

Health Issues Centre

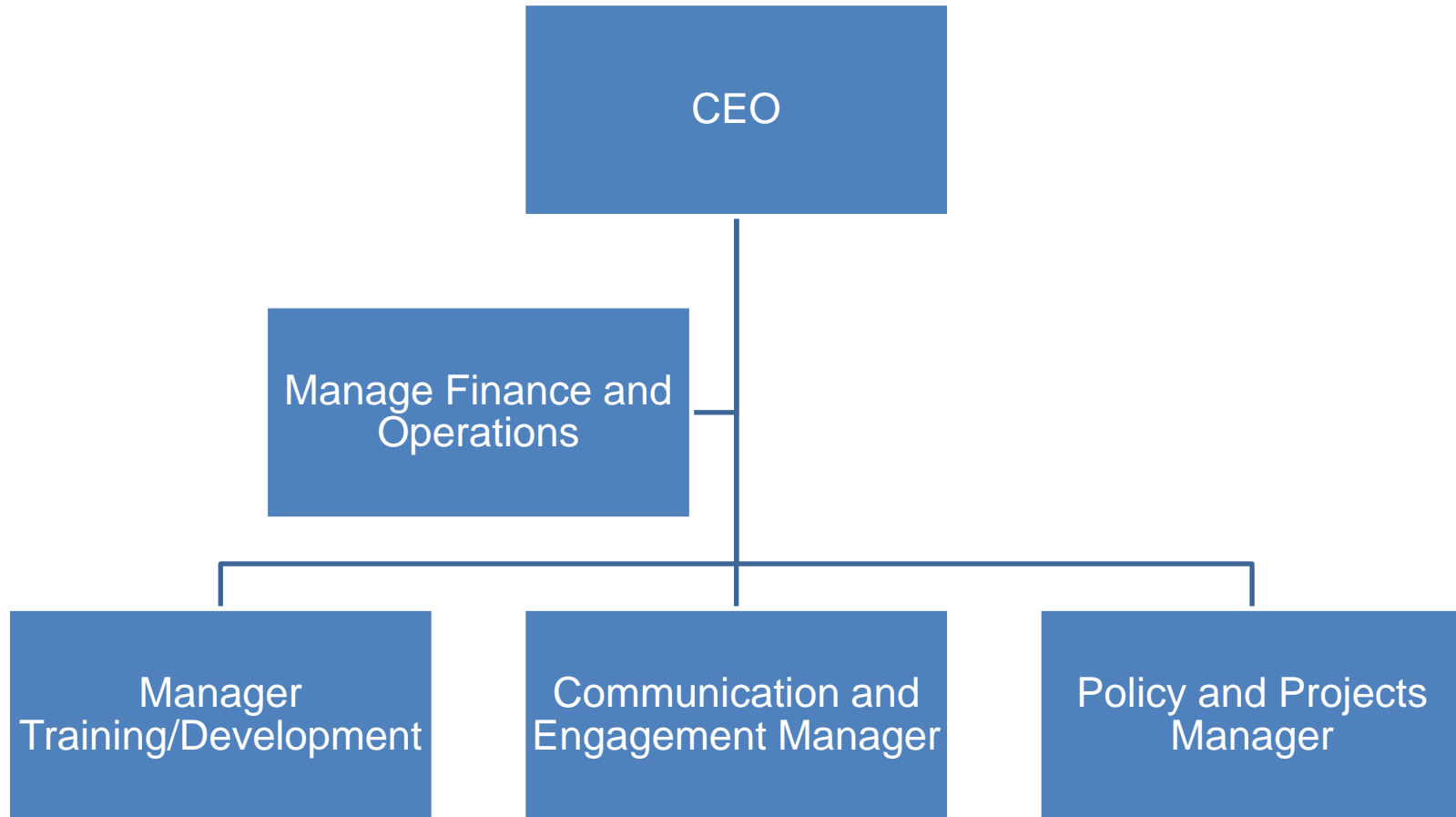
2016/17 AGM

The year that HIC found its voice

Sophy Athan, Chair

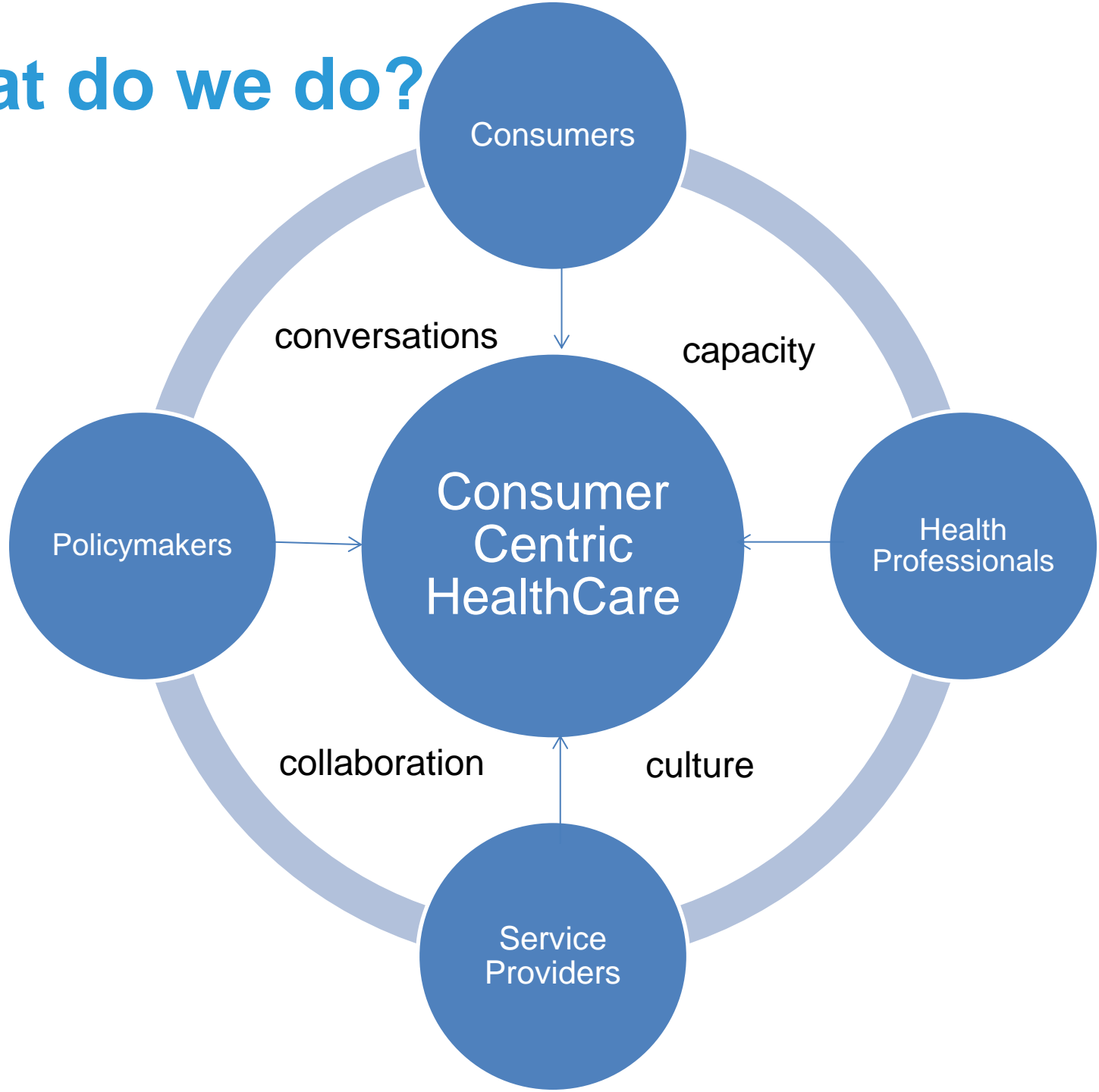
Danny Vadasz, CEO

Aligning structure and function

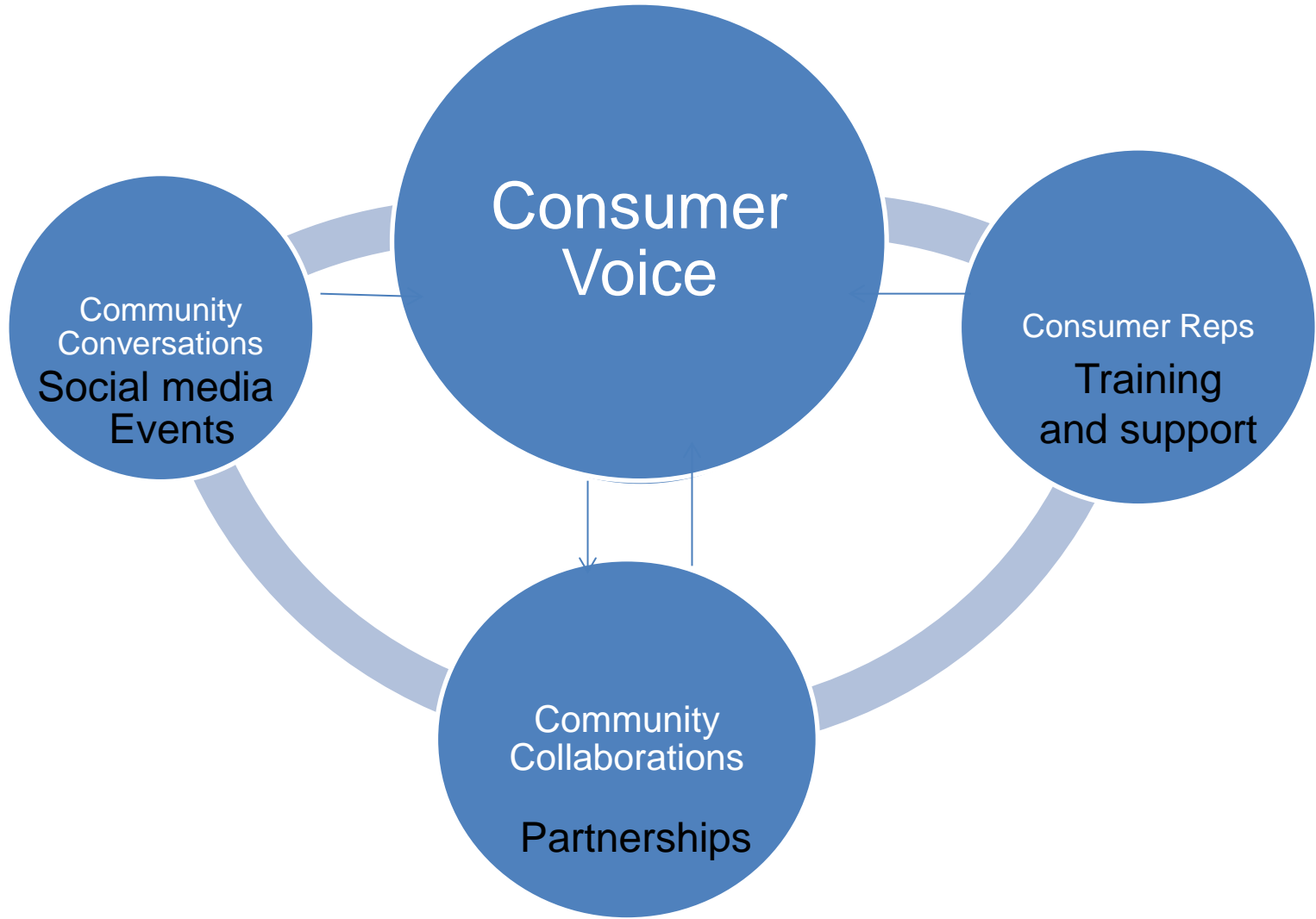


Organisation
Health Consumers' Council, WA \$1m pa state funding
Health Consumers Queensland, Qld \$1m pa state funding
HCCA, ACT/South East NSW \$880K pa funding from ACT Government some additional project/research funding
Health Consumers Alliance, SA \$550K pa
HIC, VIC \$490K pa 3 year funding agreement with DHHS Additional project by project funding Fee for service

What do we do?



Pathways to Participation



Collaborations

Health Services

Community Organisations

Professional Associations

Academic institutions

Health Agencies



Influence

Advisory Committees

Reference Groups

Councils

Clinical networks

Judging panels

Media contact point

Round tables

Capacity Building

Health Literacy

Co-Production

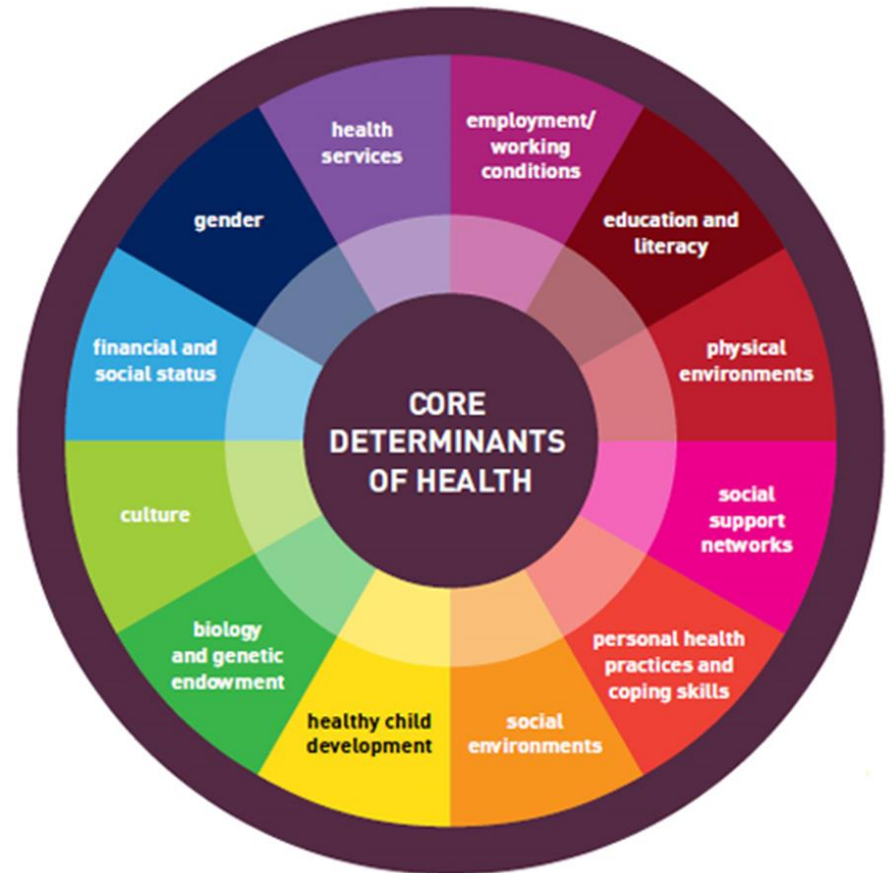
Clinical Governance

Safety and Quality

Outcome and impact assessment

What's wrong with diversity?

The social determinants that deny access to health also inhibit participation



Consumer Reps – Key Selection Criteria

Lived experience plus

- Health literate
- Articulate
-
- Insider knowledge
- Processes
-
- Availability
- Self-confidence
- Resilience

What is Consumer participation?

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.

The wisdom of crowds

Collective lived experience

Self-directed inquiry

Sentiment analysis

Insight

Hypothesis testing

Representation



COLLECTIVE EXPERIENCE	SENTIMENT ANALYSIS	INSIGHT	REPRESENT	SHARE DECISIONS
Enable consumers to express their needs, fears, objectives	Identify commonly expressed themes and sentiments	Form and test hypothesis	Policy, design and evaluation are informed by and reflect population sentiments	Choices are based on collective wisdom
You get to speak your mind	We acknowledge a plurality of views	We gain insights	Your opinions will be represented	You have contributed to the outcome



The tools of collective experience

- Videography
- Self directed conversations
- Social Media
- Open ended surveys
- Performance art

Vox pops

Conversations require common language

<https://youtu.be/IVrAXSwUFpE>

Self-directed conversations

End of life

ACTION METRICS	TOTALS
Reactions	49,719
Comments	14,981
Shares	7,680
Total Engagements	72,380

— Are you stubborn or independent?

“Not stubborn just that we don’t want to go just yet.”

“...to be told what to do by others when you still have your own mind and thoughts can almost be bullying!”

“Just trying to be independent as long as possible, so that I’m not a nuisance to my family.”

“...giving it up is the beginning of the end, regardless of your age.”

“As I get older I realise that getting old is not for sissies and losing any tiny bit of independence is heart wrenching! Not being able to drive at night, not getting the lids off bottles even not being able to clean parts of your own house.”

Does becoming old mean becoming a burden?

“I hope I am never a burden, then my choice would be a nursing home.”

“...you have to make an effort not to be a burden. Fingers crossed.”

“I really hope I kick the bucket before I become a burden to anyone.”

“I don't want to be a burden to anyone. I hate the thought.”

“I've already told my kids as payback for their behaviour I'm going to retire in their adult homes where I will demand food, someone to dress me and cater for my every whim. They think I'm joking...”

“I stay away from my family in fear that I don't want to get screamed at and hear the “f” words when they talk to me... I'm alone.”

How do you feel about residential age care?

“Run for the hills.”

“Bring on euthanasia!”

“I will not end my life in an old peoples factory... I want life and community. Or beam me up Scotty.”

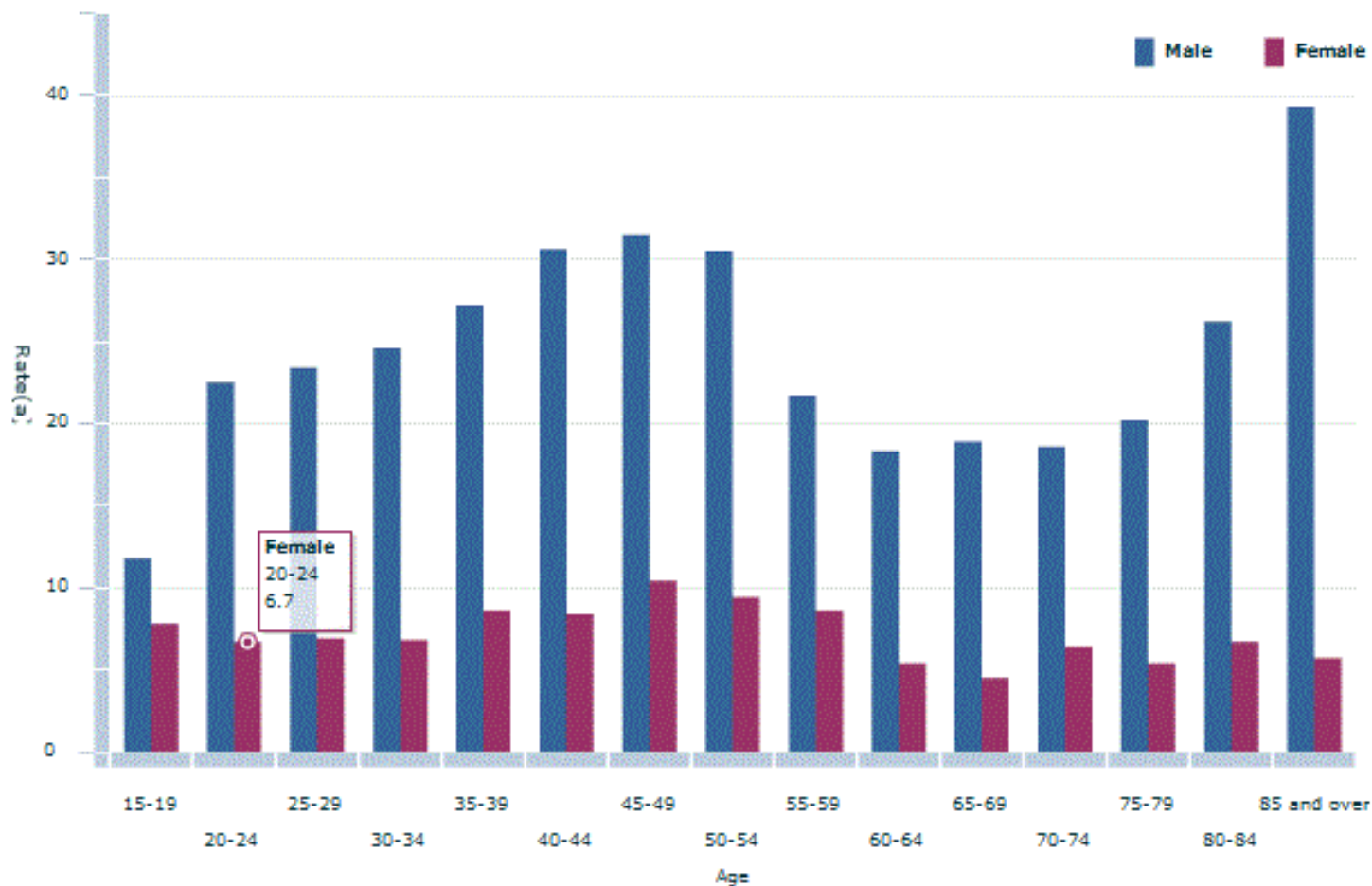
“Aaaaarrrrgh!”

“In the Filipino culture our ageing parents live with their children or relatives, no matter how poor we are...”

“I’m going to kill myself before that time. Hoping I have another 10 years first.”

Age related suicide deaths

Age-specific death rates for Intentional self-harm, by sex, 2015 (a)(b)(c)



Save Chart Image

Australian Bureau of Statistics

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Making end of life choices

1. What are your thoughts on the potential legalization of assisted death in Victoria?
2. What does a dignified death look like to you?
3. Is an assisted death everybody's civil right or should it only be available to those with a terminal illness suffering unendurable pain?

Long form Surveys

Understanding Pelvic Mesh

“Many women in Australia have undergone pelvic mesh implants. Many did not give their informed consent. Many have suffered crippling adverse side-effects.

Nobody knows how many.

We need to hold the health system accountable to these women. The first step is to understand the extent of the problem.”

Understanding of the implications of surgery involving mesh implants	Did not feel fully informed about mesh surgery and/or regret having the surgery	Not being fully informed about what the surgery involved and/ or not being told about the potential complications. Many of these women explicitly stated that they regretted having the surgery. A large number of the respondents commented that mesh should be banned as they did not want others to suffer as they had.	120
	Felt well informed about the surgery	Felt they had had the procedure clearly explained to them.	12
	Doctors dismissed my symptoms	Feeling distressed because symptoms could not be explained/believed. Being made to feel that their symptoms were not real and/ or unrelated to the mesh implant and in some cases being made to feel they were to blame for their problems. Difficulty obtaining information from health professionals about possible side effects of mesh.	54
	Unsure if problems are related to mesh implants	Significant symptoms following surgical procedures for prolapse but unsure if they had had mesh implants or they knew they had mesh implants but were unsure if their symptoms were due to this.	60

“What Will Become of Me?”



Thank you

Sophy Athan
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