**RESPONSES TO TARRYTOWN 2011 COMMUNICATION SURVEY**

*Questions are labeled A–M, and each question starts a new page. Responders are numbered 1–40, and if a responder chose not to answer a particular question, the number is retained and simply followed with a blank space (or sometimes, to save pages, the numbers are listed together); the same number always refers to the same person. Within a response, some people started a new line for a new thought or topic, and that has been retained (as a manual line break, to simplify formatting); we could lose a couple of pages if they were run in.*

A. What are the key human biotechnology initiatives/issues/campaigns that you are working on now?

1 Exposing high school and middle school teachers to this history as well as equipping them to explore it with their students.

2 Direct to consumer genetic testing

3 - Gene patenting
- Synthetic biology

4 I lost my earlier submission (was incomplete), so in case it did not come in, I am doing very quick answers this time....
ART issues, SCNT and egg extraction risks in particular

5 ART use
biobanking and informed consent
global market in human cells, tissues

6 Public Health and Safety, Injured Workers Rights and Application of humane biotechnology to ensure human rights

7 Property in the body, including egg sales, pregnancy outsourcing, and gene patenting
"Me medicine"--personalized genetic testing, enhancement and private umbilical cord blood banking

8 race, intellectual property, health disparities

9 1. DNA forensics: a UK campaign to engage the public in the new Protections of Freedoms Bill (which will implement the 2008 judgment of the European Court of Human Rights that the UK breached human rights law). Focus on getting innocent people's records deleted (DNA, fingerprints, police records).
2. DNA forensics and human rights (international). Working with the Council for Responsible Genetics and Privacy International to seek to establish international safeguards to protect human rights in the context of police DNA databases.
3. Human genetic testing. Regulation of gene test claims within the EU (independent oversight of whether they are valid and useful for health); tackling conflicts-of interest in health research priorities in UK to counter hype about gene screening; safeguards for privacy and rights, including opposing attempts to sequence DNA without consent in the UK NHS.

10 Current work focuses on the convergence of human biotechnologies, genetic engineering of plants and animals, use of synthetic biology and nanotechnology and the general manipulation of the human environment to fit an industrial system/society.

11 Responses to genetic reductionism, genetic determinism, exaggerated claims about genomics, and genetics and race.

12 gene patents, genetic privacy

13 Sex differences in the brain and effects of gonadal (sex) hormones on behavior, cognition, emotion and interests.

14 race and genomics

15 Working with CGS, I touch the gamut, but I am particularly interested in the abuse of forensic DNA, including claims that genetic analysis can predict criminal behavior, and more generally the issue of DNA analysis being touted as predictive. I am also fascinated by, and interested in exposing, the advocates of transhumanism and related concepts such as the "singularity" idea.

16 surrogacy laws in India and reproductive tourism

17 Assisted reproductive technologies, enhancement, rights versus dignity, transhumanism.

18 Ethical Governance, Trans- National & Cultural Cooperation, Public Health, Life Sciences, Health Communication, Biobanking, Genomics, interdisciplinary research and capability development; China.

19 ART, techno-eughenics, cloning research, synthetic biology, UCB/NLBL's push for a second lab campus in the SF Bay Area

20 Guidelines for the extension of storage of gametes and embryos beyond the statutory (10 years) period.
Export and Import of gametes and embryos
Informed Consent issues associated with the use of ART

21 non-invasive prenatal genetic diagnosis

22 Racialization of pharmaceuticals.

23 Historically (since 1999)have worked on issues related to biological weapons/Biological Weapons Convention, issues which are intimately connected to biotechnology developments/related ethical issues. Beyond general interest in other related issues, not currently actively involved on this individually or organizationally (Physicians for Social Responsibility).

24 public perceptions of genes as causes of human difference
genetics/genomics in public health
genetic information in epilepsy

25 Tarrytown Meetings

26 The use of unauthorized samples to fill genomic registries and the continued use of race in these registries.

27 DNA databanks in the criminal justice system.

28 egg donation, ARTS/surrogacy, DNA vaccine technologies

29 My program's research involves preconception and in utero exposure to environmental chemicals

30 The DNA revolution and Race
Race in Medicine
Personalized Medicine

31 Biobanks
Stem cells
Intellectual Property

32 Anti-human trafficking in organ transplantation

33 Hematopoietic stem cell transplantation from child donors;
genomics and genetic testing, including whole genome testing, preimplantation genetic diagnosis, preconception genetic diagnosis;
synthetic biology

34 My issues of interest and research
Ethics and practice of enrolling individuals into studies/biobanks/registries in which genetic data are collected
Personalized medicine in the context of clinical care: Are providers and consumers prepared for the integration of genetic data collection into routine clinical practice?
The widening science-public knowledge gap related to the expanding applications of genetics into healthcare

35 I am writing about the specific ways the post Bayh Dole industrial model has changed the conduct of medical research and the provision of healthcare. This includes academic medical research and writing, the provision and pricing of medicines as well as newly collaborative models and the conduct of research and provision of medicine to the developing world.

36 I am working on the development of a genetics curriculum with the the Biotechnology Reference Group of the Canadian Council of Churches (CCC). We have just completed the pilot phase and plan to revise the curriculum into a final version over the next year.

37 My research areas include: disability accessibility; access to, and efficacy of, high technology health care including applied genetics; and eugenics.

38 Genetic privacy and discrimination (especially regarding the workplace and risk-rated insurance)
Gene patenting
Direct to consumer marketing of genetic testing
Oversight/governance of human genetic databases/biobanks

39 Regulation of biomedical enhancement technologies (primarily pharmacological).
Pharmaceutical company efforts to boost drugs sales by increasing patient compliance with prescription drug regimens

40 influence of new genetic technologies on understandings of human diversity (and specifically how they are contributing to the molecular reinscription of race / the reification of race as a biology)
ethical, legal, and social issues associated with them

B. Who are your primary target audiences for these? Who do you most want to communicate to about your priority concerns?

1 Organizationally speaking, our primary target audience is educators and through them students. It would be advantageous to connect w/ scholars of this history and policy makers.

2 Consumers, public health providers, and policy makers.

3 - Gene patents: target audience is policymakers, Hill staffers; secondary targets are the general public
- Sytnethic biology: target audience is mostly civil society and social movements, secondary target is science and technology policymakers

4 general public, especially women

5 academics
law & policy

6 The public, academia, policy makers

7 Popular, activist and academic. I have been trying to increase my popular audience in the US (I'm based in the UK) and did a twenty-station radio "tour" in 2008, when my book Body Shopping came out.

8 scholars, professionals, policy makers

9 1. Governments and members of the public.
2. Medical professionals and scientists.

10 Regulators, journalists/members of the media, legislators, various stakeholder groups and NGOs

11 Other academics and students.

12 general public, legislative bodies

13 Parents, teachers from preschool to community college, career counselors, education policy-makers.

14 the greater academic community outside of my field of sociology
eventually, i'd like to write for the general public

15 I would like to reach the broadly progressive political audience, in part by framing the subjects from an egalitarian perspective.

16 policy makers, like-minded communities concerned about such matters and lay audiences

17 Scientists, academics, anyone involved in the technological project. I'd like to get the people who are so involved thinking about the profound questions raised by their work.

18 Scientists, Public Health Professionals and Policy Makers, Stake Holder Groups

19 students, fellow college instructors, local activists, local city government

20 ART stakeholders: fertility clinics, consumers of fertility services, children born as a result of ART, women's groups, Maori
Civil society
Minister of Health who is responsible for the Human Assisted Reproductive Technology Act which covers treatment and research using ART
Ministry of Health

21 the general public, scientists, policymakers, Ob-Gyns

22 Currently just focusing on academic audiences. Would want to reach more general audience.

23 Predominantly health professionals within the medical and public health community, including students, some general community outreach. Main thrusthas been to offer a public-health based critique of "biodefense" initiatives that have offensive capabilities, and various deleterious public health impacts. Desire to increase support for a stronger Biological Weapons Convention with adequate, strengthened verification/inspection protocols.

24 I see clinicians and policy makers as my primary audiences.

25 Other funders

26 legislators, parents, government regulators, and researchers

27 courts, politicians, the press.

28 students, academics, women, especially young women

29 clinicians, researchers and policy makers

30 Academics (Researchers) and health professionals

31 press

32 ministries of health
legislators
healthcare professionals
journalists

33 Doctors, politicians, patient groups, the general public sphere

34 Healthcare providers
Consumers of healthcare
Patients (and their families) who are recruited into clinical studies
Media
Health policy and regulatory bodies
Scientists

35 My topic is broad and the interests are catholic. But I especially want people to understand that the damage and perils of medical monopolies such as patents extend far beyond gene patents.

36 Active members of the member denominations of the Council.

37 academics; law and policy-makers

38 General community
Political leaders
Health professionals
Regulators
Consumer and advocacy groups

39 1. Enhancement regulation: legal scholars
2. Compliance programs: the public

40 - Other research scientists (geneticists) and biology teachers
- Journalists who cover these issues
- Members of the public (including members of Native American tribal groups)

C. What are the major challenges you experience in trying to communicate to these audiences?

1 The challenge is not so much about being able to reach educators, but rather the impact of external factors that can limit the amount of time they can devote to professional development or teaching of this history.

2 - The uncertainty of the scientific data on the risk and benefits of the use of genetic technologies in
clinical practice

3 - Issues are complex
- Very difficult to overcome messaging of the biotech industry

4 varies - one issue is that our critique of SCNT is also voiced by the religious right, and this can cause problems

5 stylistic and editorial constraints of publishing in law reviews

6 Conflicts of interest, resistance from mass media, varying education levels, lack of venues

7 Sensationalism, particularly with Body Shopping--but even more, the assumption that anyone who's at all critical of biomedicine must be a religious fanatic.

8 framing the message appropriately

9 1. Hype about genetics which oversells the benefits (for both crime and health)
2. Vested interests

10 Maintaining a proactive rather than reactive media message and campaign. Connecting the dots between seemingly isolated stakeholders as well as seemingly unconnected series of events also proves to be difficult in the mainstream media. Lastly, combating the myths perpetuated by the business industry and a sympathetic media posse can be a major challenge.

11 Not sounding anti-genetics yet commenting on exaggerated claims.

12 narrow focus of the issues, understanding of the science involved

13 Distilling complex biopscyhosocial concepts into soundbites that can compete with the opposing camp that preaches biological determinism and "hardwiring."

14 as a postdoctoral fellow, i have few resources to organize interdisciplinary conversations between scientists, critics, and the greater public

15 Attracting editors! It is possible that editors who are reluctant to publish pieces on these issues from the CGS (and related) perspective do know their audience, but I suspect that the gatekeepers tend to be more accepting of technology and less critical of it than the public in general.

16 lack of concern or shared perspectives

17 People who are scientifically literate tend to scoff at any ideas that do not seem expressed solely in the language of science.

18 Missing awareness, conceptual language and framing narratives between different cultures and disciplines.

19

20 Preparing Discussion Documents concerning particular ART issues that are clear and readily understood yet accurate.
Preparing advice to the Minister of Health to whom I report that are readily understood by him given that he has no detailed knowledge of this area. We spend much time at this point because once I met with him and he said he was having great trouble with our advice on PGD and he pleaded for more simply written documents.

21 contacts

22 Convincing people that it is dangerous to target pharmaceuticals to groups based on the idea that they are somehow genetically different.

23 Virtually complete ignorance of the issues and import; in the case of the medical and public health community, dificult to convey that so-called "defensive" measures may in fact be counterproductive to public health.

24 I have not experienced major challenges.

25 Lack of responsiveness

26 getting them to listen

27 an overwhelming fear of crime and the idea that anything that might make us safer is good, regardless of actual evidence that it works.

28 pressures of academia

29 we are concerned about health consequences from preconception and prenatal exposures to environmental chemicals and other stressors - one challenge is not attributing "personhood" to a fetus - and related issues of language, law and policy; another challenge is not putting the burden of prevention on the shoulders of pregnant women; while there are steps individuals can take to prevent harm, for the most part, policy is what is needed to prevent these exposures. Exposures like air and water pollution and in the workplace are generally not avoidable on an individual level - but individuals (pregnant women) tend to be looked at as the responsible party.

30 Because my targeted audience so far has been folk in the academia, the challenges are more related to academic work such as insufficient number of interdisciplinary journals and conferences, etc.

31 reducing complexity is difficult

32 current love of all things "market" oriented

33 That is a very detailled question. Cannot give a simple answer.

34 Thus far, I have utilized academic dissemination channels, e.g., peer-review journal articles, conference presentations. Last year, I submitted a proposal to sponsor a regional community forum on genetics which was ultimatly not funded. As I am still in the process of conducting research in this area, I have not explored all opportunities for communication, so I have not confronted challenges, yet.

35 Most people see patents on medicines, processes and tissues as arcane issues and not as immediate threats to health and autonomy. Additionally, industry has promulgated its exculpatory messages very efficiently and countering them is not easy.

36 Trying to address issues of genetic technologies for those at the education level of a high school graduate.

37 General complications with publishing in law reviews--topics not perceived as traditional and valuable, lag time between acceptance and publication

38 The need for intelligent use of human genetic information, and for sensitive regulation in the public interest, which allows sound research and clinical practice to go ahead while providing sufficient assurance to the community that there is policy and practice in place to ensure that the social, ethical and legal implications are understood and dealt with effectively.

39

40 preconceptions about race and racial difference
lack of knowledge about genetics

D. What process do you or your organization use to develop messages for communicating with these audiences?

1 Large outreach efforts are managed by the central office and individual outreach to teachers for workshops or seminars are managed from the local offices of which there are eight nationally and three internationally.

2 - Mailing list
- Educational and training webinars
- Some social media

4 no one process- we usually work in collaboration with other groups.

5 The law school and the university have media offices.

6 We are developing public health and safety and human rights narratives to counter prevailing narratives which are inaccurate and often abusive. We use blogs and video and conferences.

7 I rely on the presentation skills for radio and television which I was coached in as an academic for the UK Open University, which uses non-print media extensively. I also write regular articles for Project Syndicate, which appear in about 100 newspapers around the world. I started life as a journalist, so those skills are important too.

8 I simply submit articles to relevant publications

9 1. Direct communication via our website, briefings to politicians (UK and EU)
2. Press work (UK jouranlists, national and specialist press)

10 Each message must be tailored to a specific issue and specific audience. Some relate to jobs or equality and social justice and others relate to the rights of the commons and public welfare.

11 I publish books and articles; The Council for Responsible Genetics publishes a popular magazine "GeneWatch."

12 academic setting allows for colloquia and public symposiums

13 None at present. I give a lot of talks to such groups, and like to think I've honed my message through feedback from these sessions, but I've never led a focus group or anything like that.

14 we have lecture and film series that draw an interdisciplinary crowd at my academic institution
the STS department i belong to also uses facebook and twitter

15 Internal discussion, mostly informal

16 most of the communiucation is through e-mail or online articles

17 Blogging, publishing, all with a mind towards respecting and dealing with scientific facts.

18 Key group participation & interaction, problem-oriented approaches, emphasis on shared concerns, pragmatic framework (thin ethical theory)

20 In New Zealand every piece of advice to the Minister of Health must be preceded by a public consultation. Written submissions are sought and for some topics meetings with stakeholders, Maori or the general public are held.

21 None

23 Mostly powerpoint presentations on the subject, as well as writing articles.

24 I publish research in journals read by my intended audiences.

25 Collaboration with CGS

26 none thus far

27 filing lawsuits, talking with the press, writing articles,

28 websites, community briefs

29 we work closely with our allies in women's health and reproductive rights/justice;

31 none

32 providing stories about the lives of the people affected by organ trafficking

33 Skilled writing. Serving media requests promptly.

34 As an academic institution, in addition to utilizing the dissemination methods targeting academic peers, we also have available our university-sponsored publications, press releases. Individual investigators or divisions separately may develop dissemination strategies or products targeting policy and lay audiences, e.g., town halls, briefs, in-service training, etc.

35 I write and speak.

36 We update members by posting progress reports on the Canadian Council of Churches website and through reports to the Governing Board of the CCC.

37 N/A

38 We work with in-house journalists, using them to translate our research and policy work for the media and the internet (including our own website).

39 1. Legal scholars: draft academic articles
2. The public: I'm currently developing a pitch for a piece in a news mag

3, 19, 22, 30, 40 — no response offered

E. Roughly, how many times a year do you send out a press release?

1 During the school year monthly, though not always about content related to these issues. In addition to monthly outreach for workshop we send out e-updates every two months or so and then start outreach for summer seminars starting around the 1st of April.

2 N/A

3 8

4 2

5 n/a

6 Me...none. The groups I work with...maybe 4 per year.

7 None

8

9 About ten.

10 Roughly two dozen a year.

11 Personally, no times.

12 I do not do so personally

13 Zero, but an organization I'm affiliated with does so a few times per year.

14 n/a

15 Personally, none. CGS, not as often as they used to, I believe.

16 In my new role I have not sent any press releases

17 None

18 6 times

19 once

20 Whenever we launch a new Discussion Document or promulgate new Guidelines or release a decision on a potential new procedure (eg the use of in vitro maturation) , we issue a press release. Last year there would have been two or three.

21

22 N/A

23 None on this, not a priority issue for PSR or APHA, organizations within this work has been presented.

24

25 never

26

27 varies -- maybe 10 on all topics, 2 or 3 relating to DNA

28

29 my program sends out a press release a few times a year; we expect to increase that as we increase our capacity - this has been very successful when we have had the time to do it

30 I never did

31 none

32 about monthly

33 Once

34 Never

35 N/A

36 We have not sent out a press release as yet.

37 almost never

38 Now that I'm back in a university, maybe 6-10 times per year. In the previous decade, when I headed up a publicly-funded legal and policy think tank, the number was much larger (perhaps treble).

39 never

40 0–1

F. Roughly, how many times a year do you talk with a reporter?

1 Not that frequently, maybe once or twice a year. The national office is in more frequent conversation w/ reporters and handles more challenging communication or communication w/ larger organizational implications.

2 N/A

3 20

4 50-60

5 4-Mar

6 Twice

7 Twenty

8 2

9 About 100.

10 At least once or twice a week.

11 Between 12-20 times a year.

12 none

13 30

14 last year, i spoke with two reporters

15 Rarely. Maybe twice.

16 4-5 time a year

17 Rarely

18 6 times

19 We try not to talk to them. We've given a few interviews and don't enjoy the experience. Reporters don't seem to care to get the info straight, they're more concerned with nailing an angle.

20 Once or twice

21 2

22 N/A

23 5-10. Not on this issue, but more often on core issues of PSR: nuclear weapons and power, climate change, environmental pollution issues. This year in the wake of Fukushima disaster have had much more media contact:reporter calls/interviews, many radio interviews throughout the country.

24 3

25 never

26 varies sometimes every 2 months sometimes twice a year

27 50-100 -- maybe 20 on DNA issues.

28 1

29 our program director speaks regularly with the press - I do occasional (<2 times/year) radio interviews

30 I never did

31 10

32 several times per month

33 20

34 Once or twice

35 30

36 I have not talked to a reporter in over 10 years.

37 10-May

38 Quite often - probably 20–30 or more interviews per year for print, radio or screen, but also at least 20 "background briefings" per year.

39 once this year; generally, never

40 5+

G. Roughly, how many times a year do you publish an on-line or print op-ed or article (not including blog posts)?

1 Not very often, as it’s less central to my job description and daily tasks.

2 N/A

3 2

4 3-Feb

5 2-Jan

6 zero to one.

7 Six

8

9 About ten.

10 Rarely (as an individual)

11 2-3 times a year

12 once or twice

13 once per year

14 n/a

15 Not enough. Once or twice.

16 I have not done so in the past three years

17 Five

18 4 times

19 Half a dozen or so. It varies.

20 We do not do that

21 1

22 N/A

23 1-2 on the average although this year have contributed to 3 chapters (co-authored 1) plus an article (climate change) just about to be published in American Family Physician.

24

25 every 5 years

26 never

27 5, including our website.

28

29 we have not prepared op-eds (but likely should!)

30 I never did

31 1

32 once or twice

33 2

34 I have submitted academic articles primarily.

35 3-Feb

36 I publish article once or twice per year, the most recent being an article on Canadian gene patenting published with fellow members of the Reference Group.

37 once

38 10–12 (but not all of them focus on genetics, law and society)

39 just starting, but twice this year

40 1 (not including peer-reviewed scientific articles)

H. Do you or your organization have a blog?

1 We don’t have a blog, but are increasingly making use of social media w/ Facebook leading the charge. Additionally, we offer RSS feeds, E-Updates, and community News for non-educators, parents and community members.

2 No

3 Yes

4 yes

5 Yes, the law school has one.

6 Yes

7 No

8 no

9 No.

10 Yes, my organization does.

11 CRG has a blog

12 no

13 yes, but I rarely update my personal blog

14 i have a personal website

15 CGS does, and I am a regular contributor.

16 No

17 Yes

18 yes, just emerging

19 No

20 No

21 no

22 N/A

23 PSR (National) and SF-Bay Area chapter of PSR each have blogs.

24 no

25 no

26 no

27 yes -- organization does.

28 no

29 we have a column in a hyper-local electronic newspaper - Mission Local - called "The Clinic"

30 No, I don't

31 no

32 no

33 no

34 Yes, the institution does.

35 No

36 No.

37 N/A

38 No. (My previous organisation did contain a number of blogs/discussion boards.)

39 my organization does: http://blogs.law.stanford.edu/lawandbiosciences/

40 No.

I. If you have a blog, how often do you post to it? On the average, how many unique viewers access your blog each week?

1

2 N/A

3 NA - my organization has a blog but I do not post on it

4 Our DAILY BLOG has 16,000 - 17,000 users per month, who view about 25,000 pages per month.

5

6 I post whenever I find something interesting...Maybe every other day. I do not know how many visitors I get per week.

7

8 na

9

10 Weekly

11 N/A

12 no

13 rarely; I don't have any idea about numbers of viewers

14 n/a

15 Weekly, on average. CGS has the reader figures.

16 Not applicable

17 Post once a week or so. Fifty to a hundred unique viewers weekly.

18 ---

19

20

21

22

23 Rarely post to organizational blogs; have no idea how many access, would need to check with our SF chapter staff.

24

25

26

27 rarely.

28

29 we post weekly (but are currently in arrears due to staffing vacations, etc) - I am not sure of how many unique viewers each week - have heard about 2,000

30

31

32

33

34 I have not yet.

35 NA

36 We don't have a blog on this project

37

38 N/A

39 I won't know until I start up in August

40

J. Roughly, how many times a year do you appear on local or national television or radio?

1 0-1

2 Zero

3 4

4 8-10 (used to be much more)

5 once every two or three years

6 Rarely

7 Six

8 1

9 About ten (mostly UK national).

10 Never personally

11 1-2 times

12 none

13 4-Mar

14 n/a

15 Not for a while.

16 2-3 times

17 None

18 3-4 times

19 We have done it and we might again but, typically, we don't.

20 Once or twice. These are usually in response to a particular issue highlighted by the media or because there is discussion of an issue on which we have released a Discussion Document containing draft guidelines.

21

22 N/A

23 2-3 on the average; this year close to 20 (all radio this year).

24

25 never

26 never

27 10

28

29 zero

30 I never did

31 2

32

33 3

34 Never

35 35-40

36 Not for over 10 years.

37 from time to time

38 I average 100+ appearances per annum when I headed the Australian Law Reform Commission. Now, as a research and teaching law professor, the figure is more like 20–30 times pa.

39 Once in the past year

40 0–1

K. What other modes of communication do you use to get your messages across, other than those just mentioned?

1 Because of the nature of my work, most of my communication is directly with teachers, primarily through email and the same holds true for my colleagues. Once or twice a year each office holds a Community Conversation, which are forums we use to engage with the general public and for general outreach purposes. In most cases these feature authors, scholars and in some cases film makers.

2 #NAME?

3 Listserves, twitter, facebook

4 participation on various committees that evaluate the current status of a women's health issue (often research-oriented); newsletters; public speaking (50-60 engagements a yr)

5 I (an academic) work with organizations that focus on similar issues.

6

7 My own website, with its frequently asked questions feature

8 conferences presentations and guest lectures

9 Presentations to public meetings, political committees, scientific meetings, conferences etc.

10 Twitter, facebook, etc.

11 The classroom

12 none

13 Occasional Twitter tweet

14 i have a professional facebook page

15 I did write a book, and did some (not enough) publicity around that, including a few personal appearances.

16 no other

17 Print long-form journalism

18 Direct mailing, personal visits

19 Public speaking, college presentations, small local meetings, publications, website, internet, periodic newsletter.

20 Website

21 academic articles

22

23 That's abbout it.

24 Publishing research, giving talks at conferences, giving presentations at grand rounds, etc.

25 presenting at funder meetings

26 writing academic articles and speaking at academic conferences

27

28 teaching

29 our web site (under development); presentations at scientific meetings; meetings with key decision makers in clinical and policy arenas; written materials for patients and clinicians

30 Peer reviewed Journals, Conferences and collaborative work

31

32

33 conferences, seminars, lectures in the university

34

35 Magazine articles, books, and lectures.

36 No other modes at present.

37 law reviews and journals

38 Social media (especially Facebook; the Australian Law Reform Commission also uses Twitter). Blogs and online discussion forums, such as The Drum (operated by the Australian Broadcasting Corporation) and The Conversation (operated by Melbourne University).

39

40 public lectures; classroom teaching; professional development workshops for local high school teachers

L. What capabilities would you like to develop to enable you to communicate to target audiences more effectively?

1

2 Writing press releases and consumer articles

3 Better media lists, better issue framing

4 Increase funding capacity to work with more staff and interns on our various issues

5

6 Need to find people with varied expertise in running and maintaining an orgazinization. Need IT specialists and media specialists. Need organizing specialists.

7 More contacts with US media, especially because I have two new books forthcoming

8 nothing particularly comes to mind

9 More time and capacity!

10 Identifying sympathetic media sources and oulets. How to get work published in the absence of a dedicated media team or PR company.

11 N/A

12

13 Public use of Facebook.

14 i'd like to have more contacts in the press and begin contributing to periodicals such as the new yorker, nation, harpers, etc.

15 Better hooks, better framing, better tone (I'm guessing)

16 how to communicate complex issues without dumbing the message i.e.oversimplifying it

17

18 cultural literacy, science literacy, risk literacy

19

20 Communication in this area is often difficult because of the background knowledge of the general public. I have raised with the various Ministers of Health to whom I have reported during the last 6 years the fact that the legislation has not given my committee or any other group the function of education and hence resourced that activity. All such activities need upfront resources.

21 Methods of getting an op-ed published and being identified by the press

22 Not sure.

23 Not sure-major problem for me is time as I still work fulltime as a physician, and all the above is within the rest of my "volunteer" existence.

24

25 I will listen carefully for possibilities at Tarrytown.

26 ways to turn my academic articles into press releases and short fact sheets for the media and regulators

27

28 I really have not thought about this. networking and working with others with similar concerns seems to be an important first step.

29 time, skill and capacity - we recently engaged professional communication experts to develop a strategy for us and are in the process of implementing it so we are at the cusp of increasing our foray into this arena

30

31 Tips for more effectively getting the big picture through.

32

33 Finding the right symbols, images, comparisons, and narratives. Doing "soundbites".

34 I would like to find ways of using popular media and methods to bring both positive and concerning advances in genetics/genomics into the public eye. I would also like to consider how to expand and design engaging and accessible public and professional education to address scientific, social, cultural, ethical issues related to the advances in health and healthcare since the mapping of the human genome.

35 More efficient public speaking.

36 Once the curriculum is completed, we would like to make its availability known through journals, church newletters, and websites.

37 op-ed writing for major papers, including good contacts at the papers

38 Maybe how to use blogging more effectively — especially how to locate the relevant/target audiences

39 I'd like to develop connections in the news magazine world, particularly among editors.

40

M. What questions do you have about effective communications that you would like to have addressed?

2 How to understand target audience needs and their prefered communication channels?

4 Would like to keep better updated on the effective use of social media to disseminate advocacy messages.

8 none

10 How can we as a movement frame complex interconnected issues in a way that is both easily digestable and easily translatable for the written press and 7-second sound bite?

11 N/A

13 How to find the time to tweet, blog, etc!!

15 How to achieve better hooks, better framing, better tone!

16 how to use the new media such as social networking or twitter for messaging around particular issue

18 How to advance serious, sober language in science reporting that avoids hype, panic and reductionism & that can convey a sincere message about what science can and cannot do and how this relates to other human capabilities?

20 Methods will vary depending on who is the target audience. Tailoring the message for the audience is very important.

23 None at the moment, reflective of my lack of time to really think about this.

25 I will listen carefully for possibilities at Tarrytown.

26 how to get your point across using different media outlets

28 I am reluctant to talk with reporters. I would like to hear approaches to do so.

29 I think the era of sound bite-size messages is inconsistent or at least troubling considering the complexity of the issues at hand --- we aim towards/are engaged in communicating critical thinking about complex scientific and ethical issues - the general modes of communication tend to favor short and simple --- I see the import of that but many of our issues are not simple and need to be chewed on and reflected upon; also the idea of privacy has been eroded culturally (although perhaps there is a limit as indicated by current events in re Murdoch in the UK at the moment) --- this too is a very big challenge I think because the threshold for what people are willing to share about themselves publicly seems to generally be quite low --- so our concerns about privacy in general may not be intuitive to the public anymore.

31 I'd like to understand how journalists work; what they can quote, what they have to check, etc. I'm afraid I'll be misquoted

33 How to create a well-informed and critically-reflective publis sphere?

34 Identify most effective communication mode and message to reach selected audiences
How to deconstruct complicated scientific and/or ethical/legal issues to be clear and meaningful to targeted audiences
How to engage genomic/genetic science community in this discourse without it seeming threatening.

35 NA

36 None at present, given that we do not have a commercial product available at this time.

37 possibilities for co-authoring op-eds; legislative connections

38 Always useful to disucss how to convey complex, nuanced issues (whether science or social policy) in a manner that is accessible to a general audience but is not overly simplistic.

1, 3, 5, 6, 7, 9, 12, 14, 17, 19, 21, 22, 24, 27, 30, 32, 39 & 40 — no response