THE PATIENT’S VOICE IN PUBLIC DELIBERATION – REACHING COLLECTIVE RECOMMENDATIONS ON ALLOCATING RESOURCES FOR CANCER DRUGS

Colene Bentley, PhD

Canadian Centre for Applied Research in Cancer Control
Cancer Control Research, BC Cancer Agency
ARCC’s Mission
To improve cancer control and the delivery of cancer care through interdisciplinary, pan-Canadian leadership, in health economics, services, policy and ethics research, capacity building and knowledge translation

ARCC Co-Directors: Stuart Peacock, DPhil and Kelvin Chan, MD
Public deliberation event

“Making decisions about funding for cancer drugs – a deliberative public engagement”*

- Vancouver, British Columbia (BC)
- September 2014 – two weekends/4 days
- 24 members of the BC general public
- Facilitated small and large group discussions
- Expert speakers, booklet, website

Patients’ or public perspective?

HTA mechanisms commonly incorporate social preferences into allocation decisions
– patients and public value health states differently – which to use?
-- an unnecessary dichotomy?

Fulfill deliberative public engagement objectives:
• To produce collective decisions after a process of exchanging views and increasing knowledge
• To explicitly address trade-offs (costs, interests) to determine what trade-offs are publically acceptable
• To provide DMs with guidance from the public that has sufficient authority
Create a mini public

Goal of recruitment – create a “mini-public”

A mini public is

- a representation of the larger public from which it is drawn
- represents “the diversity of social characteristics and plurality of initial points of view in the larger society” (Goodin and Dryzek 2006).
- ideally free from sectarian interests that can steer discussion in a particular direction and thus undermine civic trust in deliberative processes (Warren 2009).
Recruitment

24 members of the BC public were recruited based on:

• **Demographic characteristics**: stratification by age, sex, geography, ethnicity, chronic disease experience (y/n), parenthood (y/n), income, education

• **Screening criteria**: no financial relationship with tobacco; not a health advocate or policy maker; no market research study participation in previous 6 months; availability to attend event
Playing decision makers

Decision scenario:

How much additional duration of life is needed to justify doubling the budget? (explicit trade-off b/w cost and quantity of life)

- 3 months
- 6 months
- 12 months
- 18 months
- 24 months
Patients’ perspectives

Day 3, Large group:

KYLE: [S]ix to twelve [months means] you got time to get your stuff together, and approach it....[F]or some people six months is plenty, for other people a year.

SARAH: I think the 12 months and higher was if you looked at only money....I sat there trying to decide between 12 and 6 [months] because I'm like, well, if we're talking dollars, 12. If we're talking emotions, 6.
Recommendation

To justify doubling the cost of the treatment, we recommend that:

There needs to be a minimum of 12 months of additional duration of life.

YES = Most
Playing decision makers

Decision scenario:

How much additional quality of life is needed to justify doubling the budget? (explicit trade-off b/w cost and quality of life)

• 10 point increase – from 50 to 60 on the Quality of Life Scale
• 20 point increase – from 50 to 70
• 30 point increase – from 50 to 80
• 40 point increase – from 50 to 90
Measuring quality of life

Tests and diagnosis → 98
Stage I localized → 86
Stage II/III early/late locally advanced → 68
Stage IV metastasized → 38
ANNA: I have cancer...and I'm not expected to get 70 or 80 [on the QoL scale].... So if I could get 10 percent [increase], that is a lot in a cancer patient....Ten percent quality improvement is -- I could live with that.

DEBBIE: To me 10 percent is good. It makes a big difference, and I totally agree with what you're saying. I worry that we're -- when we say things like 20 [points] and again, with the 12 months [additional length of life] too, we're setting the bar too high.

(Large group, Day 3)
Patients’ perspectives

ANNA: I think you're right. For myself personally, 60 [on the QoL scale] I can live with. But if I'm looking at the cost, which this whole thing is about, I think you're right: 70 cost-wise makes more sense. You know, if I...took the cost out, I would live with 60. I would take anything. But cost-wise, to make [the decision] relevant and beneficial for more people, you know, you have to [look at it] that way.

(Small group G, Day 3)
Recommendation

To justify doubling the cost of the treatment, we recommend that:

There needs to be a minimum of 20 points of improvement [from 50 to 70 on the QoL scale] in quality of life.

YES = Most
Disinvestment

Under what circumstances is there an obligation to continue to fund a cancer drug?

– Key themes: patient choice and fairness
Patients’ perspectives

ANNA: So I think the patient should have some say in....may decide, for whatever reason, she would prefer the older [drug].

REBECCA: Yeah, I had to take Tamoxifen for five years....I had to stop taking it because it was just making my life hell. So they gave me Zoladex which...didn’t give me the same side effects. So I think, yeah, like I agree with that.

(Small group G, Day 2)
DIEDRE: There's a certain amount of fear around taking a new drug, and so switching a drug is almost quite personal. With a grandfather [clause] and stuff like that, it's not like the person has to stay on the old drug....[W]hen you struggle with a disease, you'll hit sort of a stable point and it's like, I don't want anything changed....So yeah, I think switching somebody's drug is something that you shouldn't do it too often.

(Large group, Day 4)
Recommendations

There is an obligation to continue to fund a cancer drug if it is significantly easier to use compared to other drugs or treatments (for example, oral vs. intravenous drugs).

(Most)

Patients who are taking an existing drug should have the option to stay on the existing drug even if it is more expensive than a similar new drug.

(All)
Summary

Why highlight patients’ viewpoints in a public deliberation?
Summary

• Patients’ views - part of an informed mini-public
  – Recruitment strategy: chronic disease (y/n), no advocacy groups, no DM

• Capacity for civic-mindedness
  – Balance cost with compassion (“If we’re talking dollars, 12 [months]. If we’re talking emotions, 6”)
  – Capacity for disinterestedness (“I would live with 60. I would take anything. But cost-wise, to make [the decision] relevant and beneficial for more people....You have to [look at it] that way.”)
  – Patients, public are not essentialized by their health states
In their recommendations, participants supported the following principles:

- Resources are limited – no participant said “fund everything”
- Necessity of making cost-benefit assessments + trade-offs
- It is appropriate to set thresholds; use money as a unit of comparison
  - Quality of life was important with some willing to lower the threshold of benefit from expensive drugs in order to get it (10pts increase in QoL scale)

These guiding principles are acceptable to an informed, diverse public when addressing controversies over funding cancer drugs.
Next steps

“Making fair and sustainable decisions about funding for cancer drugs in Canada” – cross-Canada deliberations in 2016

• 6 deliberations (May-October 2016): Ontario, Nova Scotia, Saskatchewan, 2 Quebec (Eng, Fr), pan-Canadian

• Canadian Partnership Against Cancer – RFP based explicitly on the BC event

• Co-PIs: Stuart Peacock, Julia Abelson, Michael Burgess

• Input from key DMs: cancer agency CEOs, MoH, CADTH

• Final report: March 2017
Acknowledgments

Research Team
Stuart Peacock, PI – BC Cancer Agency (BCCA), Canadian Centre for Applied Research in Cancer Control (ARCC), Simon Fraser University
Mike Burgess, Co-I – UBC
Helen McTaggart-Cowan – BCCA, ARCC

Dean Regier, Co-I – BCCA, ARCC, UBC
Colene Bentley – BCCA, ARCC

Event Team
Sarah Costa, Sonya Cressman, Holly Longstaff, Emily McPherson, Reka Pataky, Lisa Scott, Kim van der Hoek, Liz Wilcox

Funders

ARCC is funded by CCSRI (Grant #019789).
“Making Decisions about Funding for Cancer Drugs: A Deliberative Public Engagement”

Questions?

Contact: cbentley@bccrc.ca

DONNA: I've gained a lot more respect for the decision makers - big time!