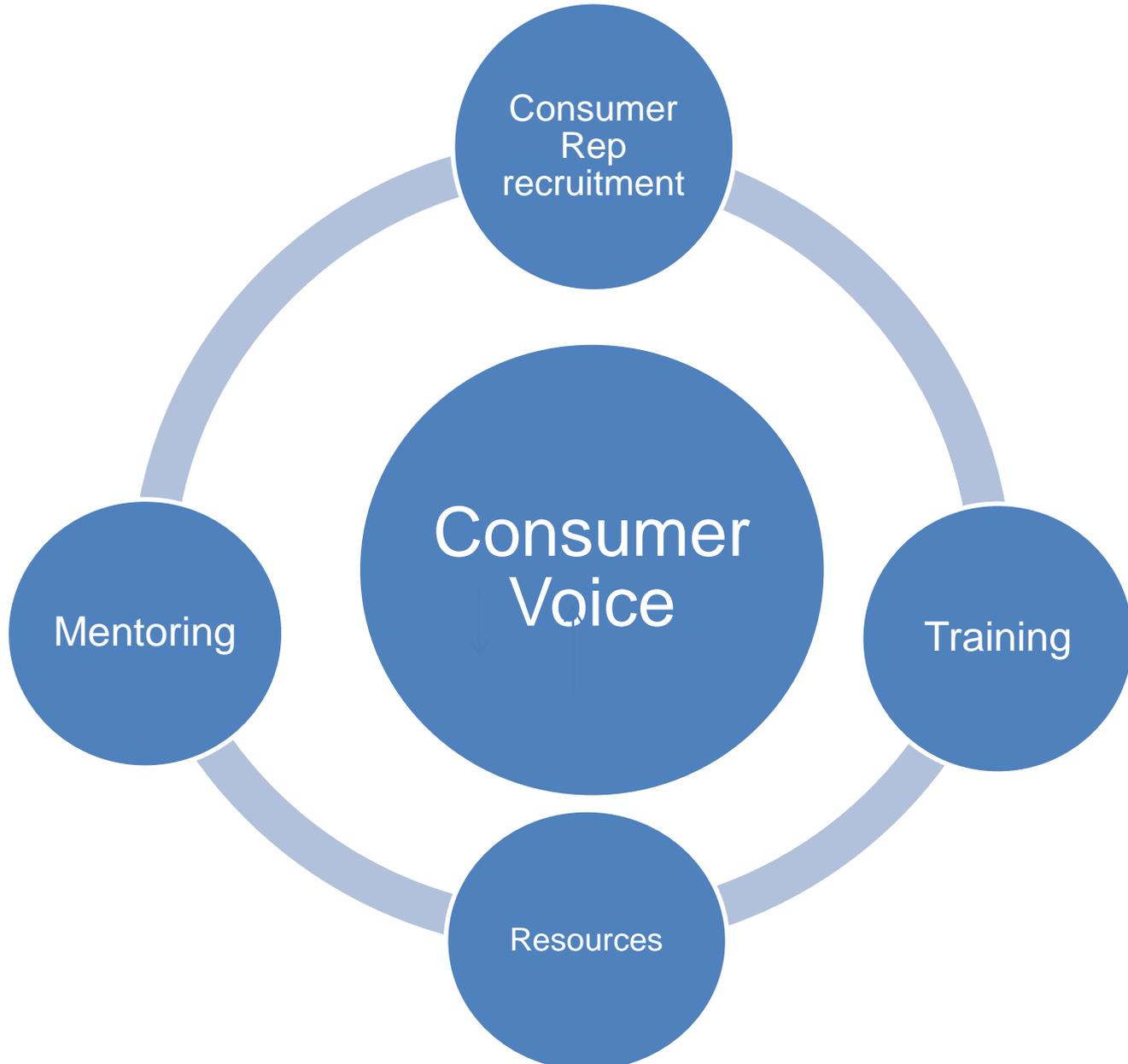
Danny Vadasz
CEO
Health Issues Centre

Who are we?

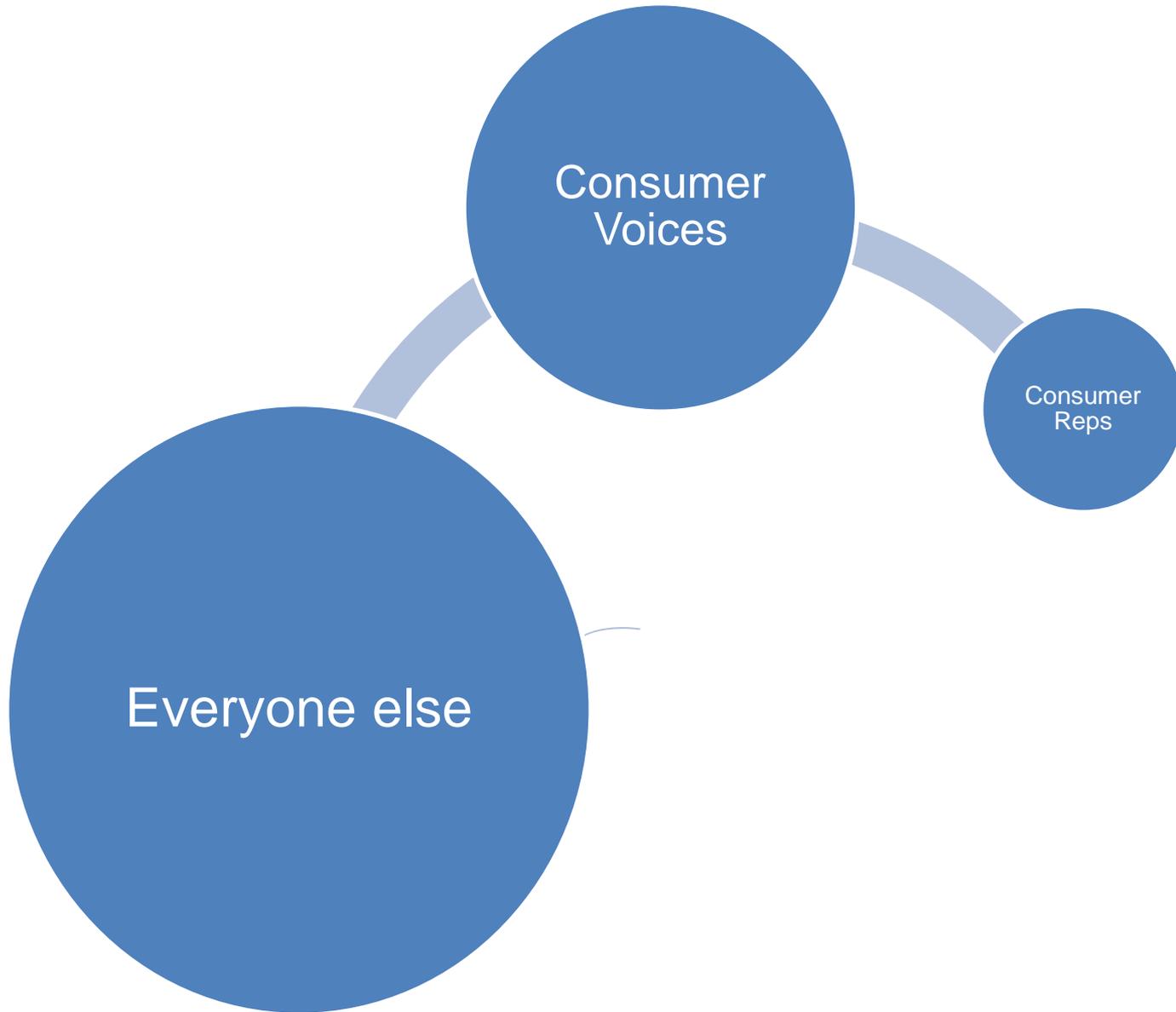
What do we do?



Consumer Representation



Who represents the absent voices?



WHO? WHAT? HOW? WHY?

IAP2'S PUBLIC PARTICIPATION SPECTRUM

The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process.

INCREASING IMPACT ON THE DECISION

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To provide the public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISES TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

Myth-Busting

Consumers represent

Surveys/focus groups fill the participation void

Big data tells us everything

Engaging absent voices is too hard/costly/time consuming

Co-design addresses people problems

We all want to be decision-makers



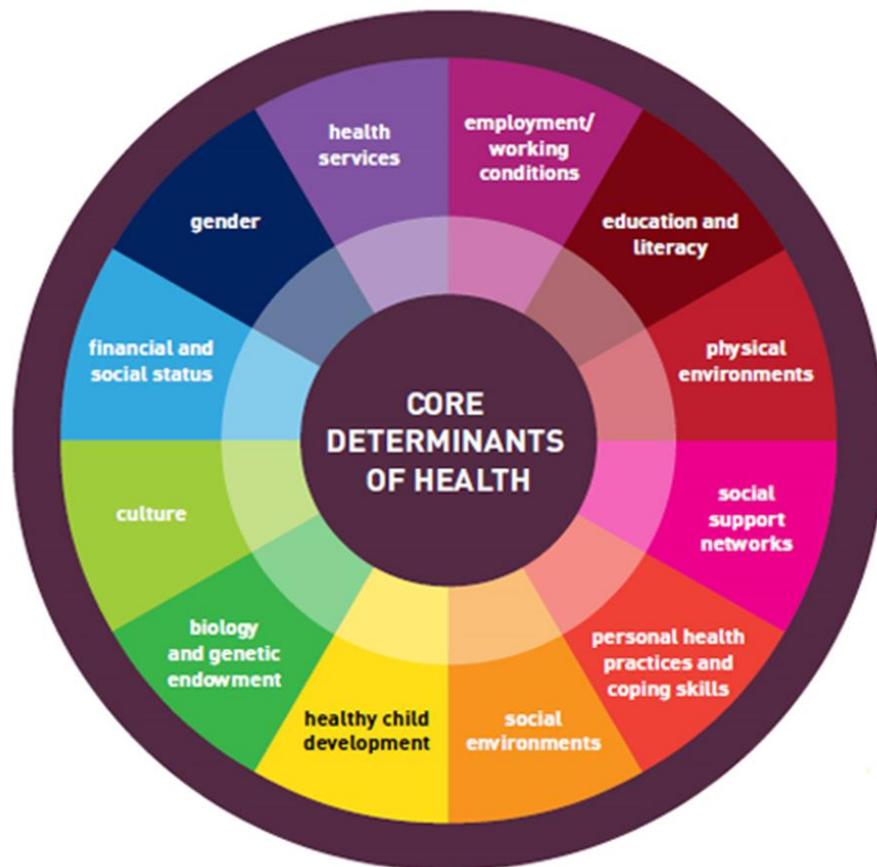
What would a
“*Gold Standard*”
look like?

“A true participatory model embraces diversity, the vulnerable and the ‘hard to reach’ so that they too may influence outcomes.”

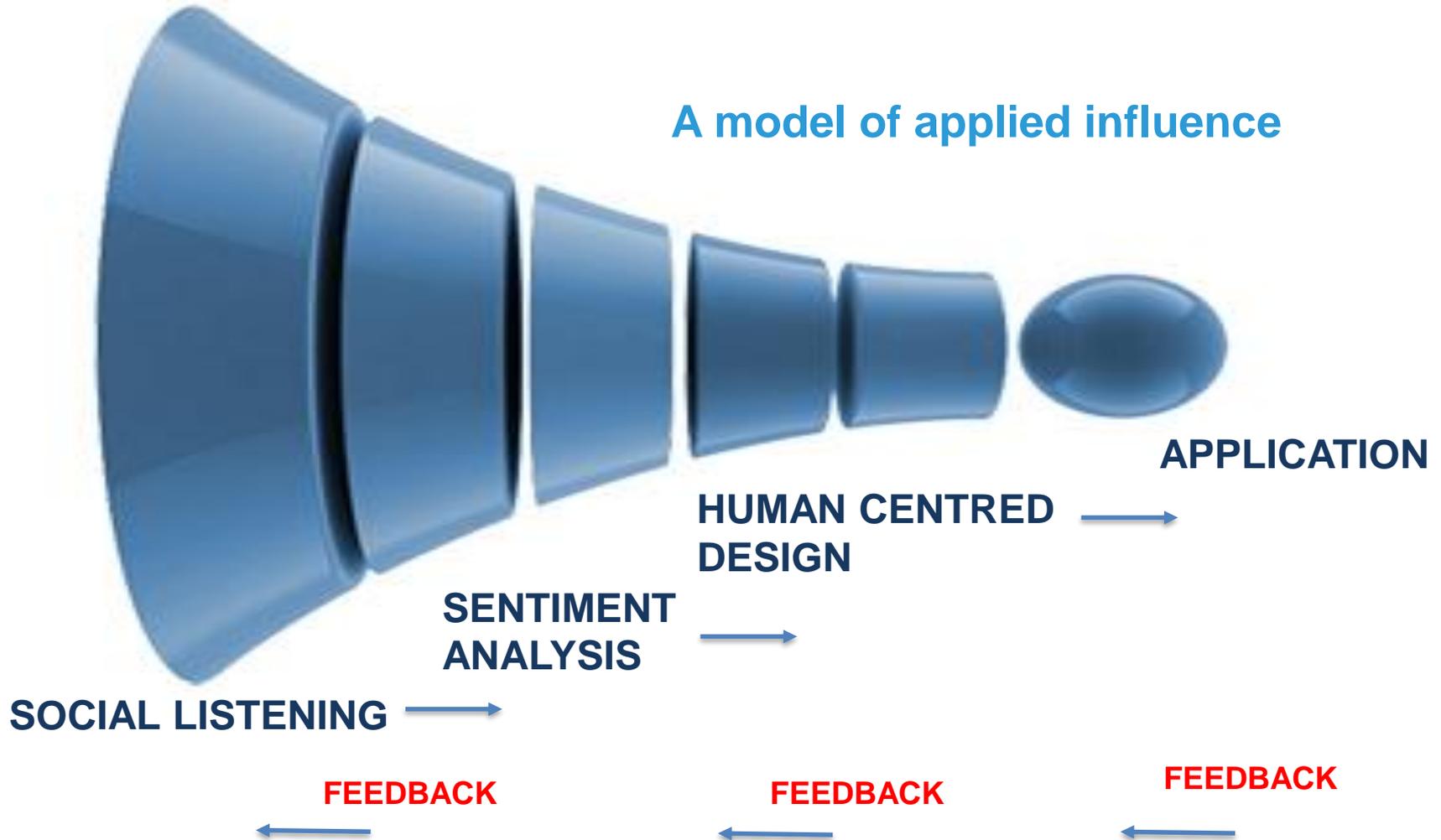
- HIC definition

Can Health Literacy deliver diversity?

The social determinants that deny access to health also inhibit participation



Consumer Driven Outcomes



A New Participation Toolbox

SYSTEM CENTRED	PERSON CENTRED
Consumer representation	Social Listening
Patient Experience Surveys	Consumer generated surveys
Focus Groups	Social Intercepts
Data analysis	Sentiment analysis
Co-Design	Human Centred Design

What is Social Listening?

The art of finding what you weren't looking for

Social Interception

Self-directed Conversations

Consumer generated surveys

Trusted informants

Sentiment analysis

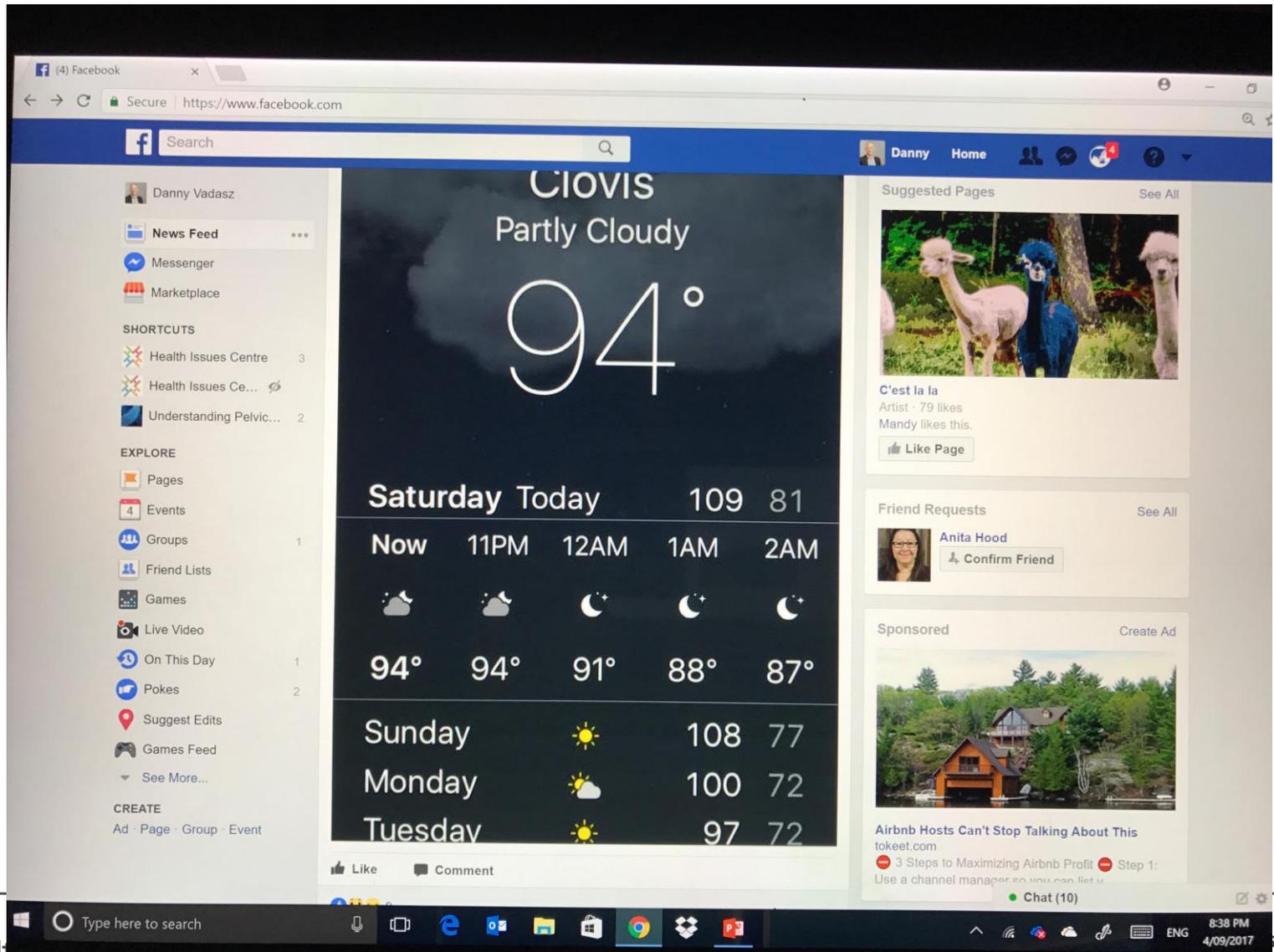
Social interception

Conversations require shared language

<https://www.youtube.com/watch?v=8mRoLI8uLjI>

<https://youtu.be/IVrAXSwUFpE>

Social Media as a Research Tool



What is a self-directed conversation?

- 1 . Create a dedicated page or use your organisational Facebook page.
2. Create a post that poses a generic “provocation” or question
3. Define your target audience and boost your post (question)
4. Collate data and conduct a sentiment analysis and word cluster search
- 5 . Use the analysis the results and generate the next question
6. Repeat
7. Identify key issues and create a survey to test hypothesis

What do you think of...?

Voluntary Assisted Dying Legislation

Q 1. What are your thoughts on the proposal for legislation to enable assisted death in Victoria?

32,744 People Reached

40% 1,756 Engagements

433 Comments; 1,172 Likes, 151 shares

30% \$400.00 Total Spend

20%

10%

0%

13-17

18-24

25-34

35-44

45-54

55-64

65+



Voluntary Assisted Dying

Lisa Upton I'm to selfish, I want my family with me. But I don't want them suffering either.

[Like](#) · [Reply](#) · [Message](#) · 1 · December 15, 2016 at 10:14pm



Maxine Walton Should be allowed

[Like](#) · [Reply](#) · [Message](#) · 1 · December 15, 2016 at 10:20pm



April Gates Our system should be able to deliver effective means of ensuring that people can pass without fear of suffering and pain. I don't think people should suffer, so why do we withhold pain treatment for the dying that is used in other areas of medicine? I'...[See More](#)

[Like](#) · [Reply](#) · [Message](#) · 1 · December 15, 2016 at 10:26pm



Iris Laughlin I agree but with careful supervision

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Babs Robson Good why should people suffer so much ,let people die with dignity .

[Like](#) · [Reply](#) · [Message](#) · 2 · December 15, 2016 at 10:36pm



Joanne Allan It's about bloody time.

[Like](#) · [Reply](#) · [Message](#) · 2 · December 15, 2016 at 11:10pm



Stella Graham Should have been available years ago, I do so hope there is a positive outcome with this.

[Like](#) · [Reply](#) · [Message](#) · December 15, 2016 at 11:17pm



Peter Robinson This isn't on your list I hope Ann

[Like](#) · [Reply](#) · [Message](#) · December 15, 2016 at 11:54pm



Deb Mcewan I have seen people suffer too many times. They want to go and ask to go so let them go.

[Like](#) · [Reply](#) · [Message](#) · 1 · December 16, 2016 at 12:08am



Brandy Wright Victorian residency will increase

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Toni Nicole Lynch Bout time we can put our animals down when suffering so why not ourselves

[Like](#) · [Reply](#) · [Message](#) · December 16, 2016 at 12:40am



Ann Skinner All we ask for is a choice if we need it at some stage in the future, all of us deserve the right to die with some dignity

[Like](#) · [Reply](#) · [Message](#) · December 16, 2016 at 12:48am



Fiona Colenso About time..... no one should have to suffer. My body, my choice when the time comes.

[Like](#) · [Reply](#) · [Message](#) · 3 · December 16, 2016 at 1:10am

Policy/Public Disconnect

1. “What are your thoughts on the potential legalization of assisted death in Victoria?”

“It’s about time” (20%); “death with dignity” (10%); “My body, my choice” (13%)

2. What does a dignified death look like to you?

“without pain or suffering” (40%); 15% not just pain

“right to choose when and how” (25%)

3. Should assisted death only be available to those with a terminal illness experiencing unendurable suffering?

“yes” (10%); “right of self-determination” (60%)

What can you achieve through Social Listening?

1. **Searchlight Program** - Adverse event prevalence data
2. **Insight Program** – Social contextualisation of health
3. **Stress testing** – Policy gaps, strategic flaws and system failures
4. **Human centred design** – Solutions to consumer problems

Searchlight Program

Medical Implants and Devices

Transvaginal mesh

Hernia mesh

IUDs

Knee replacements

Hip replacements (metal)

Breast implants

Stents

Obesity surgical devices

Intraocular lenses

Pain pumps

Resuscitation devices

Insight Program

“Its Not Easy Growing Old” – ageing in Gippsland

Physical

Tire more easily, can't do as much as previously- one busy day has a greater impact.

It is frustrating for me not being able to walk distances and do simple things like walking the dog

Cognitive

Trying to remember where I parked the car at the supermarket.

My memory is not as good as it used to be. I deal with this by making notes. Physically I can't do as much as I used to without needing a break.

Emotional

The heartaching loss as friends die.

I suffer increasingly from anxiety caused by the knowledge that my future is shrinking

Loss of identity

Maintaining my identity as an individual, not being put into a box as an 'elderly citizen'.

People not taking older people seriously. People underestimating what we can do and achieve.

Hate getting old cause people treat you like you don't know what you are talking about, like you are getting senile

Being made to feel unnesesary or irelevant by younger persons other than family even when at 76 you are in voluntry committee positions

Not being listened to. Being dismissed as being irrelevant.

Being invisible and being talked down to

I no longer feel respected and I no longer feel a sense of belonging. I am never invited to fun activities. sometimes I would like to just enjoy a conversation with someone who might respect my opinion.

Insight Program

The Spiral of Decline and Withdrawal

Incremental physical/cognitive decline

Erosion of self-esteem

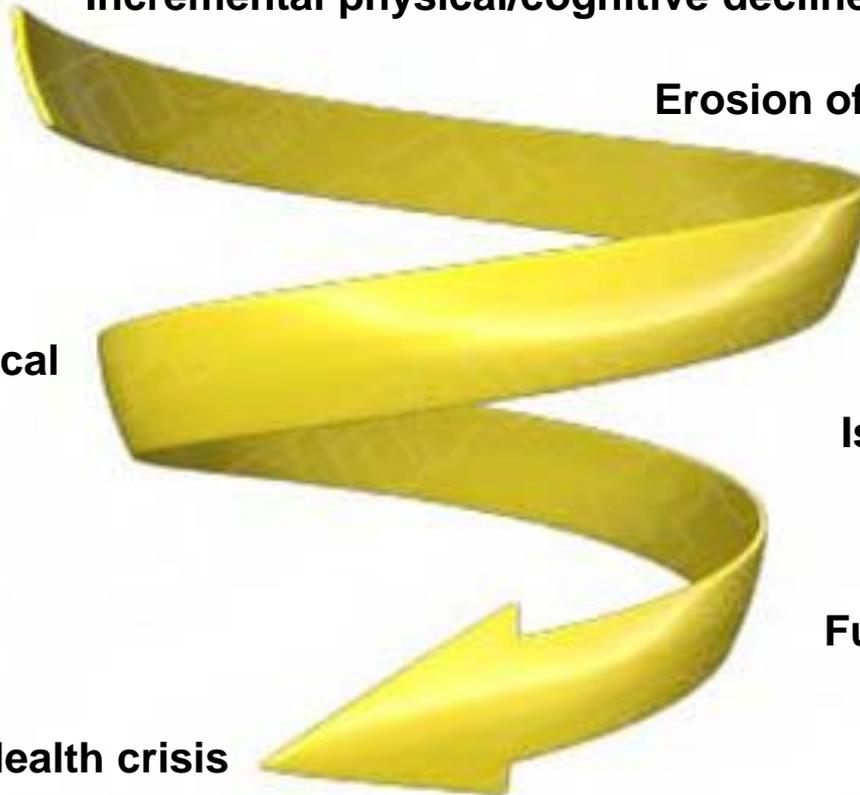
Loss of identity

**Social and clinical
withdrawal**

Isolation and depression

Further health decline

Health crisis



Human Centred Design

WHAT REALLY MATTERS?

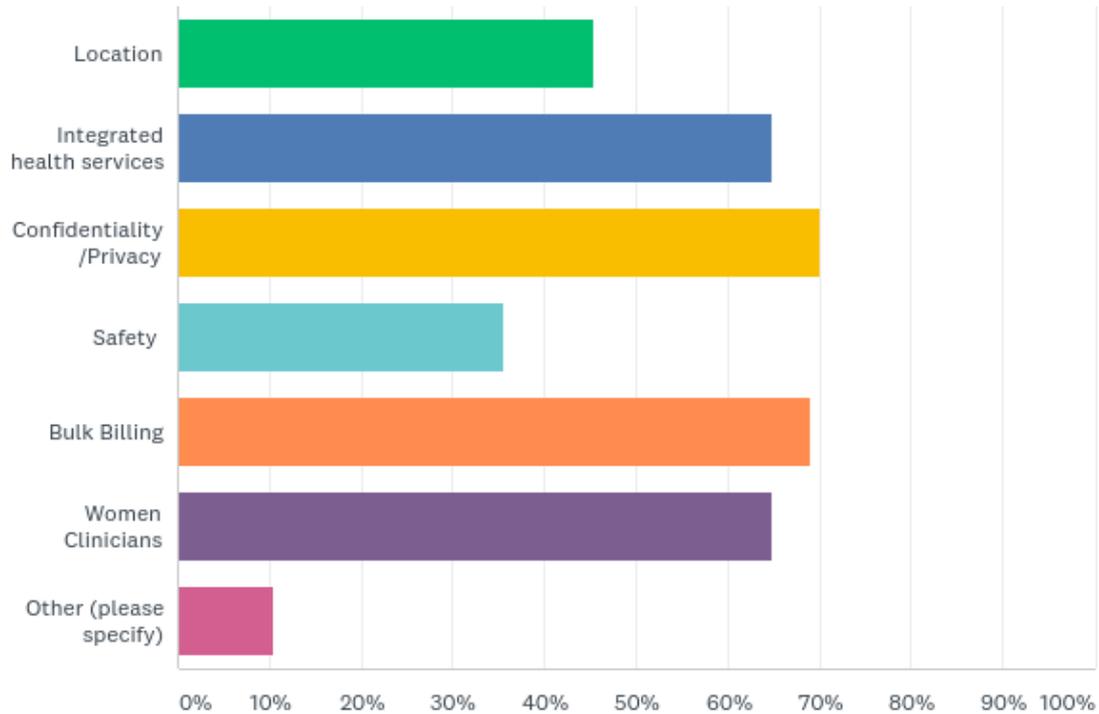
Female Parking Menopause Deal Appointments
Management Understanding Private Staff Children
Support Able Health Practitioners
Women Care Access Advice Friendly
Fitness Town Programs Confidentiality Pap Doctors
Pregnancy Think Travel

**A SOCIALLY INCLUSIVE APPROACH TO
DESIGNING THE MDHS WOMEN'S HEALTH &
WELLBEING CENTRE**



Women's Health and Wellbeing Centre

What matters most?



What concerns consumers?

- Empathy and validation
- Navigation
- Reputation
- Informed consent
- Real time information
- Complaints

Health Issues Centre

Every Voice has a right to be heard

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Health Issues Centre

Consumer voices
for better healthcare