

Citizen juries to inform healthcare policy decisions

The experiences on screening for prostate cancer and cystic fibrosis carrier in Italy

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Conflicts of interest

**I have no actual or potential conflict of interest
in relation to this presentation**

**The Italian Association for Cancer Research (AIRC) gently
supported my participation to this congress**

What is a citizens' jury?

Deliberative democracy method where a group of **lay people** with different backgrounds, values and attitudes is given **adequate** and **balanced** information to deliberate on a **question of interest to the community**.

Why screening?

Medical intervention addressing **healthy people** with concerns and consequences at the **community** and **individual** level

Value-based decision

Informed **consent needed at the community level**

 **Need for engaging the public**

Four citizen juries on screening topics in Italy

One on the **Prostate Specific Antigen (PSA)** as an individual screening test for prostate cancer (2013)

- controversial: discrepancies between literature and practice
- consequences on the community (benefits and harms)

Three on the **Cystic Fibrosis (CF) Carrier Screening** test (2012-14)

- currently offered by gynecologists in some Italian regions: unequal access
- potential consequences on people's reproductive choices

Need for a decision at the community level

What we did



Should the National Health Service discourage or recommend **PSA test** as an individual screening test for prostate cancer in 55-69 years old men?

Should the Health Service organize screening of the population with the aim of identifying **healthy people who may have children with CF?**



men and women over 18 years old
with no personal or family history of the condition
balanced for sex, age and educational level, honorarium

PSA screening test

voluntary group
supporting institutional
health campaigns

13 jurors, 8 M 5 F
(1 jury)

CF carrier screening

volunteer associations
included
in public registers

44 jurors, 19 M 25 F
(3 juries)



Booklet drafted on the basis of the literature and documents of interest, reviewed by patient associations' representatives sent to jurors 15 days before the meeting

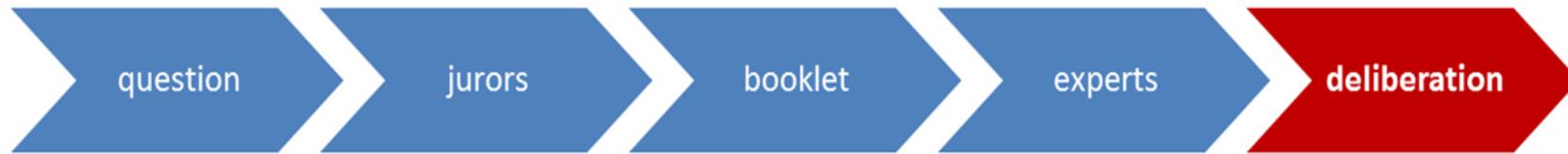
1.5 day meeting with a multi-stakeholder group of experts

PSA screening test

oncologist, general practitioner, epidemiologist, expert in health economics, urologist, policy maker

CF carrier screening

expert in cystic fibrosis, general practitioner, experts in laboratory tests, gynecologists, epidemiologist, policy maker



Jurors meeting: 3 hours and a half
Discussion facilitated by a **psychologist**

PSA screening test

The **National Health Service** should **discourage** Prostate Specific Antigen test as an individual screening test for prostate cancer in 55-69 years old men, **funding awareness campaigns aimed at GPs, citizens and citizen associations**

CF carrier screening

The **National Health Service** should **organize** screening programs to identify healthy people who may have children with cystic fibrosis (one unanimously, one by large majority, one by majority)

Final remarks

Citizen juries

- **A feasible method** to be fostered

Some open issues:

representativeness *vs decision from the community's point of view*;

balanced information;

equal jurors' participation in the deliberation;

how to handle potential influences on jurors;

transparency on research purpose *vs health policy impact*

- **Need for increasing the impact at policy levels: who is listening?**

still under-used by decision-makers

willingness to engage the public

Citizen juries' research team

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More information

Involving a Citizens' jury in decisions on individual screening for prostate cancer

PLoS One. 2016 doi: 10.1371/journal.pone.0143176

Cystic fibrosis: to screen or not to screen? Involving a Citizens' jury in decisions on screening carrier. Health Expect 2014 doi:10.1111/hex.12261.

Thank you!

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