Do-it-Yourself Healthcare Clinic. Credit: Waag Society

'Do It Yourself Biotechnology' (DIYBio) for open, inclusive, responsible Biotechnology

This policy brief assesses the potential and challenges of "Do-It-Yourself Biotechnology" (DIYBio) for the progression of open science and responsible research and innovation (RRI). It makes recommendations to the European Commission as to how it can integrate DIYBio into existing science funding mechanisms and regulatory directives, thereby maximising benefits for European stakeholders.

DIYBio activities are conducted in various private and public laboratories outside of traditional academic or corporate institutions and are therefore outside the scope of current policy. The full spectrum of DIYBio activities is also much broader than what is currently understood as Citizen Science.

The re-evaluation of funding mechanisms and regulations for DIYBio should:

- promote inclusiveness and openness in science,
- clarify ethical dilemmas,
- promote social and business innovation,
- transform education,
- enable public dialogue on responsible research in the field of biotechnology demonstrated by grassroots groups from civil society.

Understanding the Potential of DIYBio

Although the informal network of biotechnology enthusiasts labelled as DIYBio is frequently described as a collective movement with shared values and goals[i], there are significant differences between participating individuals and organizations. Often DIYBio is understood as citizens involved in biotechnology[ii], whereas DIYBio activities span open science activism[iii iv], art-sciencev, pre-competitive business incubation[vi], (speculative) design[vii], hobbyism[viii], science communication and more[ix]. In an attempt to capture this diversity, roundtables were held (Göbel et al., forthcoming[x], European Citizen Science Forum[xi]) and a video series on DIYBio was published[xii] in anticipation of this policy brief. These activities highlighted four dimensions of DIYBio that will be addressed here because of their potential value and relevance to policy making.

1) Potential for Inclusivity and Openness in Science

Practitioners of DIYBio, also known as biohackers or DIYBiologists, aim to ultimately make biotechnology accessible to anyone. This rapidly growing culture of inclusivity, which emerged in the United States in the early 2000s, challenges more conventional academic and industry structures, by promoting complete access to scientific resources such as instruments, laboratories and publications.

The aim for a more inclusive and transparent science is also a key component of the Responsible Research and Innovation[xiii] and Open Science[xiv] policy agendas promoted by the European Commission. As a community built around these values from its inception, the DIYBio movement can be a valuable model for academia as it undergoes a transition to a more open practice. Case Study 1 (below) describes how the DIYBio space "BioTehna" operationalised openness and inclusiveness.

The full use of the potential of DIYBio spaces is currently limited due to insufficient financial resources. The informal nature of the DIYBio movement, which is vital to its innovative capacity and agility, are unfit for many funding mechanisms. The lack of funding often results in DIYBiologists working during their free time and with their own resources[xv]. In an attempt to resolve this issue many DIYBio community labs already have relationships with local research universities and academics, for example allowing them to recycle equipment that is retired from institutions[xvi].

Recent discussions of DIY science by established international academies have suggested a central role in assessment and support of DIY research for the Global Young Academy [xvii]. Such connections could bring support for DIYBio through funding opportunities, access to facilities, equipment and training. However they are critically discussed within DIYBio communities for their tendency to institutionalisation and neglecting the grassroots character of the movement.

2) Potential for Ethics

The DIYBio movement has developed an alternative practice-based ethics, which complements the ethics procedures within traditional academia. This approach could enrich the discussions of the Ethics dimensions of the RRI and Open Science agendas as they develop. The ethical discussion about the regulation of the revolutionary gene-editing CRISPR-Cas9 technology is a case in point. Todd Kuiken, senior program associate and principal investigator of the Wilson Center's Synthetic Biology Project in Washington DC, explains this in Nature. He describes how the academic community could "learn from DIY biologists", who have adopted a responsible and proactive attitude towards the regulation of this technology, instead of the "post hoc scrambling that often occurs within the scientific establishment". The DIY biologist approach seems well suited at producing a robust public dialogue, resulting in safe and responsible research[xviii], for three reasons:

DIYBio practitioners explore ethical issues in a broader perspective, signal ethical issues earlier, and signal different issues. It is notable that the DIYBio community has been progressive in developing a Codes of Ethics to guide the activity of the movement[xix] and promote experimentation based on shared principles of transparency, safety, open and access[xx].

DIYBio projects have the ability to organise moral deliberation, indirectly and directly, and not just as a means to restore trust in science or communicate science. We connect here to Wynne (2006)[xxi] who makes the case against various deficit understandings of the public. Discussing ethics, parallel to other DIYBio efforts, is empowering in the sense that it enhances the collective and individual capacity to morally assess biotechnological developments and issues. For example the recent CRISPR Kitchen event[xxii] and the series described in Case Study 2 below.

DIYBio includes art-science practices, which are noteworthy for their examination of the ethical challenges of contemporary biotechnology research. The works of bioartists can signal potential complexities of new technology and challenge existing notions of living systems, by laying bare the politics of biology, and shedding light on dominant anthropocentric accounts in current research. They also increasingly bring these wider issues to a different audience, moving beyond the research context to confront biotechnology[xxiii]. Some initiatives explicitly aim to open up moral reflection and examine societal values, and should be valued for their ability to seek 'tangible encounters' with the many issues concerning developments in the field (Zwijnenberg, 2014). Projects such as Oestrofem (Marry 'Maggic' Tsang) involving reproductive hormones, DeepWoodsPCR (Paul Vanouse) exposing the historical context of discovery, and Mutate-or-die (Adam Zaretsky) or CTCAG (Špela Petrič) questioning genetics are just some of the artistic works that involve DIYBio methods and help further societal understanding of biotechnological futures. Case Study 1 (below) describes how a DIYBio space is supporting such work.

3) Potential for Innovation

The transdisciplinary nature of DIYBio often results in new methods of applied problem-solving that reflect co-production of knowledge and technologies[xxiv]. Projects such as Epidemium[xxv], where members of the DIYBio space 'La Paillasse' worked with Hoffmann-la-Roche on cancer research, demonstrate that grassroots organizations can productively interface with corporations. Other examples of innovation already resulting in market-value originating from DIYBio activities are the emergence of companies offering hardware for DIY experiments[xxvi] and DIY educational kits[xxvii]. Case Study 3 (below) on "Open Insulin" describes another grassroots initiative with an even higher level of ambition aimed at developing affordable drugs for diabetes.

The EU Responsible Research and Innovation approach encourages actors in the research and innovation ecosystem to adopt large-scale institutional change to result in a more responsible, ethical and socially beneficial practice by engaging societal actors throughout their research process[xxviii]. This new emphasis may open up a platform for contribution by DIYBio practitioners through collaborations. In particular DIYBio projects could complement academic research projects that focus on excellence, with a more frugal and direct approach towards a contribution to societal needs[xxix xxx], such as defined in the UN Sustainable Development Goals[xxxi].

As the DIYBio community started as a counter culture to academic science, it might hold the key to accelerate culture change in such institutions, by leading the way through open access, open source and inclusiveness towards innovation.

4) Potential for Education: project and practice based learning

Numerous DIYBio initiatives focus on education[xxxii xxxiii xxxiv xxxv xxxvi] and some community labs are established with the explicit goal of public engagement[xxxvii]. The open sharing of methods and skills through online platforms ensures course materials are widely disseminated and accessible to the education sector as well as self-motivated learners. Some DIYBio organisations even offer dedicated programmes to train teachers and educators in DIYBio methodology and equipment building. While some initiatives take place in the confinement of a classroom and school system, many take an open-ended, self-organized approach. Typically, DIYBio education programmes are project based and offer explicit room for improvisation and experimentation outside of the pre-set instructions and predetermined endpoints. This topic will be explored further in a future DITOs policy brief.

Considerations when adjusting funding Mechanisms and Regulation

This policy brief describes that DIYBio, often perceived as

merely life science done by citizens, is much more than low-cost gathering and processing of data and also goes beyond mere education and public engagement. As shown above, DIYBio offers many examples and interesting proposals for implementing the principles of RRI and Open Science. Also, although a very young field, practices are not at a purely conceptual and experimental stage anymore, but vibrant groups, projects or start-up companies have been established. The movement now needs additional support from the European Commission to grow deeper and wider through the availability of more funding and adjustment of particular regulations. In particular, the Science with and for Society (SwafS) program seems a suitable source.

The current system is inadequate because in funding mechanisms based on cooperation between grassroots communities and research institutions, structural tension arise from different needs and working conditions of paid and unpaid contributors to science and their different form of organization. For example, EU funding schemes usually do not permit a cooperative framing of research questions before a given citizen science project starts. Furthermore, funding structures such as H2020 and Creative Europe are unfit for small community projects. In addition, indicators for quality of research as well as eligibility criteria that focus on excellence favour established institutions over a collective of individual DIYBiologists. CSA projects such as KIICS, SPARKS and SYNENERGENE have presented methodologies to partly resolve this. A more dedicated funding call for the strengthening of informal DIY networks would be a logical next step.

While not able to outweigh such structural barriers to DIYBio in particular, and bottom-up citizen science in general, intermediary organisations and community labs, such as Waag Society, La Paillasse, BiologiGaragen or Hackuarium, fulfil an important support function for DIY communities. Beyond access to equipment and biological material, they act as catalysts for joint projects, offer space for meetings and deliberation, provide training, in some cases funding support and personnel resources, and can work as brokers to mediate between stakeholders and DIY community members. Creating a special funding mechanism focussed on such intermediary organisations could provide a partial solution.

A different recurring subject in interviews with DIYBio practitioners is their experience with restrictive legislation on biotechnology, especially in regards to genetic engineering. As signalled in EU evaluations, there are significant differences[xxx-viii] [xxxix] in the national implementation of Directive 2009/41/EC[xl] regulating the contained use of genetically modified micro-organisms. However, these evaluations are mostly performed top-down, not taking the notion of grassroots biotechnologists into account. For example in Germany, permits are only awarded to academically qualified individuals[xli], while in The Netherlands permits are awarded to legal entities. Some DIYBio practitioners have indicated that the scope of their projects is limited due to these regulations and have called for the resolution of the heterogeneous distribution of regulations across Europe.

Recommendations

Based on the points discussed above, the following recommendations are made:

1. Recognition of complementary roles for DIYBio and traditional academia in the scientific endeavour through dedicated indicators. Funding schemes adapted to enable access by community stakeholders or even dedicated support.
2. Increase the level of understanding of DIYBio by providing networking opportunities among key players, including different Citizen Science and DIY Science communities as well as stakeholders.
3. Inclusion of DIYBio methods in Responsible Research and Innovation approaches to bring the public in close encounter with biotechnology.
4. Include DIYBio practitioners and non-institutional actors in the evaluation of biotechnology regulations across Europe and permit application processes for DIYBio.

How to Cite

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Colophon

This policy brief was facilitated by the lead authors (Waag Society) through open interaction and discussion with the European DIYbio community, which is partly documented as a vlogging series known as #OPENBIOTECH on YouTube. While this was carried out as part of H2020 'Doing It Together Science' (DITOs) Coordination and Support Action project, the views expressed in this policy brief do not reflect the consensus opinion of DITOs partners.

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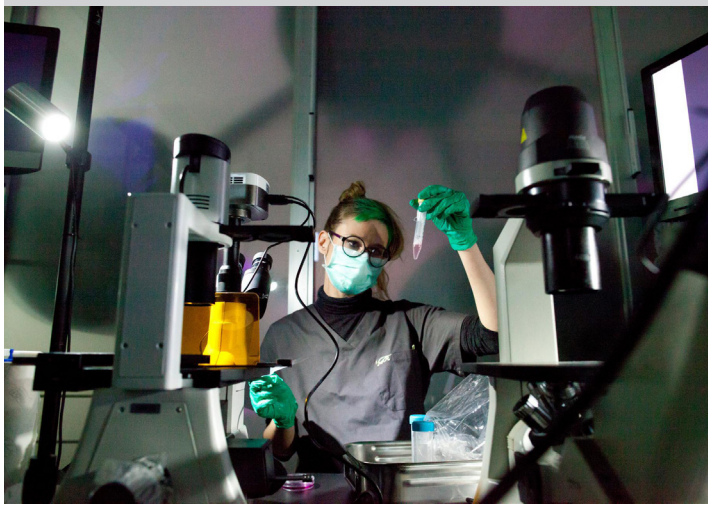
Case studies

Case Study 1: Art+Science at Kersnikova Institution, Ljubljana

At Kersnikova, DIYBio is practiced at the BioTehna. The lab was incepted with the help of Hackteria in 2012 and has been upgraded many times until its present shape. The lab offers space, equipment, materials, and experts as a supportive environment to artists and art projects produced by Kapelica Gallery - another department at KI that focuses on production of hybrid (bio)art projects. In so-called 'incubation' processes, artists are put in contact with (DIYBio) scientists and experts that help implement the art project by offering assistance with complex scientific protocols outside institutional frameworks - mostly because access to physical spaces and high-end equipment inside mainstream scientific & research institutions are off-limits to 'general public' - in this case, artists. The nature of contemporary hybrid (bio)art projects is the implementation of biotechnological processes and protocols in the artwork itself, which can lead to specific demands regarding the equipment and knowledge needed, but it may also provoke reflections of values and ethical restrictions.

The most notable examples would be hybrid art projects by artists Špela Petrič (a former biology phd scientist turned (bio)artist) and Maja Smrekar (a fine-art artist turned (bio)artist) who utilized the knowledge and expertise of DIYBio individuals, the equipment and materials provided by BioTehna in the development stages of their project.

Špela Petrič developed the Strange Encounters phase of her "Confronting Vegetal Otherness". The DIYBio part of the project was focussed on facilitating in-vitro confrontations of human bladder carcinoma cells and Chlorella algae cells and custom-designing smaller and larger incubators where the cells will grow.

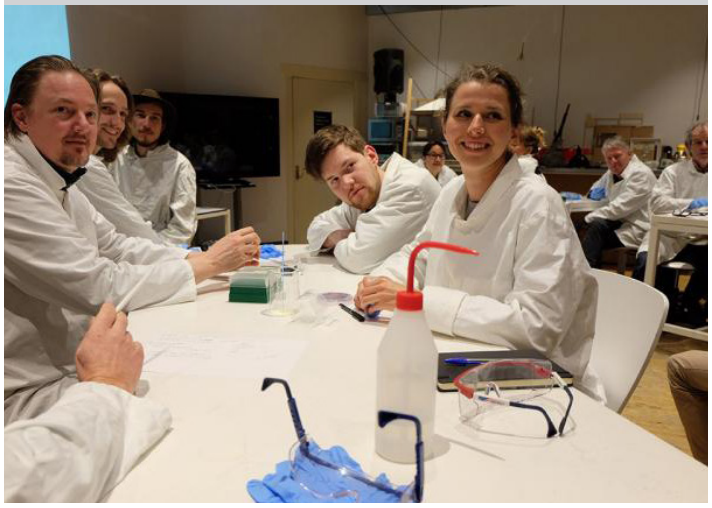


Špela Petrič developed the Strange Encounters. BioTehna also facilitated various phases of Maja Smrekar's "K-9_topology" project. One of the phases (Ecce Cannis) was to investigate the coevolution of humans and wolves, and investigating metabolic pathway processes that trigger emotional motif which connects two species: humans and dogs to successfully coexist together. The other phase (ARTE_mis) was focusing more on biotechnological potential of fusing the artist's molecular material with the domesticated dog.

Case Study 2: Het Praktikum

In order to facilitate a meaningful discussion about scientific and technological discoveries, Waag Society organised 'Het Praktikum' - a series of themed evening discussions and practicals during which the participants unravel the complex threads of cutting-edge technology and decide where they stand on the issues. The first two evenings in the series focussed on CRISPR DNA editing technology. During the first evening participants played a statement game in which the questions and answers revolved around the positive or negative effects of CRISPR technology on society. One question was, for example, "once it becomes possible to get an early diagnosis for certain genetic diseases, how will this affect how we define sickness and health?" The six possible responses to this question were defended by the participants at each table. When the evening came to an end they formulated what they would want CRISPR to achieve under ideal circumstances.

During the second evening, the participants revisited to their ideals, but this time a practical demonstration took centre stage. They unboxed the CRISPR kiti and got to work. Surprisingly, no-one decided to finish the experiment and subsequent discussion examined how and why this consensus was reached.

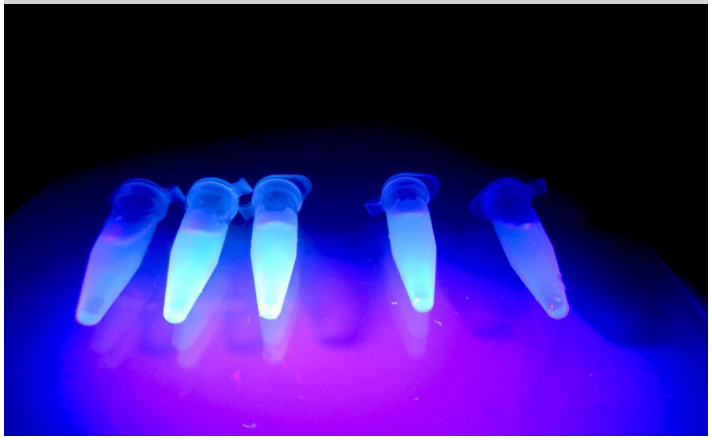


Participants of Het Praktikum ready for performing CRISPR DNA editing

Case Study 3: Open Insulin

The global insulin market is dominated by just a few companies, a quasi-monopoly resulting in high prices for patients. In order to make insulin more affordable, and thus accessible, biohackers are attempting to develop a generic drug. Ryan Bethencourt, a biohacker, entrepreneur, and co-founder of IndieBio, a biotech accelerator program in San Francisco, explained the broader goal of the Open Insulin project: "demonstrate that we can achieve usable levels of purity in a DIY setting, and to document how we do and share the knowledge". Together with a computer hacker, Anthony Di Franco, they pushed the project until, in 2015, Counter Culture Labs, a "Community Lab for biohacking and citizen sci-

ence" in Oakland, California, successfully launched a crowd-funding campaign (for $16,000) and began exploring new ways to produce insulin by genetically engineering bacteria. The project received a wide media coverage, focusing on the innovative potential of DIYBio, but also drawing attention to the broader problem of drug access for disadvantaged communities and to DIYBio as a potential solution to the crisis of drug innovation. Critics, on the other hand, have pointed out that the real difficulty lies not in the production of small quantities of insulin, but in the cost of the clinical trials and of getting approval by regulatory agencies. Whether or not the Open Insulin project will ultimately succeed in offering ways for patients to produce insulin, as simple as "brewing beer at home", it will have stimulated a critical discussion among laypeople and experts alike about the current challenges of drug innovation.



Eppendorfs containing recombinant bacteria expressing green fluorescent protein and proinsulin at Counter Culture Labs, Oakland, California, March 2017. Credit: Gabriela Sanchez.