

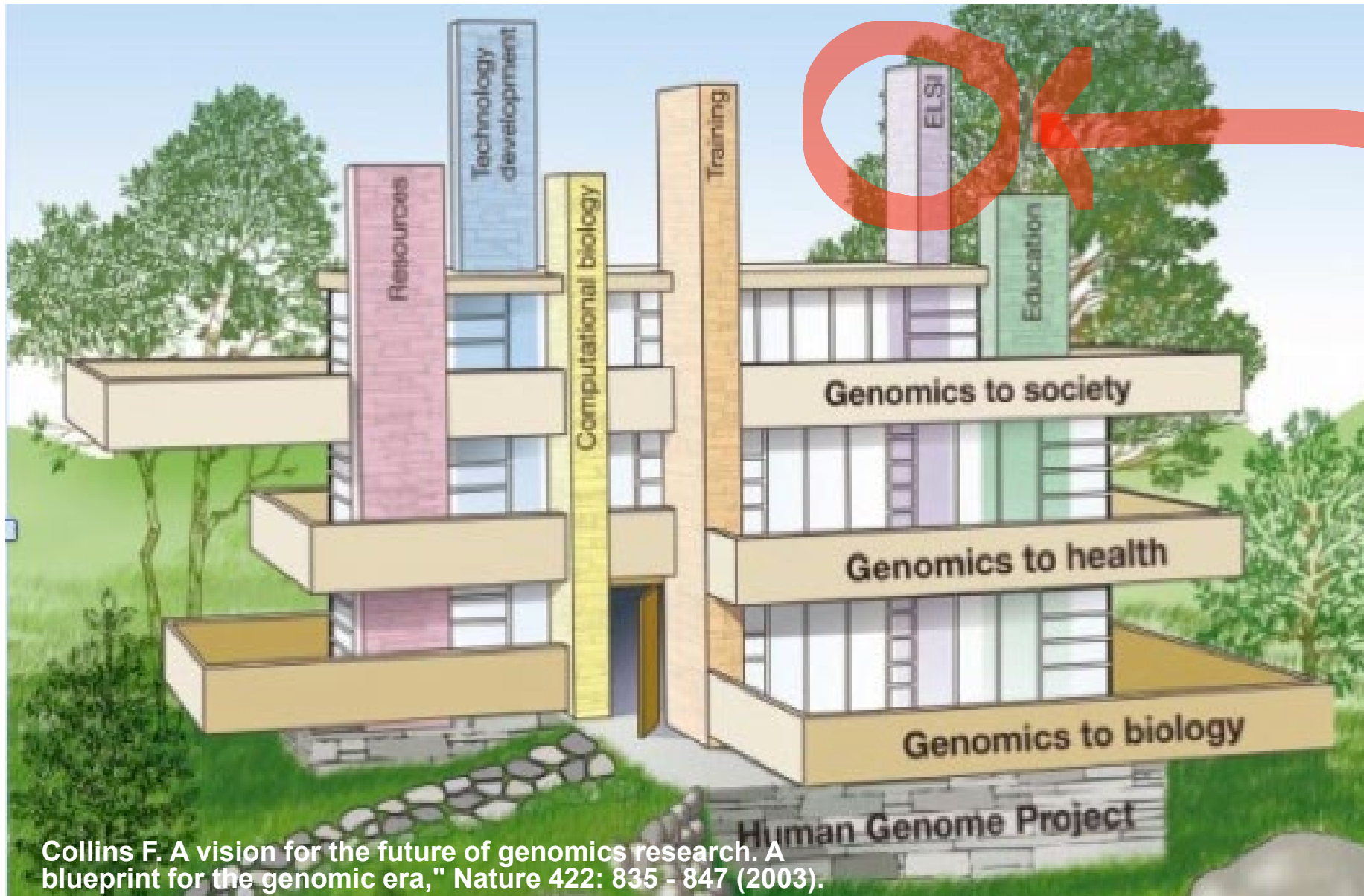
Ethical, Legal and Social Issues of Genomics: is engagement of publics meaningful?

Heidi Carmen Howard, PhD, She/Her

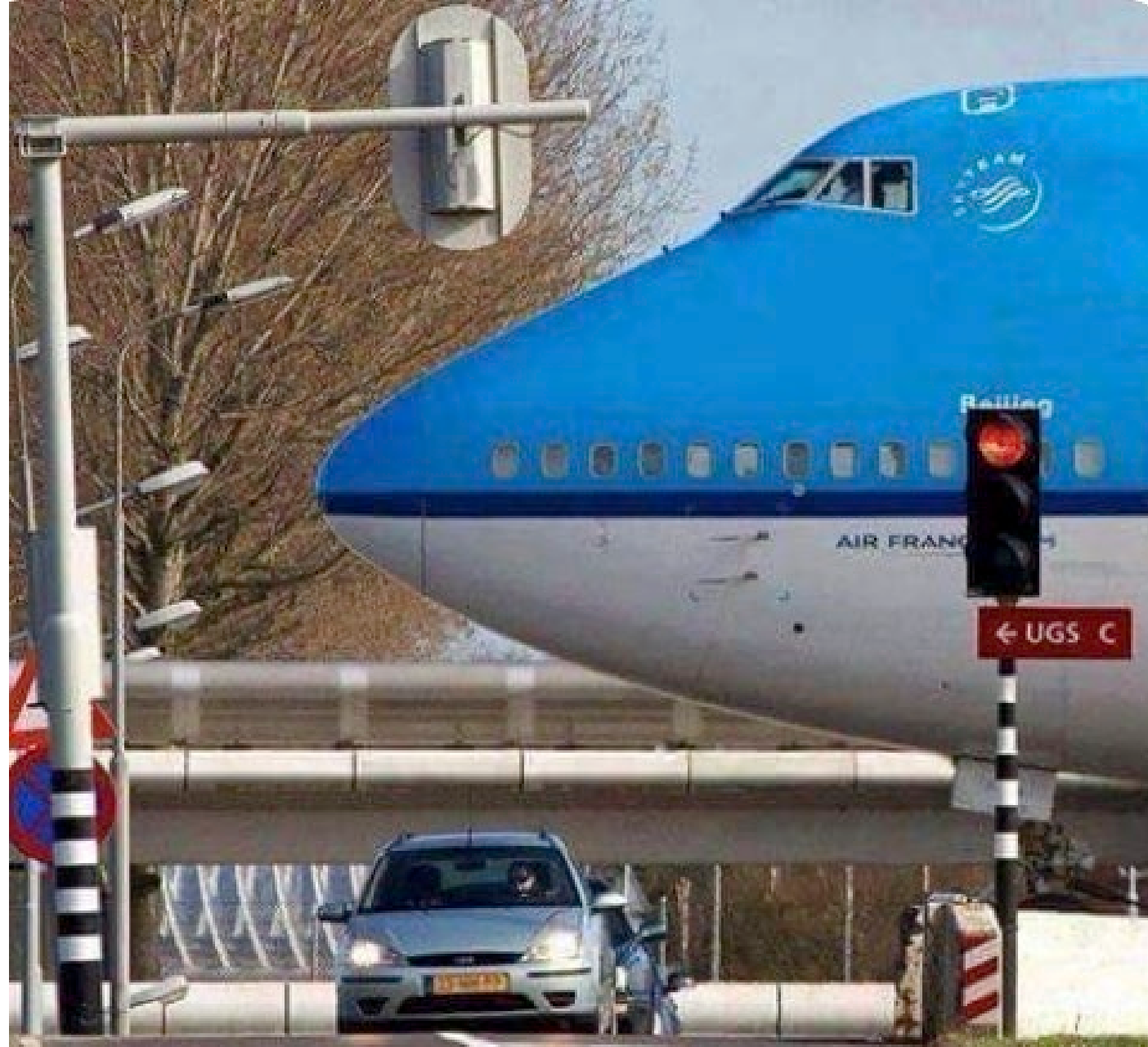
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Ethical, Legal and Social Issues (ELSI) Research: a pillar of the genomic era



Collins F. A vision for the future of genomics research. A blueprint for the genomic era," Nature 422: 835 - 847 (2003).



New technologies challenge existing ethical and legal norms

Some Ethical, legal and social issues (ELSI) in genetics/genomics

Patient/participant understanding

Consent

Counseling

Publics' engagement

Policy Making

Specific/Practical Issues

Return of Results

Duty to re-contact

Privacy & confidentiality

Testing of minors

Family relationships/dynamics

Secondary Uses/Research/Sharing

Justice/Fair allocation of resources

Meaningful public engagement?



Meaningful public engagement?

Do publics even understand the topic of the scientific research you are asking their opinion on?



Meaningful public engagement?

What is the ultimate aim of asking for publics' views?

How will this information be used?



Meaningful public engagement?

Multiple choice quantitative
questionnaires?

Asking publics' what they think
of aspects that are important to
experts.



Meaningful public engagement?

Qualitative interviews or focus groups?

Can be very informative, but must be reported transparently including all limitations.



Where to publics' opinions fit?

Into

- ethical normative guidelines?
- Policy making?





To be meaningful, ELSI research, and publics' engagement work could use some more serious attention (yes, I mean money and true experts).

Thank you. MERCI! Dank u! TACK!

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Making ELSI coherent one project at a time.

