

What is responsible cancer research?

New possibilities in cancer treatment mean better health, but also involve a risk of increased costs and more dilemmas in setting priorities. A critical discussion of the future projections made by the cancer research community may encourage more responsible research and health policies. The framework for responsible research and innovation provides useful concepts for such a discussion.

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The framework for Responsible Research and Innovation (RRI) is a cross-cutting principle for the EU's Horizon 2020 research programme (1). The Research Council of Norway has published the first version of a Norwegian RRI framework. The Research Council defines responsibility as meaning that «the processes in the research and innovation system shall increasingly be characterised as anticipatory, reflexive, inclusive and dynamic/flexible» (2, 3). It might be tempting to dismiss such characteristics as empty buzzwords. We believe, however, that the RRI framework provides useful concepts for understanding how good decision-making processes can be established in future cancer treatment.

Responsible cancer research should combine biomedical research activities with critical analysis of the same research. At the Centre for Cancer Biomarkers (CCBIO), a cancer research centre affiliated to the University of Bergen, we have chosen to integrate analyses based on the humanities and social sciences into the general scientific activity (4). What this might imply in practice we will outline in the following, with reference to the characteristics defined in the Research Council's framework.

Anticipatory and reflexive – the importance of sociotechnical imaginaries

RRI thinking links responsibility to the willingness and ability to imagine and reflect critically on possible social consequences of one's own research results. This is based on an insight derived from philosophy of science that the American Society of Clinical Oncology (ASCO) affirmed in its vision statement *Shaping the Future of Oncology: Envisioning Cancer Care in 2030* (5): «By anticipating the future, we

can shape it.» In order to make choices, we need notions of the future. In sectors where the forefront of research is rapidly moving, sociotechnical imaginaries play a key role, because the existing evidence base can be expected to become quickly outdated (6).

Sociotechnical imaginaries are defined as collective visions about the good technology and well-functioning society of the future. They postulate society's future needs and challenges as they appear to those who promote these visions, how these can be addressed technologically and the kind of scientific development that will be required to produce the necessary technology. Such ideas may influence not only political decisions, but also big and small choices in the research areas themselves. Research is not a blind walk towards truth. The choices of research foci also influence the direction in which knowledge and technology develop. Those who have the power to formulate sociotechnical imaginaries therefore wield power in society. We will return to this issue below.

Moreover, sociotechnical imaginaries are partly descriptive and partly normative, and always uncertain. When researchers and the institutions that fund research formulate their visions, they engage in what is essentially a creative exercise that not so much predicts the future as helps shape it. Such visions are often characterised by optimism. Those who are directly engaged in the field are at risk of an overly optimistic bias that causes them to overestimate the usefulness of their own research. When the RRI literature calls for reflexivity, it alludes not least to the need for self-critical reflection on our own optimism.

ASCO's vision statement (5) is an example of exaggerated optimism. In their future scenario for personalised cancer therapy in 2030, the linkage between research and treatment is closer and more immediate, and this will change a number of roles in the health services. Specialists in oncology will increasingly act as supervisors that provide quality assurance for treatment interventions that can be delegated to other health personnel. The patients will be better informed and more

involved in their own diagnostics and treatment. The requirements for quality will rise even further.

This American vision statement identifies some challenges and problems, primarily a rising cost level combined with increasing uncertainty associated with the business models of the pharmaceutical industry. The document also envisages that a system based on a more active and well-informed patient role may give rise to new forms of inequality, since not all patients are motivated or have the personal resources required to assume such a role. However, these challenges are not discussed in any detail. Instead, it is presumed that increased resources will become available for cancer treatment. It is also presumed that cancer treatment will become precision medicine to an extent that adverse effects will diminish, and that the costs of treatment will not necessarily increase significantly.

This is a familiar motif in sociotechnical imaginaries created by the researchers and innovators themselves. They identify possible advances and problems, ending up with a generally positive vision by anticipating the advances while failing to anticipate the problems. This imparts a bias towards technological optimism and diverts attention from the increasing complexity and cost level involved in technological systems.

Responsible cancer research in the RRI sense involves taking this optimistic bias seriously and teaching the researchers how to exercise self-criticism. In practical terms, this can be implemented in a number of ways (7). At the Centre for Cancer Biomarkers we have chosen to introduce critical perspectives from science and technology studies, philosophy of science and ethics in our research seminars, in addition to training younger researchers through dedicated PhD courses.

Inclusive – the relationship to the public

The choice of sociotechnical imaginaries may have considerable political and scientific influence. Helping ensure that these



Illustration: Ørjan Jensen/Superpop

notions are realistic, fair and sustainable is therefore an important social responsibility.

Cancer is associated with especially strong cultural and political notions (8). The media have a number of standard narratives about cancer, but very few of them appear to be useful when it comes to understanding the complex associations between disease, science and economics. One such narrative is the technologically optimistic one, which portrays research findings as revolutionary and as the advance that will solve the cancer puzzle. Another narrative is the scandal-mongering one, which describes individual patients who have been denied costly treatment and portrays the authorities in a negative light. An interview with representatives of the pharmaceutical industry is frequently included, presenting them as the adversary of the authorities and the patients' friend.

Brekke and Sirnes (9) describes the emergence of a new type of identity in the Western world, referring to it as «the hypersomatic individual» – the human whose identity fully and completely consists in its existence as a mortal body, but who refuses to accept this fate. The hypersomatic individual believes that science is potentially omnipotent, and that disease and death are avoidable. These people therefore hold the authorities publicly accountable for their

disease and death, since they have failed to provide medical science with sufficient latitude and resources. Brekke and Sirnes highlight an increasing alienation from disease and death. The medical communities need to ask themselves whether they inadvertently contribute to this trend, and the question of how we can establish an informed public debate about the cancer therapies of the future remains unanswered.

However, the public encompasses far more than media and individuals. A number of public documents provide guidance for Norwegian cancer policy, not least the national cancer strategy for the period 2013–2017, *Sammen – mot kreft* [Together – against cancer] (10), the input to this strategy from the Directorate of Health (11) and the general report from the commission on health priorities (12). There are virtually no references to personalised medicine in these strategy documents.

The report *Persontilpasset medisin i helsetjenesten* [Personalised medicine in the health services] (13), on the other hand, provides examples of what will be required to even begin to imagine the scientific, technological, clinical and societal future. For example, it discusses trastuzumab and imatinib not only in light of opportunities for clinical advances. The report also points

to future capacity requirements in terms of infrastructure and guidance, the need for innovation in clinical research design, and not least to the effect of possible changes in the patients' perceptions of needs as a function of developments in other countries and commercial options on the Internet. The report should be applauded for speculating about such connections between scientific, technological and social development trends rather than ignoring them. It would have been even better to explore these hypothetical connections with the aid of philosophical analysis and science and technology studies.

Responsive – are there any roads from criticism to action?

What is described as «responsive» in the English original is referred to by the Research Council as «dynamic and flexible» (3). The efforts involved in imagining the future, practising self-criticism and including other stakeholders in the discussions should be more than just an intellectual exercise; it should give rise to more reflective choices in terms of health policy, in the implementation of technologies and even in the research process itself.

Translating this requirement into practice is an experiment in its own right. We can provide an example from our own experi-

ence. A vital topic for our centre is the relationship between academic research and industrial innovation. Our research focus is biomarkers. In simple terms, biomarkers are molecules or other measurable biological parameters that provide diagnostic, prognostic or predictive information, for example about therapeutic response. In drug-based cancer therapy, many patients draw little benefit, and sometimes even considerable risk or harm, from therapies that nevertheless provide benefits at the group level. Potentially, biomarkers can help pave the way for a future when therapies can be better targeted. Moreover, if a biomarker does not involve major diagnostic costs, it can help improve the therapy without raising costs to the same extent as new drugs.

This, so to speak, is the optimistic side of the coin. On the other hand, it is less easy to draw up a complete sociotechnical imaginary about biomarkers that also promises a viable business model for the pharmaceutical industry. It is a boon for patients to avoid taking drugs that are of no benefit to them, but from the industry's point of view the sales of each drug will decline. Biomarkers in combination with personalised medicine will result in small patient groups that will undergo the same treatment. The price per patient will therefore rise, and conflict with the limits that the authorities will fund through the public purse. In informal conversations with some industry stakeholders we have therefore seen a lukewarm attitude to biomarkers.

Moreover, there are major knowledge gaps, for example with regard to what makes a biomarker a good biomarker. Kern (14) points out that only one per cent of all biomarkers that are launched from biomedical research end up being applied clinically. As conscious and reflexive cancer researchers we therefore need to combine our belief in working for a future where there are more precise therapies that do not accelerate costs, with doubts regarding the realism and economic viability of this vision. This is a challenge, including in terms of motivational psychology. However, we believe that removal of the false security provided by exaggerated optimism about the potential in basic research will spur creative thinking.

Could other principles for payment of drug-based cancer therapies be envisaged (15)? Could we envisage a future when patents and profits play a lesser role, thus making biomarkers less of a concern for the industry's business models? Such questions are relevant for choices in clinical trials – for example whether the researchers primarily seek to test new drugs or whether they would rather attempt new combinations of known drugs. These are difficult considerations not only for individual researchers and research groups, but also for institutions that fund research when designing their programmes.

«Responsible cancer research» as defined by the RRI framework does not make a researcher's life easier, nor more productive, perhaps, when measured in the short term and according to conventional criteria. Nevertheless, given that the complexity in the relationship between science, technology and society has been recognised, the alternative appears problematic, both ethically and intellectually.

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The author has completed the ICMJE form and declares no conflicts of interest.

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Received 3 April 2016, first revision submitted 30 August 2016, accepted 22 December 2016. Editor: Lars Frich