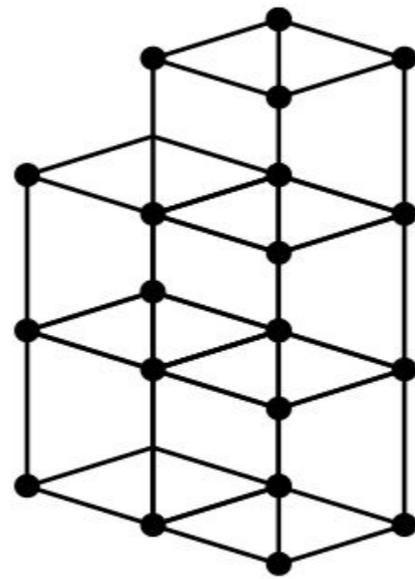
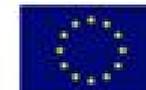


# DITOs EU citizen science project | Horizon 2020



**doing it  
together  
science**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 709443





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# CRI PARIS

is leading  
**Work Package 1** on

## ***Biodesign***



# OBJECTIVE

*To engage  
citizens,  
scientists  
& policy makers*

in shaping and  
conducting  
research in **Biodesign**



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# HOW?

1- By promoting

*collaborative  
practices*

between **biologists,  
designers, artists,  
engineers,  
scientific facilitators  
and scientists  
in Biodesign**



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# HOW?

**2- By making**

***new models of  
research***

**more tangible  
by introducing  
public debates  
and social uses of  
science in the  
laboratories**



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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<sup>i</sup>, there are significant differences between participating individuals and organizations. Often DIYBio is understood as citizens involved in biotechnology<sup>ii</sup>, whereas DIYBio activities span open science activism<sup>iii</sup>, art-science<sup>iv</sup>, pre-competitive business incubation<sup>v</sup>, (speculative) design<sup>vi</sup>, hobbyism<sup>vii</sup>, science communication and more<sup>x</sup>. In an attempt to capture this diversity, roundtables were held (Göbel et al., forthcoming<sup>x</sup>, European Citizen Science Forum<sup>xi</sup>) and a video series on DIYBio was published<sup>xii</sup> 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<sup>xiii</sup> and Open Science<sup>xiv</sup> 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<sup>xv</sup>. 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<sup>xvi</sup>.

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<sup>xvii</sup>. 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.

# DIY Bio Policy Brief

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



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# VOICES OF CITIZEN SCIENCE & DIY BIO



Voices of Citizen Science  
and DIY Bio - Thierry



Voices of Citizen Science  
and DIY Bio - Luc Henry -



Voices of Citizen Science  
and DIY Bio - Emma van der



Voice of Citizen Science  
and DIY Bio - Pablo



Voice of Citizen Science  
and DIY Bio - Paolo



Caroline Bonnefoy  
Inspection Académie



Voice of Citizen Science  
and DIY Bio - Cissi Askwall -



Voice of Citizen Science  
and DIY Bio - Eleonore



Voices of Citizen Science  
and DIY Bio - RRachel



Voices of Citizen Science  
and DIY Bio - Rémi



Voice of Citizen Science  
and DIY Bio - Henk Mulder -



Voice of Citizen Science  
and DIY Bio - Jacqueline



Voice of Citizen Science  
and DIY Bio - Jenny Molloy -



Voice of Citizen Science  
and DIY Bio - Rachel Aronoff



Voice of Citizen Science  
and DIY Bio - Simona

The 'Voices of Citizen Science & DIY Bio' YouTube videos are available here: <http://bit.ly/2xgbkSI>



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# CITIZEN SCIENCE



# DIY BIO





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**2) Practice-based research**  
The practice-based research approach would enrich the research process and the development of 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<sup>xviii</sup>, 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<sup>xix</sup> and promote experimentation based on shared principles of transparency, safety, open and access<sup>xx</sup>.

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)<sup>xxi</sup> 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<sup>xxii</sup> 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<sup>xxiii</sup>. 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 'Maggie' 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<sup>xxiv</sup>. Projects such as Epidemium<sup>xxv</sup>, where members of the DIYBio space 'La Pailasse' 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<sup>xxvi</sup> and DIY educational kits<sup>xxvii</sup>. 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<sup>xxviii</sup>. 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<sup>xxix,xxx</sup>, such as defined in the UN Sustainable Development Goals<sup>xxxi</sup>.

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<sup>xxxii,xxxiii,xxxiv,xxxv,xxxvi</sup> and some community labs are established with the explicit goal of public engagement<sup>xxxvii</sup>. 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

# DIY Bio Policy Brief

**DITOs consortium, (2017). 'Do It Yourself Biotechnology' (DIYBio) for open, inclusive, responsible Biotechnology. DITOs policy brief 2.**



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

1. Promote **inclusiveness** and **openness** in science
2. **Clarify ethical dilemmas**
3. Promote **social and business innovation**
4. Transform **education**
5. Enable **public dialogue on responsible research** in the field of biotechnology demonstrated by grassroots groups from civil society.



## Recommendations:

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.