

Panel Discussion: Ethics

Rinke van den Brinke (RB), Anna Wagstaff (AW), Diana Garrisi (DG) (Chair – Alan Taman (AT))

[AW] [On reporting of nano-technology cancer drugs] We're a group of journalists and we are responsible. At the end of the day we are responsible. But I appreciate the question, because where did this come from, the 'Holy Grail' [of cancer drug treatment]? Yes, I guess it came from academic clinicians. Had I had time I probably talk about that because it is a very important part of it. They call it a holy grail because the idea is a good one. This is the first use of nano-technology, these little 'stealth bomber/Robo-things'. It's an old drug attached to a new targeted drug. Basically, when you've had your Herceptin and you're no longer responding to that they use Herceptin to keep going to the bits it's no longer stopping but they attach something to it and it's meant to take the chemotherapy direct to the cancer cells and therefore you can have a lot more chemotherapy going exactly to where it's needed without poisoning the rest of you.

That's the theory. It's a fantastic theory, and maybe one day it will work really well. But like so much of science, just at the moment it's not. You can see people are really having quite a tough time with it. It's not either delivering a cure or anything that is remotely devoid of side effects. 'Holy grail' – of course, they didn't make it up. It came from an academic clinician. What do you do with these things? I don't know. A few months ago I was doing some media training with some clinicians. One of the things we went over was the reality of progress in cancer treatment is of incremental benefit. There just aren't these breakthroughs – show me the breakthroughs.

We decided to do some interviews of this and asked them what they would like to be interviewed on. We had one on immunotherapy. He stood there and said 'This is it! This is the answer! We've really cracked it this time!' But it's just not true. He knows it's not true. He would never say that to his patients. But he will say it to the press. Very often, they think the science will lead there in the end. The chances are it actually won't lead there in the end. But it certainly hasn't led there now, and they like to blame us. It is them a lot of the time. But we're journalists, and what we write to have to be responsible for and we can quote them but we also have to quote how many times that's been said in the last 50 years.

[Unattributed] There's a very good article in *Cancer World*, some time ago, where you did a very detailed analysis in Germany the trials that had been run there, the claims that had been made about it, it was very sophisticated and authoritative article about why you would want to question some of the claims about the benefits of the drug. But there's no way that anybody sitting in a newsroom could do anything like that. Essentially journalists are the handmaidens of the academic community and they ring up and ask 'what's the truth on this Professor X?' and Professor X tells them and that's what they print. To ask them to go up against Professor X is unrealistic and the very people who have tried get into a lot of trouble.

[Matthew Hill, BBC] The day I saw the press release about that drug it was from Roche. It didn't really make clear the benefits. BBC Radio Bristol were covering the local consultant behind the drug trial, so I said look do you realise this is very marginal. He did admit to that. That's the sort of thing

which as health correspondent I see as being there to try to make sure we do get things right and in context but it doesn't always happen.

[RB] You can do something against the 'holy grail'-like stories. When I started in health journalism I had a very bad experience with a professor explaining to me a wonderful breakthrough in cancer which worked right away. I was enthusiastic about this story. We broke it, and we got lots of phone calls because there we didn't alert the public that this would take some years to be a success. So he was very unprudent and so was I. Lesson learned. We did a thing on immunotherapy last Thursday I think. Eight patients reacting wonderfully and I explicitly asked him to explain that eight patients is nothing but promising research that might give results and might not. And he did. So you can ask them,

I always tell them the story I just told you and how the phone rang and there were patients believing they were cured, and safe from cancer. When you explain that, most of the time the doctors are very rational individuals who accept the lesson I have learned and share with them, and are very careful in the way they express. So you have to ask them, alert them, and that helps.

[Eleanor Lisney] Disability and health are very closely linked. For a lot of disabled people, things like euthanasia is a very touchy topic, because it also links with doctors. In the UK it's not like in the Netherlands or in Belgium. But there have been loads of motions put through to the House of Commons of allowing assisted suicides. The reporting there is that if you are disabled most doctors will be doing you a favour because they are helping you to die. A lot of disabled people say they don't want to die. A lot of the time even their relatives are not given the choice. To quote a case, the Baroness Jane Campbell. She was terrified because they thought that they would just give her notice not to resuscitate. Her husband had to rush home and get all her certificates to show that she was actually and active member of the community because they were frightened that they were going to switch off the machine. I think that goes back to what Anna was saying about dignity in dying.

We talk a lot about dignity in dying but people don't talk about support in dignity in life, so when you are a journalist the focus is on sensationalism. Journalists have told me that; they've said 'who wants to read about how a person wants to live?'

If your family think you are a burden to them it seems obligatory to say that yes euthanasia would be a better way but they are not given the choice of saying that what if we have the right support? You might then consider life. Most disabled people would say that if you have the experience for over a year, you might change your mind but death is final.

In the case of journalists, you do have to have the responsibility of also giving a voice to disabled people who say that they want to live. If you are a disabled person most people would say 'I couldn't live like you. You would need this and this. I couldn't imagine a life like yours. I would want to die'. But actually most disabled people live a very happy life. Why would people say that? It's because they cannot imagine what life would be if weren't what you are. It takes time, and a lot of people who become disabled take at least 3 years to reconcile the loss.

[RB] This euthanasia law in the Netherlands is in effect quite simple. A person who wants to die with dignity when his life is at an end has to explicitly formulate the demand for it while his mind is clear and not one doctor but two doctors should agree on it that there is no more normal life possible. He is ending his life and it's just a way to help him do it quicker. If you sign a euthanasia declaration now and tried to use it in say 20 years I would have to repeat my demand and repeat the explanations of why I am demanding it. You can't say to a disabled person 'I'm going to end your life because it's not worth living'. A disabled person can ask for his life to be ended when it's without perspective in his own opinion so it's not a 'legal murder'.

[EL] I understand that. I'm just saying that it's the way journalists report it. For example recently a mother killed three of her children because they had a condition called SMA. You should read the press on that. The sympathy was with the mother. If these children were not disabled nobody would say 'the poor mother' because it was murder. There was a South African politician who tweeted how brave and courageous this mother was for euthanasing her children. You would never say that for children who were not disabled. You don't euthanize children. You euthanize maybe your pet. This is murder. It's the way journalists try to balance it.

[RB] I agree with you.

[Richenda Power] I am a person with an invisible disability in that I have an old brain injury. I would like to draw together links with what Eleanor has just said, which is about consciousness raising amongst writers. With other stereotypical agendas like antenatal screening that doesn't even let children with Down's syndrome be born, with the senselessness value of elderly people which is how so much elder abuse goes unreported and undealt with. You've touched on such an important issue that is vital to all our training.

[C. Velayutham, India] For the past 5 years, particularly in India, there is a trend where all the health journalists focus more on reporting medical negligence. There are a lot of articles and follow-ups and in India they took a note of it and decided to do an investigation on it. They found out that there is a lot of expectation from the health journalist and the victim to get more compensation from the hospitals. So this is one plan which has been going on in India for at least the past 5 years and I think these ethical issues have to be handled very effectively in any press council or in the media in India. This is really a problem where you cannot identify the victim, because they tend to take the victim's side. They never take the side of the hospital. So they have a nexus where the victim, the family and the journalist ask for huge compensation from the hospitals. They tend to get it, including the journalist.

[Shaun Lintern] We have talked about ethics in lots of different ways. Given that we all write about the medical Royal Colleges and things like that and we have a National Union of Journalists, but I wonder in a similar way to the medical or nursing professions whether it would be a good idea to have a 'Royal College of Journalism' that can call the industry out when it does something wrong. So for example a Royal College could say a story is absolutely rubbish, as the way to hold ourselves to a higher standard. Which a union isn't necessarily there for as a trade union but a Royal College stands on a higher plane.

[AT] There are considerations of power and authority there of course. Ethics are great and we've all got an individual conscience. But for ethics to work as a profession, as a group, it's got to be somehow supported collectively. So you can reach a decision on your own morals, anyone can do that, and you can reach your ethical decision as a journalist but unless you've got the support of your organisation or someone with as much power backing you to support that ethical decision to persuade someone not to do something, then really it's a waste of time. Personal courage isn't enough and neither is personal conviction so maybe that is one idea that could work.

[Unattributed 2] Researchers do sometimes to hype things up. I always try to ensure any limitations are included, eg saying their study has found this but is hasn't found this. It's trying to get that balance in taking your interest in telling this story but also keeping it in proportion. How do you make that balance in telling the story and say that you should also consider this, that if you are going to tell people this there is another side that you should know? You're then making the researcher aware as well, that unless they have actually found something in a study you are not going to say it.

[Roy Lilley] Look at the Leveson Inquiry. Press can't agree their response to that, they are fighting like ferrets in a sack. That's not going to work. No one wants a licentious press but a free press is very important and they should be free to get it wrong. We're sitting here piously thinking everything's going to be reported and balanced and correct – grow up. People buy the newspapers that most reflects them and their lives. If people want to buy the *Daily Mail* and stuff their heads with crap there's plenty of alternatives. It's a free press and a free country and I am appalled that journalists are sitting here trying to find reasons not to be free. You're barmy!

[AT] As I said, there are important considerations of power!

[John Matthews] One of the recommendations of the NUJ made to the Leveson Inquiry was that NUJ members and others get fed up with stories appearing in newspapers with their name on it which is nothing to do with what they wanted to say but has been changed and come up with different information and it's not what the journalist wanted to put. The NUJ at Leveson was saying that journalists should have the right to insist that their name is removed from that story so it's clear they didn't write that, it was not the journalist. Leveson agreed with that and put that down. The problem has been, as with a lot of the Leveson Inquiry, is getting newspaper owners and others to do it. They're the ones that are not doing it. The NUJ has pushed for that and got Leveson to support it.