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# From Citizen Science to Do It Yourself Science

## An annotated account of an on-going movement


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Abstract

This report offers a selection of projects that account for an emerging movement that is not what often is described as *citizen science* but what we designate here by *do it yourself science.* The report accounts for private or community based initiatives that use scientific methods combined with other forms of enquiry to engage with techno-scientific issues and societal challenges. The first section of the report focuses on what is usually described as *citizen science* where in most cases projects are led by institutions, such as universities or other research institutions, which organise, call or promote different forms of citizen involvement in their endeavours. The second part of the report looks into developments in what is designated as *do it yourself science*. It outlines developments in this deeper form of engagement of citizenry with techno-science, where the DIY scientist appears as someone who tinkers, hacks, fixes, recreates and assembles objects and systems in creative and unexpected directions, usually using open-source tools and adhering to open paradigms to share knowledge and outputs with others. We also observe that although these movements link well with other changes of the scientific endeavour, such as open science, the 'do it yourself' movement takes us to another dimension of engagement, of greater agency and transformative power of research and innovation. We conclude that Irwin's imagination of a citizen science is gradually emerging, at the moment materialised in the on-going DIY science movement and others alike. The European Commission should seize such momentum as well.

# From Citizen Science to Do It Yourself Science[1]

*An annotated account of an on-going trend*

Susana Nascimento
Ângela Guimarães Pereira
Alessia Ghezzi

[1] The opinions expressed in this document are sole of the authors and can never be attributed to the European Commission.

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# Summary

This report has been prepared at request of DG RTD for the initiative on Science 2.0[2] and it was part of the background information for the Validation Workshop organised by DG RTD on Citizen Science held in Bucharest on 20th November 2014[3]. Besides a review of citizen science projects, this report offers a selection of initiatives that account for an emerging movement that is not what often is described as *citizen science* but what we designate here by *do it yourself science.* Hence, it traces a movement of co-existing initiatives where citizens get involved in science and technology producing knowledge in different fields traditionally dealt with by science. We start by looking at the meanings that *citizen science* has acquired throughout the practice in different fields and the development of information technologies, which we consider pivotal in the change of meanings and agency with which citizens engage with science and technology developments.

The first section of the report focuses on what is usually described as *citizen science* where in most cases projects are led by institutions, such as universities or other research institutions, which organise, call or promote different forms of citizen involvement in their endeavours. Through an extensive literature review of projects where citizens have been involved under what is called *citizen science* and *do it yourself science,* we give an account of authors' perspectives with regards to such experiences; yet, another type of analysis would be required instead to capture the experience of citizens.

The second part of the report looks into developments in what is designated as *do it yourself science*. It outlines developments in this deeper form of engagement of citizenry with techno-science, where the DIY scientist appears as someone who tinkers, hacks, fixes, recreates and assembles objects and systems in creative and unexpected directions, usually using open-source tools and adhering to open paradigms to share knowledge and outputs with others. The report accounts for private or community based initiatives that use scientific methods combined with other forms of enquiry to engage with techno-scientific issues and societal challenges.

This report does not give exact numbers about the development of these movements, as we have relied on what is indexed through different Internet search engines and we cannot ensure that we have not missed out some projects. Hence, the projects mentioned are illustrative or just emblematic of the fields where they have developed, or promoted by equally emblematic institutions, or because they are illustrative of different perspectives of citizen science and DIY science.

We also observe that although these movements link well with other changes of the scientific endeavour, such as open science, the 'do it yourself' movement takes us to another dimension of engagement, of greater agency and transformative power of research and innovation.

We conclude that Alain Irwin's imagination of a citizen science is gradually emerging, at the moment materialised in the on-going DIY science movement and others alike. The European Commission should seize such momentum as well.

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[2] http://scienceintransition.eu/validation-workshops/
[3] http://scienceintransition.eu/validation-workshops/workshop-20-11-14-bucharest/

## Introduction

Until the late 19th century, science was mainly in the hands of self-funded scientists who had other jobs and affiliations, dedicating voluntary time on scientific activities (Silvertown 2009; Hacklay 2013). Popular examples of this are Charles Darwin, who joined the Beagle voyage, not as a professional naturalist but as a companion to Captain FitzRoy (Silvertown *Op. cit.*), Anthoine Lavoisier who held a share in a financial company. In fact, at those times, most scientific endeavours were led by what became known as gentlemen scientists who engaged in collecting and classifying the natural environment or in technological inventions.

With the professionalization and institutionalisation of science since the 19th century, the actors and *loci* of the scientific endeavour have been progressively demarcated. As Hackley (2013) noticed "**citizen science can only exist in a world in which science is socially constructed as the preserve of professional scientists** in academic institutions and industry". That makes a clear distinction from Darwin, Lavoisier, Franklin, Volta, etc. who as independent citizen scientists had also the necessary agency to decide on their research questions and research process. As we shall see, what today is mostly called 'citizen science' encompasses very different degrees of agency with regards to the research process, very different relationships with the professional scientists and very different degrees of influence on policy relevant scientific projects where citizens contribute to as 'citizen scientists'.

On the other hand, the practice of citizen involvement in scientific projects as *citizen scientists* is not really new (Cohn 2008) in some fields, especially in environmental monitoring projects, including biodiversity[4]. For example, the National Audubon Society's[5] annual Christmas Bird Count, began in 1900. Nowadays more than 60 000 volunteers participate in that survey (Cohn 2008; Sullivan *et al.* 2009); the United Kingdom's Breeding Bird Survey[6] (Risely *et al.* 2008), and the United States Breeding Bird Survey[7] (Sauer *et al.* 2008) also engage tens of thousands of participants. Also during the 19th century, in the United States the records of rainfall and air temperature were done through volunteer observers that reported to the National Weather service (Firehock & West 1995), lighthouse keepers were collecting data about bird strikes in the 1880s, and a group of amateurs started the Astronomical Society of the Pacific in 1889; the National Weather Service Cooperative Observer Program began in 1890 (see Bonney *et al.* 2009). During the 1920's the Izaak Walton League of America (USA) surveyed water quality and pollution in US rivers through a group of volunteers. Those data were supplied to the Federal government and others and used for raising public awareness.

**Box 1.1. Love Canal** was a middle class neighborhood built on an old chemical site. After a while mothers started to claim that their children had health issues, which were later confirmed by MDs.
The experts (paid for by the company and the national officials) investigated and said that is implausible- more or less impossible. This was where housewife epidemiology developed. Instead of looking at things in the standard way, the mother began tracing and mapping the cases and could see that there was something going on in the areas. Experts said it was implausible because of their methods. What seemed to be implausible from technical epidemiology became obvious from anecdotal evidence. Much later, in January 1979, a EPA Administrator during those years, Eckardt Beck, wrote as follows in the EPA journal,
…Everywhere the air had a faint, choking smell. Children returned from play with burns on their hands and faces. And then there were the birth defects. The New York State Health Department is continuing an investigation into a disturbingly high rate of miscarriages, along with five birth-defect cases detected thus far in the area…
See. e.g. Levine 1982.

[4] We would like to point out that this report does not cover any other forms of public engagement in science and technology or any other forms of public engagement in environmental planning or policy making.
[5] See http: http://www.audubon.org/
[6] See http://www.bto.org/volunteer-surveys/bbs
[7] See http://www.mbr-pwrc.usgs.gov/bbs/bbs.html

During the 1990s in countries like for example, Canada, community-based ecosystem monitoring activities increased, probably due to the raising of environmental awareness and public knowledge about the anthropogenic impacts over nature (Whitelaw *et al.* 2003).

Another well-developed area of early forms of rather 'bottom-up' citizen science is in the fields of epidemiology, environmental health and community-based health research – see e.g. Corburn 2002, 2007; Brown 2003; and from a very recently published special issue with *Progress in Community Health Partnerships: Research, Education, and Action,* see Bryant *et al.* (2014) and Kondo *et al.* (2014) and others in that volume. On the other hand, the Love Canal story is emblematic of systematic research by non-specialists – see box 1.1 and a whole body of literature on *housewife epidemiology*. In the field of environmental health, people involved have been implementing the 'do it yourself' (DIY) science before today's 'DIY' hype.

What is new? One may ask.

One may capture the essence of what is new through Goodchild (2007)'s piece with the instructive title 'citizens as sensors'; as the author suggested, there were then more than 6 billions of human (networked) sensors. The Internet and in particular the advent of web 2.0, broadband communications, *smart* mobile computing, cheap electronics, miniaturisation of sensors, open source and crowd-source, social networks, satellite position systems (such as GPS), makes it possible for each of us to share our knowledge in collaborative distributed virtual "places". Moreover, in the later decade what is called the Internet of Things is adding a layer of possibilities and challenges for knowledge production, assessment and governance.

As we will see further, the number of studies and activities that engage citizenry as 'scientists' has been on the rise (Cohn 2008; Gouveia & Fonseca 2008; Catlin-Groves 2012; Morzy 2014) due to information technologies, engaging citizens in larger numbers. Despite the long tradition of citizen science, the rise of online communities and their contributions have the potential to greatly expand its scope and contributions (Lukyanenko *et al.* 2011). As Newman *et al.* (2012) suggested, the future of citizen science lies with emerging technologies such as smartphones and other mobile, web-enabled equipment.

In addition, the collectable data types (Cohn 2008) are much different from say 20 years ago, and the availability of large scientific data sets through the Internet has allowed citizen science projects to engage volunteers in new ways (Raddick *et al.* 2010), as well as to fields of research where such engagement was not possible beforehand (Morzy 2014). Information technologies have been also changing the geographical and temporal scope of many areas where citizen science is practiced – see e.g. Paulos *et al.* 2009.

Yet, we would argue that the 'do it yourself' movement sustained by and sustaining the 'Open everything' paradigm (see e.g. Steele 2014) has been, indeed, fuelling computer science and electronics, paving the way for the next steps for 'citizen science' and science for that matter. That is what we designate here as *do it yourself science*, in areas such as biology, environmental health, epidemiology etc. Because of their, by design *free format*, they naturally appear as trans-disciplinary projects engaging the sciences, the arts and the law.

This report starts with a review of meanings of citizen science over the past decades. It goes on illustrating this practice with emblematic projects collected both through the Internet and through literature review. It then takes the reader into what we see as the on-going development of the field, introducing and reviewing current practices of what we designate here as 'do it yourself science'.

# 1 Citizen Science

> "[citizen science] conveys both senses of the relationship between science and citizens (...) 'Citizen Science' evokes a science which assists the needs and concerns of citizens – as the apologists of science so often claim. At the same time, 'Citizen Science' implies a form of science developed and enacted by citizens themselves." (Irwin 1995, p ix)[8]

> "[citizen science]: another method of engaging the public in research is to involve individuals in actual scientific studies, either by providing opportunities for people to serve as research assistants or by enabling them to conduct their own original investigations" (Bonney 1996; 2004, p. 201)

It is interesting to see that both definitions were proposed in the middle of the 1990s being born within the environmental field, both emerging out of the recognition that relevant knowledge to deal with environmental issues cannot be produced by scientists alone. But, it is interesting to see that the proposed contemporary definitions come also from very different fields of practice. However, they are very different on what they assume and expect from citizen engagement in science. In fact, the second definition is implicitly grounded in the so called "deficit model"[9], i.e. it assumes that the lack of scientific literacy impairs one's ability to reason about issues where science is relevant and ultimately frame one's views against techno-science. The first definition emphasises, instead, that there are bodies of knowledge other than science that may be the relevant ones to address the societal issues of concern.

The report looks at projects that invoke one or both definitions indicating how citizen science projects have appropriated and extended these two foundational meanings.

> "With time, these **terms** have changed: amateur science, crowdsourced science, crowd science, networked science, volunteer monitoring, street science, digital science, grassroots supercomputing, volunteer computing, technology-mediated citizen science"

Although, not equivalent, other terms to designate "citizen science" are for example: *amateur science*, *crowdsourced*[10] *science*[11], *crowd science* (e.g. Aoki *et al.* 2008), *networked science*, *volunteer monitoring* (see Carr 2004; SciStarter; Franzoni & Sauermann 2014), *public participation in scientific research* (Haywood 2013), *street science* (Corburn 2002, 2005), citizen cyberscience (Aguado Sanchez *et al.* 2011) or digital citizen science (Hand 2010), grassroots supercomputing (Bohannon 2005), volunteer computing (Anderson *et al.* 2006), technology-mediated citizen science (Nov *et al.* 2011) citizen-science alliances[12] (Brown 2013), community based auditing (Tattersall 2010). Also, in Geography, Goodchild (2007) has coined the term *volunteered geographic information,* which designates an activity of citizens interested in mapping and geo-referencing citizens' neighbourhoods features. Based on their project

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[8] According to *google scholar*, this book has been cited more than 1100 times as we are finalising this report.

[9] See Wynne 2001.

[10] In other contexts, 'crowdsourcing' was described as cheap labour (Howe 2006).

[11] Kyba *et al.* 2013 suggest that citizen science projects are the scientific equivalent of crowdsourced projects like the Wikipedia and open street maps.

[12] This term appears in the context of epidemiology in Brown (2013), who states that *popular epidemiology* is a sub-set of citizen-science alliances. Whereas citizen-alliance is a more institutionalised approach, *popular epidemiology* refers to grassroots efforts begun by citizens, involving activities such as "lay mapping" i.e. maps of disease clusters made by residents (Brown 2013). In these processes laypeople often recruit scientists to help determine possible causes, sometimes through health studies or simply to seek regulatory or legal action or to organise politically (Brown *Op. cit.*). For more reflection in differences between ways of knowing about environment health issues, see Brown (1992).

Senses@Watch, which aimed at providing a platform for citizens to geo-reference situated environmental threats through sensory data, Gouveia *et al.* (2004) proposed what they described as *environmental collaborative monitoring* systems.

A number of **reviews** on citizen science have been produced in the last years (Bonney *et al.* 2009; Conrad & Hilchey 2011; Wiggins & Croston 2011; Catlin-Groves 2012; Roy *et al.* 2012; European Commission 2013; Seth *et al.* 2014). Most of these are actually linked to environment action and research. We do not wish to repeat those efforts, as they would be out-dated the day after the publication. Instead, our purpose is to account for the different guises and gazes of citizen's involvement in scientific projects and how the digital culture has been changing the process of engagement of citizens with the science and technology development.[13]

In Bonney *et al.* (2009) citizen science projects reviewed in their report were described under three headings: *contributory projects*, in which data collection is the primary task; *collaborative projects* where tasks include also analysis of the data and their dissemination as well as some degree of cooperation at the level of research process; and *co-created projects*, which are co-designed together by researchers and citizens.

The literature review and the Internet has prompted us to suggest that different typologies of citizen science projects and programmes can be framed on the following categories, based on:

1) the type of function citizens are asked to perform
2) the issue of concern
3) the geographical and temporal scale of the issues
4) whether there is an invitation to collaborate from the scientific community
5) the types of impacts expected for the scientific endeavour and for the invited community

In any case, all projects are institutionally led which make them distinct from those that are grassroots.

In this section we provide a selection of projects on what has been described as citizen science, focusing on the definition of what Bonney (1996) had described as "citizen science", i.e. scientist-driven public research projects. In the subsequent section we have investigated instead projects that are more akin with what Irwin (1995) described as citizen science, i.e. "a science, which assists the needs and concerns of citizens (…) [implying at the same time] a form of **science developed and enacted by citizens themselves**" (*Op. cit.* emphasis added*)*. This latter view recognises that others than scientists can legitimately ask the questions that need to be investigated in order to solve particular problems and also use scientific methods perhaps combined with other forms of enquiry and ways of knowing to address societal matters.

[13] What is reviewed in this part of the report is different from what is called for example, "indigenous knowledge" (Agrawal 2002; Leach & Fairhead 2002; Ban *et al.* 2008), "local knowledge" (Baines & Hviding 1993; Corburn 2002; Baird & Flaherty 2005) or other kindred descriptions. In some cases, however, we will see that the knowledge produced within these projects is akin with the concept of "extended facts" that Funtowicz & Ravetz (1992) developed when they proposed post-normal science. In these cases, we are also in the realm of what Irwin (1995) described as citizen science.

## 1.1 Mapping Meanings

### *Definitions*

The **definitions** that we found in the literature describe ***citizen science*** as being performed by *citizens scientists* or by the *public* (e.g. Bonney *et al.* 2009; Silvertown 2009; Sullivan *et al.* 2009; Raddick *et al.* 2010; Wiggins & Crowston 2011; SOCIENTIZE 2014) alluded to as *non-scientists* (Trumbull *et al.* 2000; Frescher & Friesike 2013), *non-experts* (Raddick *et al.* 2010; Frescher & Friesike 2013), *non professional scientists* (Oberhauser & Prysby 2008) or *trained observers* (Howard & Davis 2008; Sullivan *et al.* 2009), *amateurs* and *enthusiasts* (Silvertown 2009; Rowland 2012; Frescher & Friesike 2013; Hampton *et al.* 2013), *laypersons* (Brown 2013) that are *used* (Cohn 2008), *employed* (Morzy 2014) or (more typically) *participate voluntarily* in scientific research (SciStarter; Cohn 2008; Couvet *et al.* 2008; Silvertown 2009; Dickinson *et al.* 2010; Catlin-Groves 2012; Robson 2012; Roy *et al.* 2012; Morais *et al.* 2014; Radhakrishna *et al.* 2014; SOCIENTIZE 2014), working in an *open collaborative* fashion with professional scientists (Scientific American; Cohn 2008; Wiggins 2013; Franzoni 2014; SOCIENTIZE 2014) in scientific projects. These citizens do not have necessarily a formal science background (SciStarter), but in some cases need to develop some expertise to participate in the projects (Goodchild 2007) and give of their time (SciStarter).

"Citizen science is scientific practice, research and conservation tool, collective intelligence, complementary of professional research practice, performed by citizen scientists or by the public, described as: non-scientists, non-experts, non-professional scientists, trained observers, laypersons, amateurs, enthusiasts, not having formal science background, who collaborate, help, volunteer in scientific research projects."

Citizen science is described as a *scientific practice* (Newman *et al.* 2012; Cooper *et al.* 2014; Morzy 2014), scientific research performed in part or in whole by volunteers (Robson 2012) and as a research technique (Bonney *et al.* 2009b) or as research and *conservation tool* (Oberhauser & Pysby 2008). Today, the call for *collaboration* or for *help*[14] (Riesch & Potter 2013) is often made through institutional or purposeful built websites and through mobile devices: "filling the gaps' where people go but sensor infrastructure has not yet been installed" (Aoki *et al.* 2008). *Online citizen science* is also described as *collective intelligence* (Tinati *et al.* 2014). Cooper *et al.* (2007) describe citizen science as a "method of integrating public outreach and scientific data collection locally, regionally, and across large geographic scales", whilst Dickinson *et al.* (2010) see citizen science "as complementary to more localized, hypothesis-driven research". Conrad & Hilchey (2011) also made the distinction of activities that engage citizens with environmental monitoring or management according to the type of institution, distinguishing academic from non-governmental organisations; taking a Canadian example, Savan *et al.* (2003) noticed that academic institutions are resourceful to the extent that they can provide concrete space to launch collaborative community research projects.

"Use of eBird data in estimating potential dangers to shore breeding birds in the days immediately following the *Deepwater Horizon* oil well blowout in the Gulf of Mexico". (http://ebird.org/content/ebird/news/ebird-gulf-coast-oil-spill-bird-tracker). Hampton *et al.* 2013

[14] In the *Zooniverse* web site, the call for *help* is also accompanied with a *challenge*: "To understand how galaxies formed we need your help to classify them according to their shapes. If you're quick, you may even be the first person to see the galaxies you're asked to classify." (http://www.galaxyzoo.org/). Another example is EyeWire: "By joining EyeWire, you can help map the *connectome* (http://eyewire.org).

First, it should be clear that these definitions however place science as the legitimate source of knowledge and those who engage with these projects need to conform to scientific enquiry, ethos, norms and methods. Moreover, in the definitions of citizen science we encountered in most projects and literature, it is assumed that science is the most reliable way of knowledge production[15].

**Citizens** are described as being *enlisted* in scientific endeavours (Hochachka *et al.* 2011), *recruited* (Suomela 2014) or more typically, they are involved as *researchers* (Kruger & Shannon 2000; Conrad & Hilchey 2010; Roy *et al.* 2012), data collectors (Couvet *et al.* 2008; Bonney *et al.* 2009, 2009b; Silvertown 2009; Devictor *et al.* 2010; Zook *et al.* 2010; Roy *et al.* 2012; Radhakrishna *et al.* 2014; Reis *et al.* 2014) or *observers* providing experimental data (SOCIENTIZE 2014), as *data processors* via their own resources such as computer and mobile Internet devices resources or mobile phones (Aoki *et al.* 2008; Aguado Sanchez *et al.* 2011; Cochran *et al.* 2009; Hans 2010; Heinzelman & Waters 2010; Kawrykow *et al.* 2012; Robson 2012; Roy *et al.* 2012; Franzoni & Sauermann 2013; Morais *et al.* 2014; Reis *et al.* 2014; SOCIENTIZE 2014), *amassing knowledge* (Delaney *et al.* 2007), as *sensors* (Goodchild 2007; Aoki *et al.* 2008; Paulos *et al.* 2009), as an *army for conservation* (Oberhauser & Prysby 2008), as *communicators and disseminators*, as *amateurs* and *enthusiasts* (Rowland 2012). Citizen science has been recognised as a way to include stakeholders and the public in general in planning and management activities of local ecosystems (Pollock & Whitelaw 2005; Lynam *et al.* 2007), influencing policy making, raise new questions and co-create a new scientific culture (SOCIENTIZE 2014). Moreover, citizen science can help with understanding of processes that cannot rely on traditional field research because they are broader in scale or occurring on poorly accessible places, or simply because there needs to be critical mass for meaningful data collection (Dickinson *et al.* 2010; Lukyanenko *et al.* 2011), e.g. through crowdsourcing for community intelligence in health (Hesse *et al.* 2011).

"**Citizens** volunteer or are enlisted, recruited, employed, involved as researchers, data collectors, data processors, sensors, communicators, disseminators, stakeholders.."

One can say, probably without risking committing huge errors, that 'citizen science' as described by Bonney in 1996, has been strongly established through institutional led projects in the field of environmental monitoring and conservation; in other words, a field that humans can connect easily as it deals with the immediate visible and often tangible issues. But in many other scientific activities such as astronomy and epidemiology, where traditionally citizens have engaged with, very different reasons may ground citizens' involvement, very often not stemming from any type of invitation. But in the last decades the expression 'citizen science' has expanded to other areas and this is strongly related to the emergence of a digital culture that has been pervasively present across all sectors of our lives.

## *Fields*

The **fields** where the call for 'citizen science' is higher are mostly the ones where precisely data collection and/or their processing are resource and time consuming, or where skill in observation can be more important than expensive equipment (Silvertown 2009), such as ecology

"**Fields** such as astronomy, biodiversity and nature conservation, environmental monitoring, genetics, health and epidemiology, environmental health, archaeology, history, geographic information, seismology and other Earth sciences…"

[15] For example, on the web site of SciStarter, it is stated that "Science is our most reliable system of gaining new knowledge".

and biodiversity, natural history, biology, astronomy, genetics, epidemiology, history and archaeology, etc.

There is a strong prevalence of projects[16] in areas such as, space exploration (e.g. Williams 2001; Bohannson 2005; Anderson *et al.* 2006; Herr *et al.* 2006; Fortson *et al.* 2011; Kyba *et al.* 2013), nature conservation (e.g. Root 1988; Howard & Davies 2004, 2009; Evans *et al.* 2005; Pollock & Whitelaw 2005; Catlin-Groves 2012; EPA), biodiversity and environmental research and monitoring (e.g. Stokes *et al.* 1990; Bonney 1996; Fore *et al.* 2001; Gouveia *et al.* 2004; Cooper *et al.* 2007; Gouveia & Fonseca 2008; Bonney *et al.* 2009; Couvet *et al.* 2008; Howard & Davis 2004, 2008; Oberhauser & Prysby 2008; Devictor *et al.* 2010; Eurolifenet 2011; Dickinson & Bonney 2012; Hochachka *et al.* 2012; Jiguet *et al.* 2012; Roy *et al.* 2012; Thornton & Machiejewwski Scheer 2012; European Commission 2013; Riesch & Potter 2013; Isaac *et al.* 2014; Tulloch 2014; Reis *et al.* 2014), including the marine environment (e.g. Goffredo *et al.* 2004; Delaney *et al.* 2007; Thiel *et al.* 2014) or invasive species monitoring (e.g. Delaney *et al.* 2008; Crall 2010; Crall *et al.* 2010, 2011), seismology (Cochran *et al.* 2009), genetics (Khatib *et al.* 2011; Prainsack 2011; Franzoni & Sauermann 2013), epidemiology (Brown 1992, 2013), health (Au *et al.* 2000; Hesse *et al.* 2011), geographical and geo-referencing of data (Gouveia *et al.* 2004; Goodchild 2007; Hacklay 2013), urban planning (Corburn 2002, 2005; Paulos *et al.* 2009; Evans-Cowley 2012; Craglia & Gardell 2014). Conrad and Hilchey (2011) distinguish what, for example, in Britain is called biological monitoring (essentially collection of data about species) from North American community-based management which can also encompass monitoring efforts of ecosystem functions and environmental quality, where citizens are part of the management of natural resources and watersheds (see for e.g. Keough & Blahna 2006 and also Cooper *et al.* 2007). One can convincingly say that without the volunteer working done by the many participants of these projects, knowledge and action in the different fields would have been much less advanced let aside possible – see Bhattacharjee 2005; Bonney 2008. Jiguet *et al.* (2012) noted that collaborations between scientists and the communities also facilitate democratic participation in societal decisions concerning biodiversity conservation, whilst providing valuable insights into large scale ongoing declines of common species in the ordinary nature as Krebs *et al.* (1999) noted in their article called “second silent spring”.

Described as open movement (Shyamal 2007; Wiggins & Crowston 2011)[17], citizen science implies a broad network of people and a trans-disciplinary scenario (SOCIENTIZE 2014) reinforcing democratic ideals (SOCIENTIZE *Op. cit.*). But the ways in which it is often described may be seen instead to correspond to situations where it is instrumental to have unpaid help with otherwise extremely tiring, costly and resource intensive tasks. Citizen science programs offer scientists a way to gather data not obtainable by normal scientific methods (Howard & Davis 2008). However, it needs to be recognised that this movement has started with rather ethically praiseworthy intentions because it aimed at involving all in the protection of our common good. But today, the scientifically framed issues that citizens engage with are rather vast and that initial motivation does not always apply. For example, “crowdsourcing” in medical and genetics research is becoming a popular activity (see e.g. Prainsack 2011, 2014; Krantz & Berg 2013). One can say that it is gradually stepping out from discovery to realms of policy making, such as environment health, including epidemiology and food, including both local issues and grand societal challenges (Newman *et al.* 2012).

### *Side effects*

To citizen science some other **subsidiary functions** are attributed such as a way of communicating science and promoting scientific literacy (Evans *et al.* 2005; Bonney *et al.*

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[16] See next section.
[17] Described also as counterculture by McQuillan (2014).

2009b; Silvertown 2009; Catlin-Groves 2012; Gray *et al.* 2012; Riesch & Potter 2013; Morzy 2014), developing scientific thinking (Trumbull *et al.* 2000; Raddick *et al.* 2010; Tinati *et al.* 2014), environmental awareness and education (Brossard *et al.* 2005; Paulos *et al.* 2009; Catlin-Groves 2012; Newman *et al.* 2012; Roy *et al.* 2012; Radhakrishna *et al.* 2014), Earth stewardship or ownership of environmental matters or medical problems (Riesch & Potter 2013; Hampton *et al.* 2014), social provocation (Aoki *et al.* 2008), learning (Brossard *et al.* 2005; Bonney et al 2009; Raddick *et al.* 2010), as well as a process of dissemination of research results, increasing participants' knowledge about science and the scientific process (Brossar *et al.* 2005; Riesch & Potter 2013) or changing their behaviours toward science and the environment (Brossard *et al.* 2005; Reis *et al.* 2013, 2014), being even offered as possible cure for the deficit model – inherent to *public understanding of science* (Morzy 2014).

But, more importantly, as a process of citizen empowerment (Gouveia *et al.* 2004; Riesch & Potter 2013; Reis *et al.* 2013), development of a "sense of place" (Haywood 2013), capacity building, (Cooper *et al.* 2007), community empowerment (Newman *et al.* 2011). Sabel *et al.* (1999) noted how some of these volunteer activities influenced regulation and were actual vehicles of connection between the local and centralised institutions representing, therefore, a democratic commitment of communities wanting to protect their own environments. Another perspective from SOCIENTIZE (*Op. cit.*) is that citizen science is the answer for a much needed *new contract between science and society* in order to resolve pressing societal problems.

"**Resolving** the "deficit model": communicating science, literate, developing scientific thinking, changing behaviours, teaching science, scientific outreach Empowerment: democratisation of expertise, capacity building, community empowerment, sense of place and stewardship, social learning"

Another line of arguments sees a great deal of benefits for research projects, namely the amounts of unpaid labour of both citizen scientists and coordinators of projects (Franzoni & Sauermann 2013) or making scientists aware of local knowledge and expertise (Carolan 2006), the possibility of long-term projects compared to the usual short-term funding of projects, quite evident in ecosystem restoration projects (see Gross 2002; Bhattacharjee, 2005; Sullivan *et al.* 2009). Citizen science projects are also offered as alternative model to *teach* science in schools, for example by creating a dialog with experts and allowing access to the primary literature, and fostering the ability of the public to critique information and evidence (Gray *et al.* 2012) or proposing scientifically sound practices and measurable goals for public education (Couvet *et al.* 2008). But Gray *et al.* (*Op. cit.*) noted also that limited resources could compromise the call for teaching science in more democratic ways.

## *Motivations*

**Citizen involvement in the scientific endeavour** has been described as an experience worth having for example, Riesch & Potter (2013) describe it as "a win-win situation, where scientists *get help* from the public and the participants get a public engagement experience that involves them in real and meaningful scientific research" or because it kills two birds with one stone since it delivers public engagement as well as scientific

"Citizen-science projects are typically founded on the thinking that participants will willingly donate their resources, both time and money, to a project whose sole reward is the self-satisfaction inherent in doing something to benefit science. Project designs are based on the formation of a scientific question, and then participants collect data to help find the answer. But too often projects are developed with little or no consideration given to the things that interest participants, and ultimately little or no user incentive or reward is built into the process. Many projects struggle to engage participants, and it can be especially hard to sustain participation." Sullivan *et al.* 2009 research (see also Raddick *et al.* 2010). Morais *et al.* (2014) suggest that effort needs to be done to keep citizens interested on the project and science behind it as way to preserve collaboration. There are many sources of motivation (Raddick *et al.* 2010; Rotman *et al.* 2012; Jackson *et al.* 2014) which are also strongly linked to the field where citizens are engaged with, namely with regards to the tangibility of the scientific topics proposed to them and individual investment (Nov *et al.* 2011); the literature in motivations for online citizen science is scarce and this is probably an area that needs more enquiry (see e.g. Holohan & Garg 2005; Nov *et al.* 2011). Roy *et al.* (2012) described as salient motivations for citizen engagement with environmental citizen science projects "are enjoyment and the enthusiasm for the goals of the project", highlighting the importance of "aesthetic appreciation, wonder and connection to the natural world" as well as ownership of projects. Jackson *et al.* (2014) highlight the importance of discovery. Cowie *et al.* (2014) note the importance of having ethically sound engagement with the participants, suggesting that training, advice or guidance should be supplied whenever necessary while paying attention to unanticipated ethical issues, also because some participants frustration arises from poorly planned activities (see e.g. Trumbull *et al.* 2000; Scott *et al.* 2007; Newman *et al.* 2012; Sung *et al.* 2003) and a lack of resources to orientate newcomers in citizen science projects (Mugar *et al.* 2014).

The number of citizen science projects may be in great ascendance, and citizen science is acknowledged to be "advancing scientific knowledge" (Bonney *et al.* 2009), as well as seen as a way to add on science delivery efforts that interest e.g. national environmental agencies (see e.g. McKinley *et al.* 2012) or spatial research but Cooper *et al.* (2014) analysing several papers in the ornithology field, sustain that "the significance of citizen science to global research, an endeavour that is reliant on long-term information at large spatial scales, might be far greater than is readily perceived". In fact, many of the papers they analysed did not acknowledge the contributions of citizen scientists for the data collection practice**.** There are of course issues related to practice and understanding of citizen science described by Catlin-Groves (2012) that can contribute to this; for example, aspects of data quality which raise concerns among the scientific community (see also Galloway *et al.* 2006; Dickinson *et al.* 2010; Franzoni & Sauermann 2013; Fuccillo *et al.* 2014). Citizen science can be seen as a new model for data sharing, and so the challenges of using and sharing data collected through citizen science projects may not be different from other data-sharing challenges (Hampton *et al.* 2013) but, the move from traditional data collection methods to data mining available datasets, poses additional challenges. Franzoni & Sauermann (2013) noted e.g. that projects' outcomes are increasingly disclosed through blogs and projects' websites; therefore the research that relies on citizen science practice is not always submitted to scientific peer review channels. But because citizen scientists tend to make observations about areas they know well, data are likely to be very detailed (Lukyanenko *et al.* 2011).

## *Open Science and Citizen Science*

In the literature there is some discussion about the mapping of citizen science and Open Science. Whilst for some authors, such as Bonney (quoted in Cohn 2008, p. 193) "Citizen science is science 2.0", Lukyanenko *et al. 2011 and* Goldman (2014, p. 47), referring to crowdsourcing that involve the publics, citizen science is 'Science 2.0' – a term used interchangeably with Open Science – we concur with authors that have reserves with such straightforward mapping. Morzy (2014) argues that open science and citizen science are not the same thing but stem from the same phenomenon, the Internet. In fact, open science does not explicitly promote the involvement of non-scientists in the process, which is the cornerstone of the citizen science movement. Moreover, as Wiggins & Crowston (2011) suggest, citizen science is not necessarily open, as 'many citizen science projects share data, but may not make the full research process publicly viewable for comment and discussion'

(Wiggins & Crowston, *Op. cit*, p. 2). Fecher & Friesike (2013) described citizen science as one of five schools of thought for open science, the “public”, described as accessibility of non-experts to the research process.

## 1.2 Projects, Platforms and APPs – a selection

In this section we account for the many citizen projects that we have found by searching the Internet during October 2014[18]. We list here a number of projects that seem to us quite significant across a number of fields. In particular we found that most projects are in natural sciences, including biodiversity monitoring, landscape, natural resources, etc. In addition many projects not surprisingly are focused on space

We have highlighted many that we consider that ought to be mentioned when talking about citizen science, mostly because of their scale or because they are emblematic in the field they cover.

The types of functions that citizen scientists perform in these projects can be largely summarised as: Collectors, Resource providers such as Computer CPU, Analysts but hardly as those who frame the questions and decide on the methods to be used.

Table 1.1 summarises some projects that are on-going. The criteria for choosing these projects from the thousands that describe themselves as citizen science projects were: field, degree of agency of citizens participating in these projects, institutions involved (e.g. NASA or CERN, etc.) and antiquity. Moreover, they are also illustrative of the kinds of impacts these projects have for the community (citizens or researchers or both).

[18] For example, Wikipedia lists around 100 projects from which 90 are active projects.

## Table 1.1 Citizen Science Projects worldwide covering several fields[19].

N.B. The text and images listed are taken directly from the source listed in the column "Organisation" unless stated otherwise.

| Project | Description | Organisation |
|---|---|---|
| **Space and Climate** | | |
| NASA Solve | NASA Solve lists opportunities available to the general public to contribute to solving tough problems related to NASA's mission through challenges, prize competitions, and crowdsourcing activities. These activities have played an important role in stimulating innovation and helping NASA develop innovative solutions. | NASA<br>http://www.nasa.gov/solve/#.VE-9FfldV8E |
| NASA – citizen science projects | A number of projects initiated or sponsored or in collaboration with NASA:<br>**Disk Detective:** Our solar system used to be a massive disk of dust and debris. NASA scientists ask for help to comb the sky to find other stars that harbour these planet-forming disks!<br>**S'Cool:** Ask CS to collect data on cloud type, height, cover and related conditions in order to validate models.<br>**Be a Martian:** Participate as a CS to improve Martian maps, take part in research tasks, and assist Mars science teams studying data about the Red Planet.<br>HiWish: http://beamartian.jpl.nasa.gov/welcome | NASA<br>http://science.nasa.gov/citizen-scientists/ |
| NASA Balloon Flight Experiment<br> | Since 2006 NASA and LaSPACE have chosen student science projects to integrate into the balloon's High Altitude Student Platform The major goals of the HASP Program are to foster student excitement in an aerospace career path and to help address workforce development issues in this area. | NASA and LaSPACE<br>http://laspace.lsu.edu/hasp/ |
| Zooniverse<br> | Several projects on space. | *See below in platforms for Citizen Science.* |
| SETi@HOME | A scientific experiment that uses Internet-connected computers in the Search for Extra-terrestrial Intelligence. | Univ. of California<br>http://setiathome.berkeley.edu/<br>funded by NASA and NSF |
| LHC@home | Platform for volunteers to help physicists develop and exploit particle accelerators like CERN's Large Hadron Collider, and to compare theory with experiment in the search for new fundamental particles. More than 60000home computers, donated by more than 30000 volunteers. | CERN.<br>http://lhcathome.web.cern.ch/ |
| Citizen Cyberscience Centre | Develops open source tools and projects for citizen cyberscience. It also organises events that promote citizen cyberscience around the globe. Projects include Forestwatchers, Feynman's flowers and Crowdcrafting – see below. | CERN<br>The CITIZEN CYBERSCIENCE CENTRE<br>http://www.citizencyberscience.net/<br>http://Crowdcrafting.org |
| **History** | | |
| Ancient Lives | It is a project of Zooniverse to help Oxford papyrologists and researchers, the Imaging Papyri | Hosted in ZOOniverse.<br>http://zooniverse.org |

[19] In appendix 1, in Table A.3 we have added a more extensive list of health related projects.

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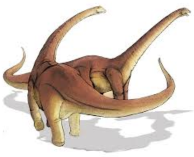
|  (CC) BY – SA 3.0 | Project, the Oxyrhynchus Papyri Project, the Egypt Exploration Society and other institutions with this work. Many papyri have remained unstudied due to a lack of resources. These writings have been digitized, so researchers are inviting volunteers to help catalogue and transcribe the text via the Web. | |
| **Natural Sciences** | | |
| Evolution Megalab  CC0 1.0 | Citizen scientists will seek out these banded snails and keep records of the locations where they are found using maps and satellite pictures on the Evolution MegaLab Web site. | Open University. Pages available in several European languages. http://www.evolutionmegalab.org/ |
| The Open Dinosaur Project  CC0 1.0 | Involves scientists and the public alike in developing a comprehensive database of dinosaur limb bone measurements, to investigate questions of dinosaur function and evolution. They have three major goals: 1) do good science; 2) do this science in the most open way possible; and 3) allow anyone who is interested to participate. | The main responsible is palaeontologist at Raymond Alf Museum of Palaeontology http://opendino.wordpress.com/about/ |
| Bee Lab  (CC) BY – SA 3.0 | The Bee Lab project applies Citizen Science and Open Design to beekeeping, enabling participants to construct monitoring devices gathering reciprocal data, motivating participants and third parties. The presented approach uses design workshops to provide insight into the design of kits, user motivations, promoting reciprocal interests and address community problems. | This project is run by Robert Philips. It is a project that lies more with our definition of DIY science. http://www.rdphillips.co.uk/132772/1836116/projects/bee-lab-citizen-science-project |
| New Jersey Audubon | The NJ Audubon Citizen Science Program aims to develop information datasets through citizen participation, on the abundance distribution, and demography of avian species. | New Jersey Audubon founded in 1897 is one of the oldest independent Audubon societies. http://www.njaudubon.org/ |
| The Whale Song Project (Whale FM)  CC0 1.0 | Citizen scientists can help study whale communications and pass along their observations through the Whale Song Project (aka Whale FM), a whale-song identification. Through the Whale Song Project, citizen scientists are presented with a whale call and shown where it was recorded on a map of the world's oceans and seas. After listening to the whale call—represented on screen as a spectrogram showing how the pitch of the sound changes with time—citizen scientists are asked to listen to a number of potential matching calls from the project's database. If a match is found, the citizen scientist clicks on that sound's spectrogram and the results are stored. The dataset generated by this project should help scientists to answer a number of questions regarding whale communication. | The Whale Song Project, available as part of the CSA's suite of Zooniverse citizen-science projects. In support of Woods Hole Oceanographic Institution in Massachusetts and the Sea Mammal Research Unit (SMRU) at the University of St Andrews in Scotland. In *Scientific American*. https://www.zooniverse.org/ |
| Snapshot Serengeti  (CC) BY 2.0 Calle v H | Snapshot Serengeti citizen science project aims at classifying all the different animals caught in millions of camera trap images taken to study animal behaviour in the Serengeti. Citizen scientists are asked to help with identification of all the different animals that appear in the photos. | University of Minnesota http://www.snapshotserengeti.org/#/home |
| SunFlower Project | Collecting data on pollinators in people's yards, gardens, schools and parks. | San Francisco State Univ. http://www.greatsunflower.org/ |
| Shermans Creek | Volunteer-initiated participatory action research | http://www.shermanscreek.org/ |

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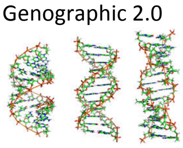
| Conservation Association | to encourage participant intervention in local concerns | |
| Missouri Stream Team Project | Address natural resource management goals, involving participants in stewardship for outreach and increased scope | http://www.mostreamteam.org/ |
| BirdTrack | Focus of scientific research goals focused on collecting data from the physical environment, usually underpinned by an hypothesis or research goal. | http://www.bto.org/volunteer-surveys/birdtrack |
| Bird Sleuth | Education and outreach are their primary goals, often data is not collected in a meaningful way that might be useful to other researchers. Often provides formal and informal learning resources | http://www.birds.cornell.edu/birdsleuth |
| eBird | This project has asked the question ''how can we build a useful resource for birders while also engaging them in science?" The shift to the latter model has resulted in expansive eBird growth, both in terms of the number of participants and the amount of data submitted." See Sullivan et al. 2009 | Since early 2000s. http://ebird.org/ |
| COBWEB "Citizen Observatory Web" | To develop a citizens' observatory framework that will enable citizens living in Biosphere Reserves to collect environmental information on a range of parameters including species distribution, flooding and land cover and use, giving them the opportunity to participate in environmental governance. This infrastructure will exploit technological developments in ubiquitous mobile devices as well as the crowd-sourcing of geographic information. COBWEB will leverage the UNESCO World Network of Biosphere Reserves (WNBR) focusing initially on the Welsh Dyfi Biosphere Reserve and validating then the work carried out within the context of Greek and German Reserves. | "Citizens Observatories" Projects funded by the European FP7 for Research, under the Environment theme of the Cooperation Specific Programme. http://cobwebproject.eu |
| **Genetics** | | |
| National Geographic Genographic 2.0  (CC) BY – SA 3.0 | The Genographic Project is a multiyear research initiative that uses cutting-edge genetic and computational technologies to analyze historical patterns in DNA from participants around the world to better understand our human genetic roots. It invites the general public to join a real-time scientific project to learn about their own deep ancestry by purchasing a Genographic Project Participation and DNA Ancestry Kit, Geno 2.0 | http:// Genographic.nationalgeographic.com/about/ |
| Phylo  (CC) BY – SA 3.0 G. Gastin | Phylo is a framework for harnessing computing power to solve the problem of multiple sequence alignments of DNA, RNA and proteins. Citizen are asked to play the game by arranging nucleotides. The goal of the game is to maximize the matches and minimize the mismatches between the DNA sequences on the digital game board. | McGill Univ. http://phylo.cs.mcgill.ca/ |
| NanoDoc | NanoDoc is a system where scientists can setup simulated tumor scenarios and players are then invited to design nanoparticles to attack the tumour. Various characteristics of the nanoparticles can be manipulated and strategies developed by utilizing players' own intuition, the | http://nanodoc.org |

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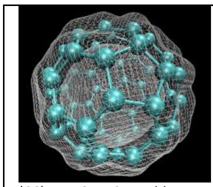
|  (CC) BY – SA 4.0 Itamblyn | true source of crowdsourced research projects. Players then participate in creating new nanoparticles and the most promising candidates will end up being validated through different university activities. | |
| Foldit Online Protein Puzzle  (CC) BY – SA 3.0 | Each type of protein folds up into a very specific shape, which specifies the protein's function. The Foldit exploration puzzle game attempts to predict the structure of a protein by taking advantage of our puzzle-solving intuitions and having people play competitively to fold the best proteins. Players can also design brand new proteins that could help prevent or treat important diseases. Another objective of the project is to find new proteins that can help in turning plants into fuel. | University of Washington Departments of Computer Science & Engineering and Biochemistry http://fold.it/portal/info/science |
| EteRNA | By playing EteRNA, citizen scientists participate in creating the first large-scale library of synthetic RNA designs. New principles for designing RNA-based switches and nanomachines--new systems for seeking and eventually controlling living cells and disease-causing viruses can be devised. By interacting with thousands of players and learning from real experimental feedback, you will be pioneering a completely new way to do science. | Stanford University School of Medicine and Carnegie Mellon University http://eterna.cmu.edu/web/ |
| NOVA RNA VirtuaLab | In the NOVA RNA Lab, citizens play the role of a molecular engineer by solving RNA folding puzzles. The RNA Lab also features a series of animated videos that explain RNA, protein synthesis, and RNA's role in fighting viruses. | *NOVA RNA VirtuaLab/PBS* http://www.pbs.org/wgbh/nova/labs/lab/rna/ |
| Rosetta@Home | Calls citizens to lend computer power to determine the 3-dimensional shapes of proteins in research that may ultimately lead to finding cures for some major human diseases. | University of Washington http://boinc.bakerlab.org/rosetta/ |
| **Health** | | |
| GO Fight against Malaria  (CC) BY – SA 3.0 | By tapping into World Community Grid Scripps Research scientists hope to compress 100 years of computations normally necessary for the effort into just one year. The scientists will use this resource to more quickly evaluate millions of compounds that may advance the development of drugs to cure mutant, drug-resistant strains of malaria. Data from the experiments will then be made available to the public. 2 million PCs have been volunteered so far by more than 500 000 people. | IBM and Grid Scripps Research http://www.worldcommunitygrid.org/reg/viewRegister.do |
| uBiome | Effort to map the human microbiome, the microorganisms that inhabit every inch of our skin as well as our ears, mouth, sinuses, genitals and gut. The correct balance of microbes serves to keep potential pathogens in check and regulate the immune system. Microbes also perform essential functions such as digesting food and synthesizing vitamins. In addition, uBiome compares participants' microbiomes with numerous past studies on the role of the microbiome in health, diet and lifestyle. uBiome also provides personal analysis tools and data viewers so that users can anonymously compare their own data with crowd data as well as with the latest scientific research. | California Institute for quantitative biosciences http://www.qb3.org |

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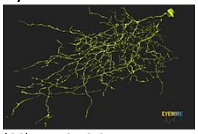
| Eyewire  (CC) BY – SA 3.0 | Inside the retina, lies an incredibly dense tangle of interconnected neurons; mapping these connections may help with better understanding of how vision works. This project seeks through a game called Eyewire – colouring brain images – the involvement of citizens could help with mapping such connections. Citizen scientists also help the EyeWire team develop advanced artificial intelligence and computational technologies for mapping the *connectome*. | Seung Lab at MIT http://blog.eyewire.org/ |
| Cushing Community | Web community on cushing illness Italian web community and forum on Cushing's disease (hyperplasia) of the pituitary gland). | A.N.I.P.I. Italia, Associazione Nazionale Italiana Patologie Ipofisarie. Sponsored by NOVARTIS. http://anipi-italia.org/forum/ |
| Scommetti che smetti | An health choice: a challenging competition involve people in stopping smoking | ASL Modena, Italy http://www.scommettichesmetti.it/flex/cm/pages/ServeBLOB.php/L/IT/IDPagina/57 |
| Medicina narrativa.eu | Narrative medicine provides space and time for greater personalization of care through patients' diaries and narratives: on myelofibrosis, chronic urticaria, multiple sclerosis . | Sponsored by Novartis. Fondazione ISTUD http://www.medicinanarrativa.eu |
| Collabobeat | Italian project from 2012 Platform for sharing doctors' visits notes. Improve trust and business.. | Digital Health Experience Srl http://www.collabobeat.com/ |
| Banca della salute | Web portal where citizens can create their health diary, enhancing their trust relation with NHS, doctors and other citizen. | Gruppo SAN S2 - Piedmont region and EU SF http://www.s2srl.it/prodotti/banca-della-salute.html#utente-cittadino |
| ACT 2015 | The ACT2015 is a collaboration of 25 youth-led and youth-serving organizations, together with UNAIDS. Launched in November 2013, this movement aims to secure a post-2015 development framework that advances the SRHR and HIV response for young people through community dialogue. | ACT 2015 http://www.crowdoutaids.org/wordpress/ |
| Microsoft HealthVault | Trusted place for people to gather, store, use, and share health information online. User decide what kind of information one shares and what level of access one gives to the person one share with. | Health Vault https://www.healthvault.com/it/en |
| Patients like me | Improve quality of life for people with a life changing illness. Share your experience, give and get support to improve your life and the lives of others. | http://www.patientslikeme.com/ USA, 2004 |
| Care pages | Share your story. Build your support circle CarePages.com is an online community with over a million unique visitors a month who come together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. | Care pages https://www.carepages.com/ USA 2008 |
| Flu near you | Flu Near You is open to anyone for browsing. Any individual living in the United States or Canada, 13 years of age or older, can register to complete brief, weekly surveys that help all of us learn more about the flu. | https://flunearyou.org/ Boston Children's Hospital |
| Health Map | From 2006 a team of researchers, epidemiologist and sw developers are utilizing online informal sources for disease outbreak monitoring and real-time surveillance of emerging public health threats, HealthMap's content is aggregated from freely available information. | http://healthmap.org/about Boston Children's Hospital |
| FightMalaria@Home | Crowd-sourcing antimalarial drug discovery Donation of computational power of the world's | http://www.fight-malaria.org/ |

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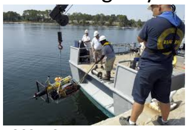
| | personal computers to target the 5,363 proteins in the malaria parasite | |
| Grippenet.fr | Grippenet, a citizen science flu-tracking project, uses the internet to allow people to contribute to public health data., part of the European network Influenzanet, with a special section on pregnant women GGrippenet | https://www.grippenet.fr/fr/ https://www.grippenet.fr/fr/ |
| Influenzanet | This is a system to monitor the activity of influenza-like-illness (ILI) with the aid of volunteers via the internet. It has been operational in many EU countries since the last 10 years. | https://www.influenzanet.eu/ |
| NutriNet-Santé | Monitoring volunteers' alimentation with periodical diary, in France. | L'Equipe de Recherche en Epidémiologie Nutritionnelle (EREN) https://www.etude-nutrinet-sante.fr/fr/common/login.aspx |
| Health eHeart | Although we would not qualify this as a citizen science project, this is an example of *big* call for involvement of people in a project that aims at predicting through behaviour, and family and personal history individuals' heart conditions. | American Heart Association and Univ. of California San Francisco https://www.health-eheartstudy.org/ |
| **Environment monitoring** | | |
| World Water Monitoring Day  CC0 1.0 | World Water Monitoring Day (WWMD) is an international education and outreach program that builds public awareness and involvement in protecting water resources around the world by engaging citizens to conduct basic monitoring of their local water bodies. A test kit enables children and adults to sample local water bodies for a core set of water quality parameters. | Water Environment Federation and the International Water Association http://www.wef.org http://www.iwahq.org/1nb/home.html |
| WeSenseIt "WeSenseIT: Citizen Observatory of Water" | To develop a citizen-based observatory of water, which will allow citizens and communities to become active stakeholders in water information capture, evaluation and communication. WeSenseIt will address the entire hydrologic cycle with a major focus on variables responsible for floods and drought occurrences. This citizen observatory of water will be tested in three different case studies in water management with civil protection agencies in United Kingdom, the Netherlands and Italy. | "Citizens Observatories" Projects funded by the European FP7 for Research, under the Environment theme of the Cooperation Specific Programme http://www.wesenseit.eu |
| TrafficTurk | Transportation researchers were asking the public for help in studying traffic patterns in New York City post-Sandy. Anyone with a smart phone can collect traffic data, anywhere in Manhattan, using an application developed at the University of Illinois at Urbana-Champaign. The researchers will analyse the data to learn about how traffic is affected by major disasters as part of the TrafficTurk project. TrafficTurk may provide valuable, real-time information to police, emergency personnel, and the public, with the goal of helping traffic flow more smoothly during major events. | Univ. Illinois at Urbana-Champaign http://trafficturk.com/home |
| Safecast | Following the Fukushima Diachi earthquake and radiation leak, joint efforts of partners such as International Medcom and Keio University, Safecast helped building a radiation sensor network comprised of static and mobile sensors actively being deployed around Japan. Safecast releases data openly and is pushing the Japanese government as well as universities and | International Medcom and Keio University Safecast is a non-profit group building Geiger counters, measuring radiation levels and making the data available to the public through maps, a Web site and data feeds to citizens, scientists and the public.http://blog.safecast.org/ |

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| | researchers to share their medical, sensor and other data. | |
| Gulf Oil Spill Tracker  | Nonprofit SkyTruth, in conjunction with the Surfrider Foundation and Ocean Conservancy, Gulf Oil Spill Tracker in early May 2010 as a way to give people a way to participate in tracking the impacts of the BP Deepwater Horizon disaster and its aftermath. Citizen scientists submit their observations online. When out in the field, they can take with them an information card reminding them of the information they need to include in their report: contact information, incident information and description, GPS location, etc. | SkyTruth, in conjunction with the Surfrider Foundation and Ocean Conservancy http://oilspill.skytruth.org/main |
| The UVA Bay Game | The UVA Bay Game is a large-scale participatory simulation based on the Chesapeake Bay watershed. The game allows players to take the roles of stakeholders, such as farmers, developer, watermen, and local policymakers, make decisions about their livelihoods or regulatory authority; and see the impacts of their decisions on their own personal finances, the regional economy, and watershed health. It is an adaptable educational and learning tool for: raising awareness about watershed stewardship anywhere in the world; exploring and testing policy choices; evaluating new products and services. The game provides players with a new sense of individual and collective agency, and game play records suggest new directions for research in behaviour change and policy development. It can be applied to other watersheds. | The University of Virginia http://www.virginia.edu/vpr/sustain/BayGame/thebay/ |
| iCoast: Did the Coast Change? | As the hurricane season approaches, the U.S. Geological Survey seek to involve citizens in a crowdsourcing application called “iCoast – Did the Coast Change?” to investigate coastal changes from extreme storms. Since 1995, the USGS has collected more than 140,000 aerial photographs of the Atlantic and Gulf coasts after 24 hurricanes and other extreme storms. iCoast allows citizen scientists to identify changes to the coast by comparing these aerial photographs taken before and after storms. Crowdsourced data from iCoast will help USGS improve predictive models of coastal change and educate the public about the vulnerability of coastal communities to extreme storms. | U.S. Geological Survey http://coastal.er.usgs.gov/icoast/about.php |
| Citclops "Citizens’ Observatory for Coast and Ocean Optical Monitoring" | The Citclops project aims at developing systems to retrieve and use data on seawater colour, transparency and fluorescence, using low-cost sensors combined with contextual information and a community-based Internet platform. Citizens will participate in the system by taking photographs of the sea surface on vessels, at the open sea or from the beach, being these data automatically uploaded to the Internet, archived, processed and finally accessed by end users through a webpage or a mobile application. The policy makers will be able to use the information to improve the management of the coastal zone and citizens will maximize their experience in | "Citizens Observatories" Projects funded by the European FP7 for Research, under the Environment theme of the Cooperation Specific Programme. More information at the project's website: http://www.citclops.eu |

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|---|---|---|
| | activities in which water quality has a role. | |
| CITI-SENSE "Development of Sensor-based Citizens' Observatory Community for Improving Quality of Life in Cities" | To develop and test an environmental monitoring and information system focused on atmospheric pollution in cities and agglomerations, which will enable citizens to contribute to and participate in environmental governance by using novel technological solutions. The three pilot case studies envisaged will focus on a range of environmental issues of societal concern like combined environmental exposure and health associated with air quality, noise and development of public spaces, and indoor air at schools. | "Citizens Observatories" Projects funded by the European FP7 for Research, under the Environment theme of the Cooperation Specific Programme http://www.citi-sense.eu |
| OMNISCIENTIS | "Odour Monitoring and Information System based on Citizen and Technology Innovative Sensors" brings together state of the art technologies and open communication capabilities in order to mitigate odour annoyance. An information system will be developed allowing citizens to act as human sensors indicating odour perception, discomfort and nuisance, through a dedicated tool on odour acceptability based on a community-based opinion. Innovative in-situ sensors will also be used and improved to monitor ambient odour exposures and, together with a specific odour dispersion fast model system, to adjust the information given by citizens via smartphones and measurements. OMNISCIENTIS system will be tested in several case studies in Belgium, France and Austria. | "Citizens Observatories" Projects funded by the European FP7 for Research, under the Environment theme of the Cooperation Specific Programme. More information at the project's website: http://www.omniscientis.eu. |

## Platforms

Below, we give examples of platforms that host different citizen science projects. Hence, these are organised endeavours whose business is to involve citizens in different types of projects. We list here some examples

**NOVA Labs** is a new digital platform where "citizen scientists" can actively participate in the scientific process. From predicting solar storms and designing renewable energy systems to tracking cloud movements and learning cybersecurity strategies, NOVA Labs participants can take part in real-world investigations by visualizing, analysing, and sharing the same data that scientists use.

Over time, new Labs covering a wide range of topics will challenge users to learn about science by actually doing it, to think like scientists and sometimes even contribute to real-world investigations. http://www.pbs.org/wgbh/nova/labs/about/

**Zooniverse** started with a project, Galaxy Zoo, which was launched in July 2007, which had a good response. Galaxy Zoo was very popular, and produced many unique scientific results, ranging from individual, serendipitous discoveries to those using classifications that depend on the input of everyone who has visited the site. Galaxy Zoo involves more than 25000 volunteers who help with astronomical data collection, helping with discovery of galaxies and understanding of the Universe (Franzoni & Sauermann 2013). Zooniverse introduces itself as committed to produce real research. The Zooniverse and the suite of projects it contains is produced, maintained and developed by the Citizen Science Alliance. The member institutions of the CSA work with many academic and other partners around the world to produce projects that use the efforts and ability of volunteers to help scientists and researchers deal with the flood of data that confronts them. The projects covered relate to Space, Climate, Humanities, Nature and Biology fields. It lists around 25 projects.

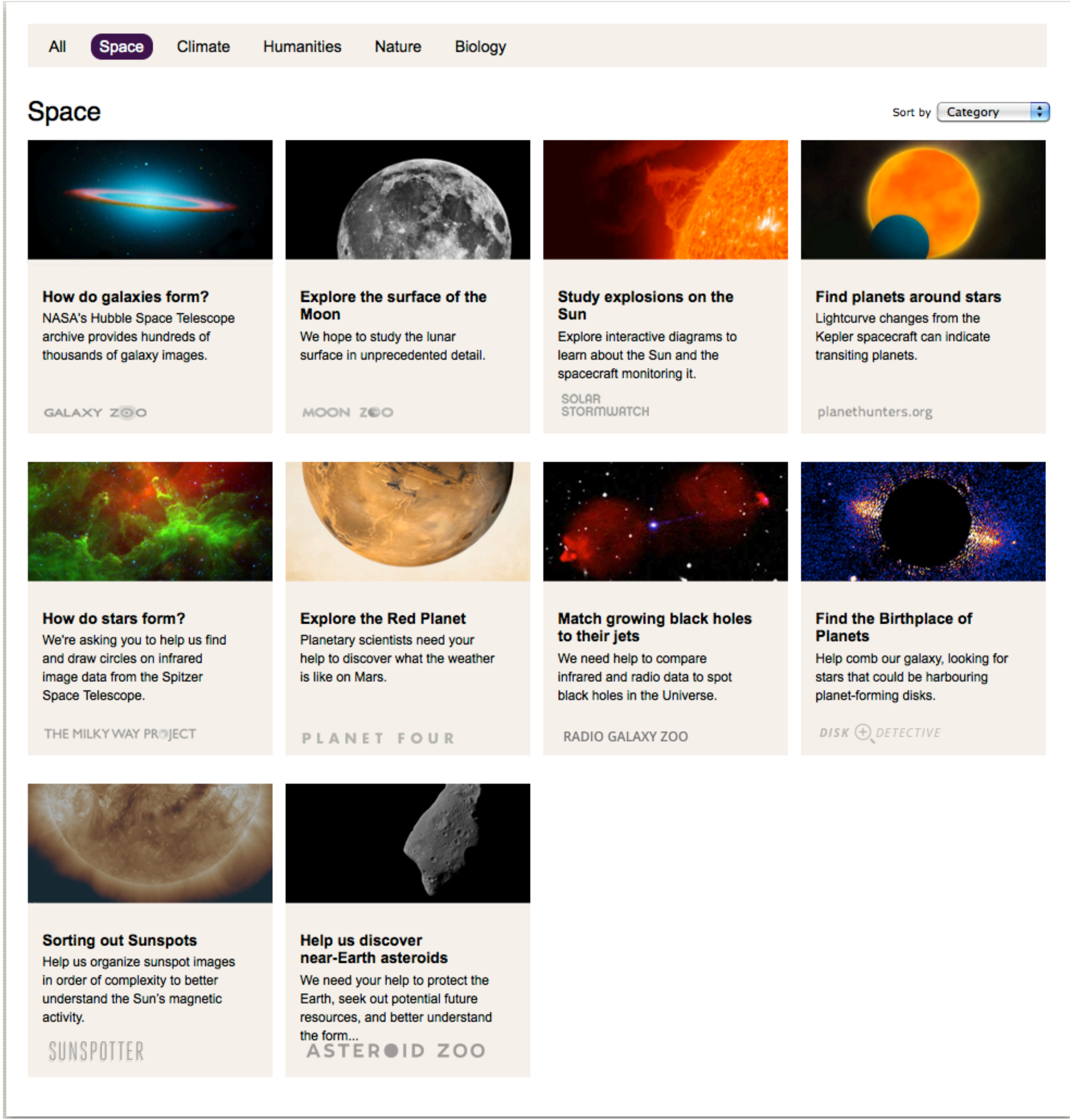


Figure 1.1 Zooniverse Web page showing different citizen science projects related to Space.
Source: This is a snapshot from the Zooniverse web site: http://www.zooniverse.org/

**The Nature Conservancy** in the USA, is an organisation that has been maintaining collaborative conservation projects around the world since 1951. It maintains a science blog, "Cool Green science" (http://blog.nature.org/science/) that features a number of Citizen Science projects (see list of 34 of these projects that have been posted since 2013 in Annex 1 - Table A1). Their projects are mostly focused on particular species monitoring found under the blog of this organisation; the descriptions are taken directly from the web page of the projects with occasional interpretation from the authors of this report.

**i.naturalist.org invites** people to record their observations of life on Earth. Hence, the vision behind iNaturalist.org, is to become a living record of life on Earth that scientists and land managers could use to monitor changes in biodiversity, and that *anyone* could use to learn more about nature. In our last visit to the site there were more than 350 projects posted through the website. See http://www.inaturalist.org/projects.

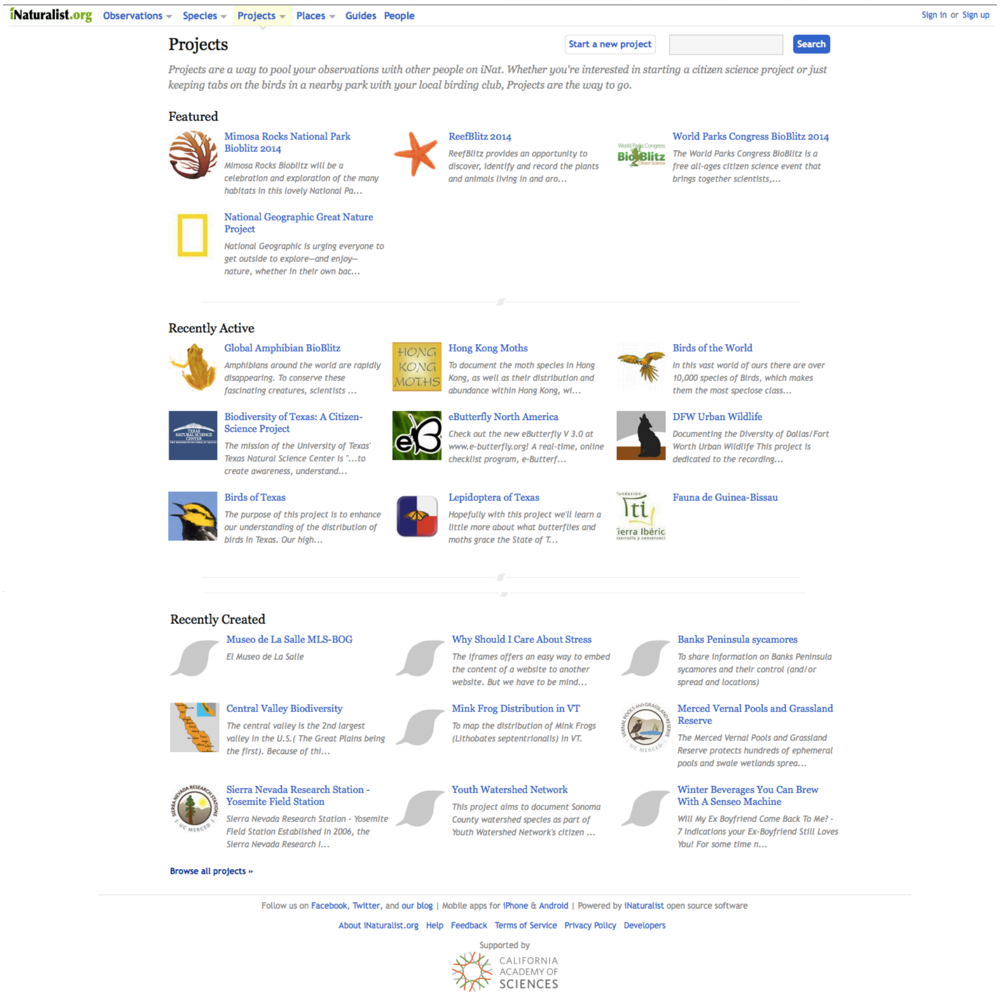


Figure 1.2 Web page of i.Naturalist.org showing featured projects.
Source: This is a snapshot from the i.Naturalist web site: http://www.inaturalist.org/

**SciStarter** (http://www.scistarter.com) provides a database of more than 600 active, searchable projects in a myriad of fields.

**Socientize (**http://www.socientize.eu/) is a project that aims at coordinating all agents involved in the citizen science process, setting the basis for this new open science paradigm – see description at their web site. The project aims at promoting the usage of science infrastructures composed of dedicated and external resources, including professional and amateur scientists, setting up a network where infrastructure providers and researchers will recruit volunteers from a general public to perform science at home.

**ExCites** (http://www.ucl.ac.uk/excites/) is a research group at University College of London that promotes and hosts different projects which according to the responsible, Muki

Haklay[20] (in Rowland 2012) responds to a more inclusive way of thinking about citizen science; their aim is to develop "a set of tools that can be used to collect, analyse and act on information according to agreed upon scientific methods" – see description at their web site.

**Crowdcrafting** (http://Crowdcrafting.org) is described as a platform where citizens and scientists can work together to create new research projects; it is created under Citizen Cyberscience Centre Projects of CERN. It uses the open source PyBossa framework; the projects uses volunteer computing combined with human cognition, knowledge or intelligence such as image classification, transcription, geocoding and more within a web browser covering a myriad of fields. There are more than 700 projects listed with completed or uncompleted tasks – see description at their web site.

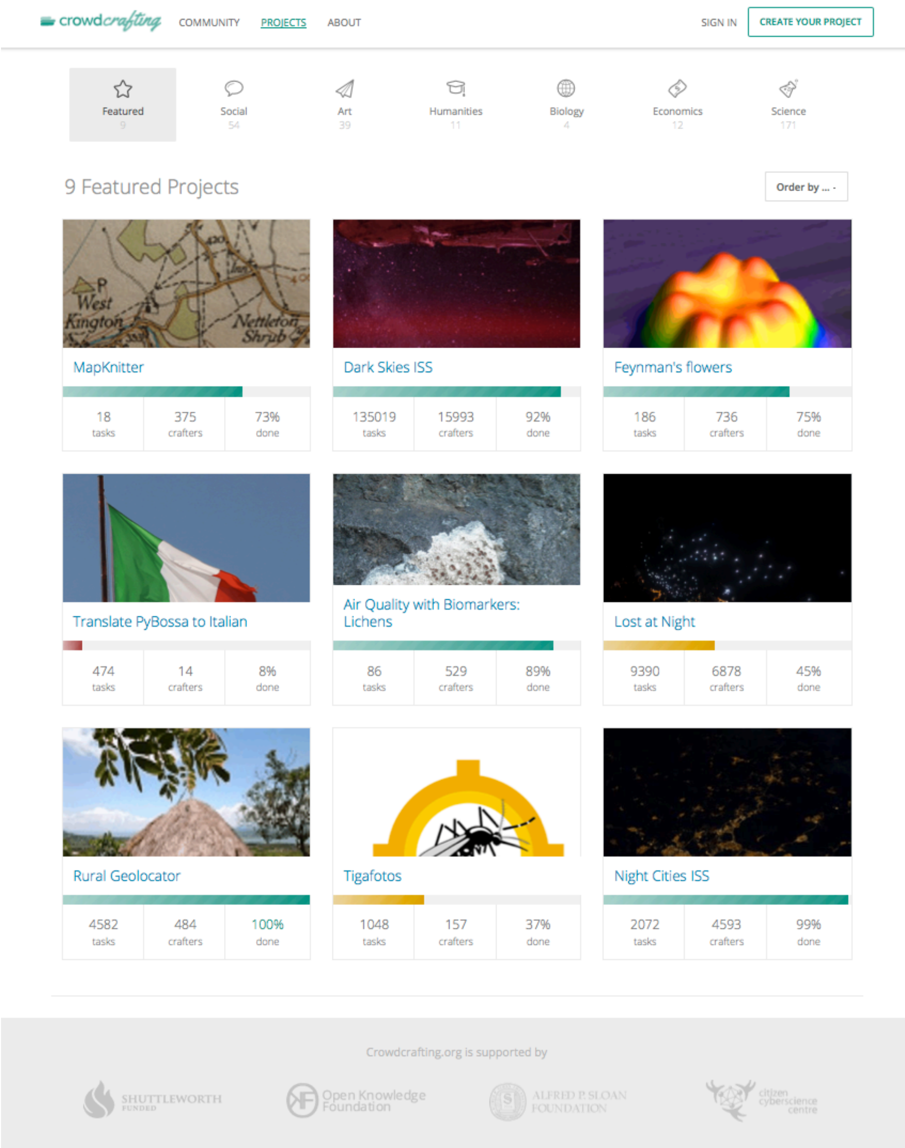


Figure 1.3 Web site of crowdcrafting.org
Source: This is a snapshot from the crowdcrafting.org web site: http://www.crowdcrafting.org/

[20] See Hacklay 2013.

## Apps

A number of Apps have been developed to help citizens become 'citizen scientists'. The list we present in Annex 1, Table A.2 is taken mainly from Scientific American[21]. Apps seem to be the ideal companion of citizen scientists. For example, for some citizen science projects focused on bird counting, Apps such as *Audubon Birds* or *iBird Pro* are essential to perform assigned tasks; on the other hand the app *Marine Debris Tracker* are used to help to find and log marine debris on beaches or in the water.

Apps therefore, constitute tools for recording, and mediating citizen science data.

## 1.3 Some reflections

Google scholar search (done on 21st October 2014), revealed 10800 publications using wording ""citizen science", project" published until October 2014[22]. If we concentrate on the trend rather than on the actual numbers, we can see through this search that in two decades (1995-2014) the number of publications listed by the search engine go from 2 to 1720 (in 2013, 2260 items). It is clear that the number of projects but also the number of publications that describe or look critically at these experiences and experiments is on the rise – see Figure 1.4.

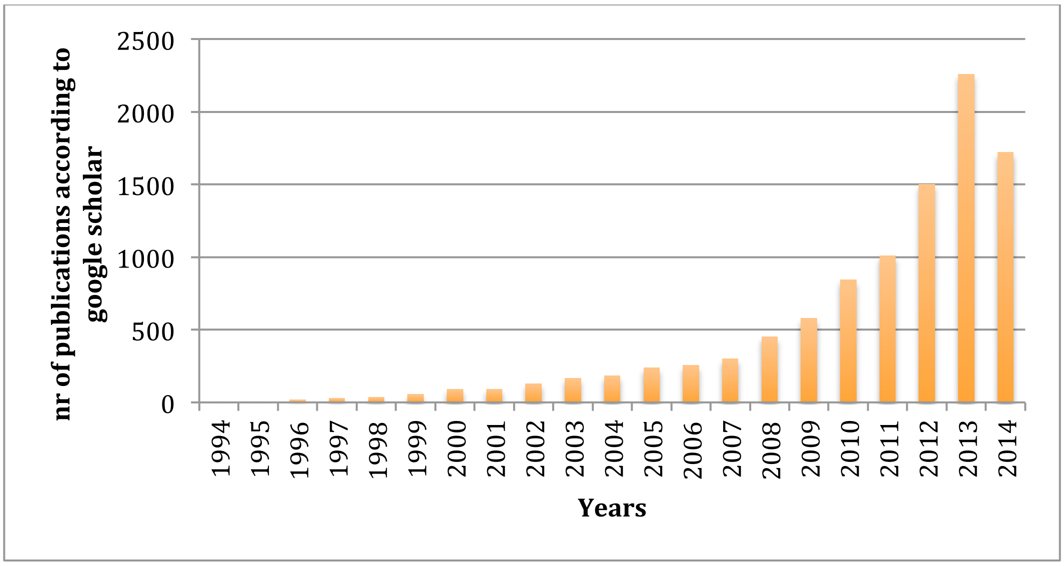


Figure 1.4 Graphical representation of citizen science publications trend in the last two decades according to scholar.google.com, using words "citizen science" + "project".

The projects listed earlier, and the platforms and Apps that support them have been growing in numbers for the last 10 years. Although we do not list all projects that exist here – an impossible task – we have listed here a great number of on-going important projects across many fields. The largest number of projects is in the field of natural sciences; this is not surprising, since not only these types of projects are more tangible to non-scientists but also they are the first history of involvement of citizens in scientific projects. Environmental monitoring has also been on the rise. This type of engagement is possible because Apps and sensors are becoming cheaper and available to anyone who wishes to contribute to measure pollution parameters in their environment. In fact, the "sensorial" function seems to be the

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[21] Mlykina, E. 2013. 8 Apps that turn citizens into scientists. Scientific American November 5th. Available at: http://www.scientificamerican.com/article/8-apps-that-turn-citizens-into-scientists/.
[22] We perfectly acknowledge the inaccuracy of this search; we have reviewed many of the publications listed and some of them are listed because they refer to some publication that contains the wording "citizen science".

most searched from the types of involvement that citizens are having in these projects. The great majority of projects presented here are institutionally led, and from their descriptions, there seems to be little citizens agency to define research questions or methods or processes through which the enquiries are done, mechanisms of extended peer review where quality is object of scrutiny by the communities involved in these projects, besides providing data or resources such as computer power. The next section will instead highlight projects where Irwin's (1995) definition of citizen science have a clearer expression.


Source: Universiteit Amersfoort, http://universiteitamersfoort.nl/

"Universiteit Amersfoort is een experimentele universiteit. Een vrijruimte voor onderzoek en ontwikkeling in Amersfoort. Universiteit Amersfoort kent geen gescheiden departementen of faculteiten. Het onderzoek dat wordt gedaan bestaat uit de projecten van onafhankelijke onderzoekers die als coöperatie samen een verzameling onderzoeksfaciliteiten delen, en van elkaars kennis en vaardigheden gebruik maken. Hoewel deze laboratoria open staan voor de meest uiteenlopende wetenschappers, kunstenaars en uitvinders, heeft Universiteit Amersfoort een aantal speciale aandachtsgebieden."

*The University of Amersfoort is an experimental university. A free space for research and development in Amersfoort. The University of Amersfoort has no separate departments or faculties. The research that is done consists of the projects of independent researchers as a cooperative sharing a collection of research facilities, and using their knowledge and skills. Although these laboratories are open to a wide range of scientists, artists and inventors, the University of Amersfoort has a number of special interests." [free translation with help of online resources]*

# 2. DIY Science

## 2.1 What is a DIY scientist?

Do-It-Yourself / DIY scientists are non-specialists, hobbyists and amateurs, but also an increasing number of professional scientists[23], doing science outside conventional university or lab settings, and instead in Makerspaces, FabLabs, Hackerspaces, Techshops, innovation and community-based labs, or even in their homes, garages or schools. When you cross citizen science with DIY, hacker or maker ways of thinking, the DIY scientist appears as someone who tinkers, hacks, fixes, recreates and assembles objects and systems in creative and unexpected directions, usually using open-source tools and adhering to open paradigms to share knowledge and outputs with others.

In a brief overview, 'Makerspace' can be used as a general term for any "innovative workshop spaces that allow people to access tools freely and make things in collaborative projects" (Smith et al 2014). 'Fab Lab', short for fabrication laboratory, is a specific initiative that emerged from the MIT's Center for Bits and Atoms (CBA) lead by Neil Gershenfeld (2007). A Fab Lab is usually a small-scale workshop with an array of computer controlled tools for rapid prototyping, such as milling machines, laser and vinyl cutters, 3D printers, and a suite of electronic components and programming tools, usually supported by open source software. 'Hackerspaces' are defined "as community-operated physical places, where people can meet and work on their projects"[24], with its origins in the counter culture movement under an ethos of individual freedom, autonomy and ingenuity (Coleman 2012, Maxigas 2012). 'TechShop' is a chain of member-based workshops in the USA equipped with typical machine shop tools (welding stations, laser cutters, milling machines) and corresponding design software. You also have other online manufacturing services such as Ponoko or Shapeways, to where users can send their digital designs, have them manufactured in laser cutters, CNC milling machines or 3D printers, and then sell their objects on demand via the sites or in their own retail outlets.

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**Box 2.1 The growth of DIY spaces**

The Fab Lab network presents a growing number of locations around the world in its 10 years of existence. From the first 6 Fab Labs in 2004, the network was comprised of 45 labs in 2010, and currently in November 2014, of 413 Fab Labs (active and planned)[25]. As for Hackerspaces, there are currently 1833 hackerspaces worlwide, 1087 of them are marked as active and 355 as planned[26]. In 2013 Shapeways had 100,000 new products uploaded per month, and 13,500 online stores (a growth of 75% from 2012)[27].

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There is now a hype revolving around the DIY/maker movement and a next generation of craftspeople, tinkerers, hobbyists and inventors (Anderson 2012, Hatch 2014). Quoting a recent report from Deloitte Center for the Edge, "making – the next generation of inventing and do-it-yourself – is creeping into everyday discourse, with the emerging maker

[23] Griffiths, A. (2014) 'DIY labs offer an agile alternative to university-based research', The Guardian, 16 June, Available at http://www.theguardian.com/higher-education-network/blog/2014/jun/16/diy-labs-exciting-alternative-university-science-research
[24] http://hackerspaces.org/wiki/
[25] http://www.fabfoundation.org/fab-labs/
[26] http://hackerspaces.org/wiki/List_of_Hacker_Spaces
[27] http://www.shapeways.com/blog/archives/2394-2013-shapeways-3d-printing-year-in-review.html

movement referenced in connection with topics ranging from the rebirth of manufacturing to job skills development to reconnecting with our roots" (Deloitte 2014). The present narrative is that anyone can and should have access to tools and communities to build anything they might want or need. It stands out as a self-empowering vision about the surrounding world, as is clearly visible in the words of Dale Dougherty, founder, President & CEO of Maker Media: "you're makers of your own world, and particularly the role that technology has in your life. (…) Makers are in control. That's what fascinates them; that's why they do what they do. They want to figure out how things work, they want to get access to it, and they want to control it; they want to use it to their own purpose" (Dougherty 2011).

**Box 2.2 The Maker movement**

One of the main supporters of the maker movement is Maker Media that offers DIY electronics, tools, kits, and books through its online and pop-up Maker Shed stores, but most importantly, is the publisher of MAKE, a bimonthly magazine showing step-by-step DIY projects, and the producer of Maker Faire. Maker Faire is a festival of science, art and crafts DIY projects which was held first in 2006 in the Bay Area with 100 exhibiting makers, hands-on workshops, demonstrations, and DIY competitions, expanding to 1,100 maker entries and over 130,000 attendees in its 2014 edition. In 2013, 98 independently-produced Mini and Featured Maker Faires also occurred around the world, including Tokyo, Rome, Santiago, and Oslo[28]. In 2014, Maker Faire Rome received 90,000 visitors and hosted more than 600 projects and 360 workshops[29].

Anyone who is fascinated or curious about science now finds a lower threshold to enter expert realms, facing DIY options, tools and spaces to build anything from scientific instruments for environmental measurements and for genome sequencing to satellites and other machines or devices. On one hand, low-cost sensors (for instance Co2, temperature, light intensity, sound, or humidity), several programming languages, open-source hardware prototyping platforms or microcontrollers (such as Arduino or Raspberry Pi) are adaptable, modular and easy to use at a starter level. When also coupled with access to digital tools (such as CNC machines, laser cutters, or 3D printers) and also hand tools in shared spaces or workshops, a wider ground for experimentation emerges. On the other hand, connection with online communities and access to online tutorials, step-by-step instructions and documentation repositories (such as Instructables or GitHub), greatly enable networks of support and collaboration with others with common interests.

As a simple example, DIY scientists can follow the instructions available at the website Instructables and turn a common kitchen scale into a snow monitor to measure the weight of fallen snow in their own backyards[30]. Retrofitting steps include opening up the scale, change the wires as needed, and also adding a microcontroller and applying some soldering techniques in case you want to boost its accuracy. Or take another example of the Build My Lab Contest[31], hosted by Tekla Labs and Instructables, which invited submissions of DIY blueprints for building laboratory equipment for science and education (such as microscopes, spectrophotometers, PCR machines, incubators, water baths, UV lamps or centrifuges). The purpose was to present simple solutions to common challenges or turn inexpensive or repurposed parts into equipment that could be used in laboratories around the world. Some of the winners included a programmable temperature controller and hot

[28] http://makerfaire.com/makerfairehistory/
[29] http://www.makerfairerome.eu/maker-faire-rome-torna-nel-2015/#more-3301
[30] http://www.instructables.com/id/Snow-Monitoring-Scale/?ALLSTEPS
[31] http://www.instructables.com/contest/buildmylab/

plate, a portable laminar flow hood, a low-cost waveform generator, a DIY-USB oscilloscope in a matchbox, or a homemade electric kiln.

Such DIY and maker incursions into science can be found in more complex fields and applications, even for citizen space exploration. DIY satellite making and launch[32] is advancing in the past years through crowdfunded campaigns in Kickstarter, such as KickSat or SkyCube. Sandy Antunes, former NASA employee and now professor of Astronautical Engineering, has published several books on the subject[33], and pursues its own Project Calliope as a home-built satellite, designed to convert the ionosphere into sound, and then send the MIDI data via amateur ham radio for anyone to hear, use, reuse and remix into music. Vendors are already offering premade platform satellite kits like TubeSats and CubeSats around $8,000, and a typical launch is estimated at $40,000. Various NASA and International Space Station projects accept some proposals using the CubeSat architecture, and the prospect of companies entering the private launch business will be a factor in the near future.

For instance, a Picosatellite is able to go to low earth orbit, at the hobbyist level lasting for 250km or from 3 to 16 weeks in circular orbit, either equatorial or polar. As Antunes points out, it can be used for science missions (for measuring), engineering missions (for testing hardware or software), and artworks, or even accomplish a decadal goal for Earth observing, heliophysics, astronomy, or planetary science. In his view, "you can launch a satellite to do anything. Send ashes to space. Ship up a Himalayan prayer flag. Launch your titanium wedding ring into orbit. Any art, music, or art/music/science hybrid idea is welcome because it's your satellite. Just give it a purpose or utility beyond just the spectacle of being able to launch your own satellite"[34].

In terms of DIY space exploration, it is also noteworthy the SpaceGAMBIT - The Global Alliance of Makers Building Interstellar Technologies, a U.S. federally funded program managed by Hawaiian makerspace, Maui Makers. According to their website, "we enable hackerspaces, makerspaces and other open community groups to work together to carry out space-related research and development, and engage any interested member of their local community in those activities"[35]. Self-characterized as an open-source, hackerspace space program, in 2013 SpaceGAMBIT launched its first open call for projects focusing particularly on education modules, space habitats or nano/micro-satellite development. The winners included for instance a hackerspace earthship, an automated algae reactor, or a prototype partial space suit. One of the requirements is that all projects must be open source, open hardware and open documentation in order to allow others to replicate the work.

## 2.2 Controversies and ethical issues

A number of ethical discussions and controversies have risen in some DIY science initiatives and projects. For instance, the SpaceGAMBIT funding by the Defense Advanced Research Projects Agency / DARPA was a controversial topic on its own, and most importantly, in relation to discussions on military funding of DIY and maker initiatives, usually through

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[32] Reyes, M.F. (2014) DIY Satellites: Now and Near Future, *Make Magazine*, April 7, Available at http://makezine.com/2014/04/07/diy-satellites-now-and-near-future/

[33] See *DIY Satellite Platforms* (2012), *Surviving Orbit the DIY Way* (2012), *DIY Instruments for Amateur Space* (2013), or *DIY Comm and Control for Amateur Space* (forthcoming), all published in O'Reilly Media (Sebastopol, CA).

[34] Sandy, A. (2014) Your Own Satellite: 7 Things to Know Before You Go, *The New York Times*, April 11, Available at http://makezine.com/2014/04/11/your-own-satellite-7-things-to-know-before-you-go/

[35] http://www.spacegambit.org/about/

education programs[36]. Another example was the $3.5 million grant to the retail start-up TechShop, and as part of that contract, DARPA employees will have access to TechShop's tools after midnight, when the doors are closed to the public. But the most visible controversy occurred when the Manufacturing Experimentation and Outreach / MENTOR program developed by Dale Dougherty of O'Reilly Media (publisher of Make Magazine, and organizer of the Maker Faire) and Saul Griffith of Otherlab, received a $10 million DARPA award, with the aim of bringing the practices of making into education and extend the maker movement into 1,000 high schools over three years.

An ethical discussion among the maker community followed this announcement. Mitch Altman, a renowned figure in the community and co-founder of San Francisco's hackerspace Noisebridge, strongly expressed his disagreement and subsequently decided to leave the organization of Maker Faire. In a text affirming his ethical standing[37], he straightforwardly rejected the choice of accepting funding from military organizations, even for education purposes: "children who are educated with DARPA funding are probably more likely to think that DARPA is a good thing, and are more likely to work for DARPA, or other military organizations. Is this a good tradeoff? I don't think so". Instead, Altman argued for alternative sources of funding from organizations or foundations that would be better aligned with the goals of the maker community. In his words, "the goals of the MENTOR program are laudable: introducing new design tools, teaching the collaborative practices of "making" to high school students, and creating "makerspaces" in schools. These are not the goals of DARPA – though there is some overlap, in as much as this helps DARPA increase the number of quality engineers at their disposal".

After Altman's announcement, Dale Dougherty published a clarification on the topic[38], stressing that all software developed under the DARPA program would be open source and that student's work would not be owned by DARPA. Furthermore, he underlined that the field of education usually works and receives grants from federal agencies, such as NASA, the Department of Education, the National Science Foundation, and also that their funding was also coming from non-profit initiatives in community contexts. As a clear response to Altman's critiques, Dougherty finally asserted that "the goals of Make and DARPA align in this instance because we have a mutual interest in seeing a more diverse pool of young people become scientists, engineers, programmers".

As another example of ethical discussion on DIY/maker funding, the Fab Foundation that supports the international Fab Lab network created controversy in June 2014 among some of its grassroots members by accepting a $10 million grant from Chevron Corporation[39]. Based upon the grant, it will open up to 10 Fab Labs across the US in the next three years, located in areas where Chevron operates, including the first two facilities in Bakersfield and Richmond, California. The aim is to provide approximately 20,000 students and adults hands-on science and technology experiences. In the words of Neil Gershenfeld, Chairman of the Fab Foundation's Board, "along with launching new fab labs, Chevron's grant will help build

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[36] O'Leary, A. (2012) Worries Over Defense Department Money for 'Hackerspaces', *The New York Times*, October 5, Available at http://www.nytimes.com/2012/10/06/us/worries-over-defense-dept-money-for-hackerspaces.html?_r=0

[37] Altman, M. (2012) Hacking at the Crossroad: US Military Funding of Hackerspaces, *Journal of Peer Production* 2, Available at http://peerproduction.net/issues/issue-2/invited-comments/hacking-at-the-crossroad/

[38] Dougherty, D. (2012) Makerspaces in Education and DARPA, *Make Magazine*, April 4, Available at http://makezine.com/2012/04/04/makerspaces-in-education-and-darpa/

[39] http://www.fabfoundation.org/2014/06/the-fab-foundation-launches-new-fab-labs-in-the-us-with-generous-grant-from-chevron/

the Fab Foundation's capacity to provide access to digital fabrication across the country and around the world".

In Europe, the question of funding for Fab Labs is also a matter of central interest for the sustainability of the labs, and is connected to access to public or private funding from European, national or regional programs and organizations. Several Fab Labs have received funds or grants to pursue their activities for educational, entrepreneurial or even specific regional aims. For instance, from 2011 to 2014 the project "Fablabs in the border region" was funded by the Interreg IV-program between the Netherlands and Flanders (European Regional Development Fund) to establish two new FabLabs in Genk, enable another in Eindhoven and expand two other FabLabs in Leuven and Maastricht. Coordinated by KULeuven (Catholic University of Leuven), the project presented the Fab Labs as educational workplaces and innovation settings, where students and individuals can create a product prototype and start a business[40].

As another example, in November 2013, the Danish Industry Foundation granted the Center for Participatory IT at Aarhus University three million DKK to fund a new research project, called FabLab@School, in collaboration with Stanford University, and also VIA University College, Microsoft school network, Spinderihallerne and school management in Silkeborg, Aarhus and Vejle municipalities. The project aims at developing children's competencies in digital media by giving them access to the newest technology and educate them on design and innovation. In the first of the three initial workshops, stakeholders and future managers of Fab Labs learned about how to establish a Fab Lab in the three municipalities involved, and teachers also got acquainted with new maker technologies and kits, such as LilyPads and Makey Makey[41].

As a last example, Ashton Community Trust (Belfast) in partnership with the Nerve Centre (Derry/Londonderry) officially launched the first two Fab Labs in Northern Ireland[42] on May 2013, with funds by PEACE III managed by Special European Union Programmes Body. The Fab Labs will offer support on a local basis to communities, entrepreneurs, students, artists and small businesses, but the funding agencies also have a specific scope. The Special EU Programmes Body is a North/South Implementation Body sponsored by the Department of Finance and Personnel in Northern Ireland and the Department of Finance in Ireland. The PEACE III Programme, funded through the European Regional Development Fund, also has a specific scope. It is designed to reinforce progress towards a peaceful, shared and stable society by promoting the reconciliation of communities in Northern Ireland and the Border Region of Ireland.

The discussions that have punctuated several networks in the DIY/maker movement are bound to continue and even to expand considering the rise of such spaces and labs. Regarding the funding models and subsequent agreements and guidelines for instance, Peter Troxler, President of the International Fab Lab Association, succinctly states that "big money does not necessarily imply bad intentions, but it might attract accusations of corporate "Fab-washing". The network has to develop a critical and constructive way of discussing how to interact with corporations, the government or the military – both as a community and at the individual labs" (Troxler 2014).

[40] http://www.limburg.nl/Actueel/Nieuws_en_persberichten/2011/Oktober_2011/Europa_investeert_5_miljoen_euro_in_grensoverschrijdende_projecten

[41] http://cavi.au.dk/news/enkelt/artikel/fablabschooldk-workshop-challenges-schoolteachers-to-program-lilypads-and-robots/

[42] http://fablabni.eu/

## 2.3 The particular case of DIYbio

Do-It-Yourself Biology, or 'DIYbio', 'biohacking' or 'garage biology', refers to the engineering of living organisms in non-traditional academic and industrial institutions, such as DIYbio Labs or Biohackspaces, influenced by open source principles in their tools and results. From amateurs and enthusiasts, to students and trained scientists, DIYbio practitioners with varying levels of expertise or professional affiliation are using available equipment in these labs to tinker with glow-in-the-dark bacteria, to create art, to make homemade equipment such as centrifuges, plasma generators or bio-printers, to produce diagnostics kits, or even to grow new materials. DIYbio labs also usually offer educational and entrepreneurial opportunities, such as peer-to-peer training on biotechnology, hands-on workshops for lay public and non-university students, and testbeds for academic, industrial or commercial applications.

The DIYbio community is conducting simple but also sophisticated experiments in nonconventional settings, many involving DNA profiling and genetic engineering, through different techniques such as PCR (polymerase chain reaction) that have become less expensive, faster and refined in recent years. From more entertaining experiments of extracting DNA from strawberries with rum (and drinking the spare reagents as cocktails), initiatives from amateur *biohackers* also include the use of DNA barcoding to identify a species' specific genome, as was the case of two New York teenagers that took on an experiment in 2008 to discover if the local sushi vendors were labelling currently their products[43], but also the workshops that Paris DIY *biohackerspace*, La Paillasse, started to organize to check food provenance after the horsemeat scandal in 2013. Now the latter regularly offer initiation workshops to DNA barcoding with a cheap and faster method that can process DNA information in 4h and for 3-5 euros per sample, compared with a commercial analysis that usually takes 3 days and 300 euros[44].

**Box 2.3 The DIYbio movement**

DIYbio.org was founded in 2008 with the mission of establishing a vibrant, productive and safe community of DIY biologists, offering a website, online forums, blog and list of local chapters. The community is rapidly expanding, with reported 14 groups across Europe and North America in 2013, to current (November 2014) 23 groups in North America, 21 in Europe, 3 in South America, 2 in Asia, and 2 in Australia/New Zealand[45]. The movement's main online mailing list boasts nearly 4,000 members[46].

One of the largest communities today is DIYbio.org, founded in 2008 by Jason Bobe and Mackenzie Cowell, with the aim of promoting the pursuit of biology by citizen scientists and amateur biologists[47]. There you can find Genspace in Brooklyn, New York, the first community *biolab* in the US, operating as a non-profit organization since 2009 with membership (by invitation) of $100 per month for 24/7 access to lab facility, equipment, and volunteer staff[48]. As one of the most renowned proponents of the DIYbio, Ellen Jorgensen, Genspace's president, has stated that "it's a movement that (..) advocates making

[43] Schwartz, J. (2008) Sushi study finds deception, The New York Times, 22 August, Available at: http://www.nytimes.com/2008/08/22/world/americas/22iht-fish.1.15539112.html

[44] http://lapaillasse.org/la-version-quick-and-dirty-du-dna-barcoding/

[45] http://diybio.org/local/

[46] http://www.economist.com/news/technology-quarterly/21615064-following-example-maker-communities-worldwide-hobbyists-keen-biology-have

[47] http://thepersonalgenome.com/about/

[48] For a US/Canada tour of biohackerspaces by Aurélien Daily and Quitterie Largeteau, members of La Paillasse, see http://world.lapaillasse.org/

biotechnology accessible to everyone, not just scientists and people in government labs. The idea is that if you open up the science and you allow diverse groups to participate, it could really stimulate innovation. Putting technology in the hands of the end user is usually a good idea because they've got the best idea of what their needs are"[49].

In Europe, there is, as mentioned above, La Paillasse, the first community lab in Europe which started in 2011 as a clandestine/squat biohackerspace, with bioscavenging campaigns for left-over lab equipment and also donations from government, academia or private firms, and has now moved with the support of the Parisian municipality to a 750m2 fully equipped space. It operates as a non-profit organization with free access for members (upon variable donation), and it defines itself as a collaborative space and a fab lab merged with a biotech research lab, joining together designers, scientists, artists, makers, entrepreneurs, engineers and citizens. It explicitly aims "to make Science and Technology more open, shareable and available to everyone", under the common values of democratization, *interdisciplinarity*, citizen counter-power, innovation, open source, and ethics responsibility[50].

Other labs in Europe include Manchester's MadLab, supported by Manchester Metropolitan University and funded by the Wellcome Trust; the London Biohackspace, an open community lab run by London Biological Laboratories, a not-for-profit organization (gold benefactors UCL's Faculty of Engineering and London Hackspace, where it is based); and the Open Wet Lab, based on the Waag Society and supported in part by the Mondriaan Fund, the SNS Reaal Fund and the Creative Industries Fund. The latter's mission is clearly defined in terms of "the design and ethics of life", as "the Open Wetlab aims to offer a platform and discuss other forms of knowledge production in addition to the scientific one. Via a hands-on approach (where the public itself enters in contact and interacts with the technology) the Wetlab wants to give a different interpretation for the debate on usefulness and desirability of Life Sciences in society"[51].

## DIYbio safety and security

Despite their public narrative around its potential of democratization, education, outreach and community building for biotechnology, the DIYbio movement faces a widespread concern from policymakers, journalists and the general public regarding its safety procedures and security monitoring. Apprehension about the danger of producing deadly viruses or epidemics, or releasing genetically modified organisms into the ecosystem, thus causing serious accidents or provoking unexpected effects or modifications in the environment or public health, is very commonly associated with DIYbio, especially regarding DNA manipulation. This movement also raises concerns in relation to dual use issues and the risk of bioterrorism, in case someone uses the equipment and materials available at DIYbio labs to intentionally create and disseminate biological weapons. These concerns are further amplified due to its independent character outside conventional institutions, usually without close government supervision.

In a report by the United Nations Interregional Crime and Justice Research Institute, in cooperation with the European Commission, a final section was dedicated to 'Amateur Biology'. In the workshop that informed the report, experts and DIYbio community

[49] Jorgensen, E. (2012) Biohacking – you can do it, too, TEDGlobal Talk, Available at: http://www.ted.com/talks/ellen_jorgensen_biohacking_you_can_do_it_too
[50] http://www.kisskissbankbank.com/en/projects/la-paillasse
[51] http://waag.org/en/lab/open-wetlab

representatives gave an overview of the situation and explicitly addressed some of these safety and security concerns. Despite the community's frequent denials of what they consider negative portraits disseminated by media, experts "called for the concerns of the society to be taken more seriously and addressed upfront, even if they are considered to be baseless" (UNICRI 2012: 124). As such, it was advised that the community should draft clear standards and governance models, codes of conduct and information materials in terms of biosafety, transparency and legal norms.

In particular, the DIYbio.org community has been more active in establishing those standards. In the survey conducted by the Woodrow Wilson International Center for Scholars (Grushkin et al. 2013), it is noted that most DIYers work in community spaces that require Biosafety Level One conditions, that is, where experiments are carried out with strictly non-pathogenic organisms, and employ professional contractors for biological and hazardous waste disposal. DIYbio and the Wilson Center also established the website Ask A Biosafety Officer[52], where citizen scientists can get rapid answers to biosafety questions.

Genspace also made available online the Open Lab Blueprint as an easy-to-follow guide to launch and develop a sustainable community biolab, including advice on biosafety procedures. In this case, it advices the implementation of mandatory safety training for all members before they start using the lab, covering general lab safety as well as chemical and biological hazards. The Open Wetlab for instance requires everyone to take a safety test and a Safety Certificate to ensure basic understanding of microbiology, personal protection equipment, safe and responsible laboratory behaviour, biological safety, waste management and documentation[53]. Also the Bay Area DIYbio lab Biocurious offers a detailed safety manual regarding their general policies, guidelines to work with microbes, plants, animals and recombinant DNA, and procedures for chemical and biological control within the lab[54]. Finally, Genspace created an external Science Advisory Board, composed of experts in biosafety, microbiology, synthetic and molecular biology, which provide scientific, safety, and regulatory guidance for projects, and eventually advice on membership requests.

However, as the technical capability of the communities labs and the skills of their users become more sophisticated, and as more labs with Biosafety Level 2 are expected to open (working with pathogens that pose moderate hazards to personnel and the environment), there will be the need to set stricter safety measures in most DIYbio labs. Already the differences between the US and the European contexts are striking, considering that certain activities, such as genetic engineering of particular organisms, are currently forbidden in most Western Europe (see subsection bellow on DIYbio governance).

## DIYbio ethics

Public backlash towards DIY or garage biology also prompted the DIY community, primarily the community labs and regionals groups, to take on further public actions and initiatives to "establish a strong culture of shared responsibility"[55]. To that purpose, the DIYbio.org organized in 2011 a series of congresses to bring together North American and European groups to come up with a Code of Ethics as an overarching and aspirational set of guidelines by which DIYbio labs were to be run. On one hand, an ethical awareness is well ingrained at

[52] http://ask.diybio.org/
[53] http://waag.org/en/open-wetlab-safety
[54] https://docs.google.com/a/genspace.org/document/d/1mYfu0hendLE0f7WQORWtTPLxgUHsPS2ew0DsuOUHNul/edit?pli=1
[55] http://2014.igem.org/Team:Genspace/Safety

least in some of the leaders of the movement, as can be clearly see in the words of Jason Bobe, a founder of DIYbio.org: "People overestimate our technological abilities and underestimate our ethics"[56]. On the other hand, it should be noted that, quoting a member of London biohacking group, "the code, to many biohackers, was more of a defensive thing, in response to a perceived view that biochaking was dangerous" (Jefferson 2013: 16).

In May 2011, individuals and delegates from Denmark, England, France, Germany, and Ireland gathered at the London School of Economics BIOS Centre to generate their Draft of DIYbio Code of Ethics. In July 2011 another congress was held in San Francisco where the DIYbio community of North American produced their version of the Code of Ethics (see box 2.4).

## Box 2.4 Code of Ethics

**Draft DIYbio Code of Ethics from European Congress**[57]

**Transparency**
Emphasize transparency and the sharing of ideas, knowledge, data and results.

**Safety**
Adopt safe practices.

**Open Access**
Promote citizen science and decentralized access to biotechnology.

**Education**
Help educate the public about biotechnology, its benefits and implications.

**Modesty**
Know you don't know everything.

**Community**
Carefully listen to any concerns and questions and respond honestly.

**Peaceful Purposes**
Biotechnology must only be used for peaceful purposes.

**Respect**
Respect humans and all living systems.

**Responsibility**
Recognize the complexity and dynamics of living systems and our responsibility towards them.

**Accountability**
Remain accountable for your actions and for upholding this code.

**Draft DIYbio Code of Ethics from North American Congress**[58]

**Open Access**
Promote citizen science and decentralized access to biotechnology.

**Transparency**
Emphasize transparency, the sharing of ideas, knowledge and data.

**Education**
Engage the public about biology, biotechnology and their possibilities.

**Safety**
Adopt safe practices.

**Environment**
Respect the environment.

**Peaceful Purposes**
Biotechnology should only be used for peaceful purposes.

**Tinkering**
Tinkering with biology leads to insight; insight leads to innovation.

In fact, it is noteworthy that each congress produced two versions of the Code with significant differences in terms of presence/absence of topics, wording and ordering. In her

[56] Zimmer, C. (2012) Amateurs Are New Fear in Creating Mutant Virus, *The New York Times* March 5, Available at: http://www.nytimes.com/2012/03/06/health/amateur-biologists-are-new-fear-in-making-a-mutant-flu-virus.html?pagewanted=all&_r=0
[57] http://diybio.org/codes/draft-diybio-code-of-ethics-from-european-congress/
[58] http://diybio.org/codes/code-of-ethics-north-america-congress-2011/

comparative analysis of these transatlantic divergences in citizen science ethics, Eggleson (2014) underlines for instance how Open Access is placed in the first position in the North American list, while Safety is on the fourth position after Transparency and Education. This order might be explained by a US national culture regarding access to information, but also importantly, to a need to downplay safety in face of previous negative portraits in US media.

It is also noteworthy in Eggleson's analysis the difference of wording in the topic of Education. While the European version uses the terms 'benefits and implications', the North American draft prefers the term 'possibilities', which may be explained by a divergence in favoring either a more normative framework or a more ambiguous and neutral term. Very importantly is also the phrasing related to Peaceful Purposes, namely the use of 'must' in the European list and 'should' in the North American one. In brief, Eggleson offers a critical assessment of the latter, by stating "accountability, responsibility, relationship with the community - these elements of citizenship are particularly fitting for the code of ethics of DIYbio, often held up as an example of 'citizen science'. Where, then, are these elements of citizenship in the North American version of the code? These absences, combined with the notion that the use of biotechnology only for peaceful purposes isn't mandatory, render the North American code a much weaker ethical framework than its European counterpart" (Eggleson 2014: 191).

This is a concrete example of present obstacles and struggles to arrive at consensus or reinforcement of stricter professional standards, codes of ethics or good practice guidelines in DIYbio. In a certain sense, "DIYbio entails a different way of engaging with science and technology, and with the making of things and futures. It is biology moving out of the institutions and to the realms of the public" (Delgado 2013: 66). That is, the development of guidelines and codes sometimes run counter not only a DIY ethos of autonomy, creativity and experimentation, but also the particular stances of DIYbio against institutional, industrial and large-scale scope of synthetic biology labs and Big Bio businesses.

## DIYbio governance

Besides international and national regulations regarding licenses and research on genetically-modified organisms, self-regulation and soft law stand out as the predominant governance model developed in the DIYbio community, such as safety guidelines or codes of ethics as seen in previous sections. The community has also partly welcomed collaboration with law enforcement agencies as both a strategy to shape the development of the amateur biology movement, and as an informal means of oversight and monitoring the activities of DIYbio labs.

In particular, the Federal Bureau of Investigation / FBI has organized regular meetings and workshops with the North American DIYbio community since 2009 with the aim of promoting a culture of responsibility and identifying risks and gaps and come up with ways of mitigation of those same risks[59]. In 2012, a workshop promoted by the FBI also invited biohacking groups outside the US, including groups from France (La Paillaisse), Denmark (BiologiGaragen), UK (London Biohacker space and Manchester MadLab), Singapore, Germany, the Czech Republic and Canada[60]. Besides this initiative, there is currently no international process or forum that serves as a contact point with the DIYbio community.

[59] http://www.aaas.org/news/fbi-aaas-collaborate-ambitious-outreach-biotech-researchers-and-diy-biologists
[60] For transcripts of the workshop http://diyhpl.us/wiki/transcripts/fbi-diybio-2012/

However, doubts about the efficiency of such self-governance mechanisms to produce consensus or even to be followed, are increasingly valid. The risks of creating pathogens and weaponizing them cannot be fully dismissed by current disclaimers based on the scientific and technical difficulties of such attempts in DIYbio labs, or even by assertions that "community labs are very social and very public spaces, [and thus] it is unlikely that someone bent on harm would choose to train and conduct work in a community lab"[61]. But more crucially, such self-regulation models continue to be mostly based on noninterventionist approaches to science and technology, following the argument that "self-regulation by the scientific community can provide an effective means of oversight, and one which avoids the potential hindrance to innovation that could be caused by excessive legislative control (…) oversight mechanisms that are better able to anticipate and manage problems and opportunities and which are also able to adapt and respond quickly to changing knowledge and circumstances are an important aspect in the governance of emerging technologies" (Jefferson 2013: 81). In this context, the proactionary principle, generally defined as the freedom and duty to innovate, is mostly preferred in DIYbio circles over a precautionary principle that looks on prevention of worst outcomes in face of complex uncertainty (Fuller 2012).

This dislike of more formal regulations is further corroborated by data from the survey conducted by the Woodrow Wilson International Center for Scholars. 75% of DIYers believe that there should be no additional government oversight, which might not be a surprising number considering that 85% of answers of the survey came from the United States and only 10% from Europe (Grushkin et al 2013: 14). When asked about future oversight, 43% answered positively but pointing towards limited types of regulation, that is, they supported 1) equal treatment compared with academic or industrial labs, 2) regulation of organisms and equipment rather than labs and individuals, and 3) regulation dependent on the state of the technology.

Regarding the European context, calls for tuning down present regulations on licensed use of genetically-modified organisms can be heard in DIYbio Europe, part of DIYbio.org. In the first DIYBio EU meeting in Paris December 2012, a central discussion revolved around the costly, time-consuming and bureaucratic process of licensing in Europe, and the convoluted legal national interpretations of European laws in this issue. As voiced by Pieter van Boheemen of the Dutch DIY Bio Group, "Europe is locking itself out of biotechnological innovation because of our ridiculously strict regulations. Biotechnology can only become a healthy industry if we foster all aspects of research and invention. Restricting access to basic resources for amateurs and start ups hinders this tremendously"[62]. With a second meeting in June 2013 and further local groups, DIYbio Europe is thus committed to act as a representative of the community and to lobby for change targeting European legislators and institutions, while promoting outreach, education and transparency as means to downplay perceived risks.

The question of regulation and governance is equally central, however, in the discussions over funding and sustainability of DIYbio labs and activities. The movement has benefited from decreasing prices in DNA synthesis techniques, and also from recent crises and technological accelerations that have generated used and out-of-date equipment that is today donated or available at low-cost in auctions. Another source of resources is crowdfunding campaigns in Kickstarter and Indiegogo sponsoring new alternative forms of funding and also legitimacy for scientific and technological projects. New possibilities emerge in this regard considering "research objectives that have been left aside because of

[61] http://2014.igem.org/Team:Genspace/Safety

[62] Winston, J. (2012) European network aims to legitimise biohacking Science, *Wired*, 12 December, Available at: http://www.wired.co.uk/news/archive/2012-12/12/biohacking-europe

economic reasons, or which were considered as trivial, pointless or even unethical, can gain in importance as the financial and symbolic support increases and reaches a critical amount. Decisions on the meaning and the importance of innovations and liabilities are partly shifted to a non-expert public sphere." (Seyfried et al 2014: 551).

When the discussion veers towards government funding, the tensions and divergences within the community tend to be more pronounced. As Phillip Bowen, a member of the London Hackspace, has stated, "there are people who would like there to be more rules and regulations in order to secure grants and funding for community projects. Others are very resistant to that" (Ireland 2014). A part of the DIYbio community strongly upholds the philosophy of independence, freedom and decentralization, while fearing that accepting governmental grants may hinder their autonomy to speak freely or to pursue their work in their own choice of direction[63]. A number of discussions are held within the community about government and private funding, and its implications for DIY activities and original purposes[64].

If the goals of independence and freedom can be said to be the core of the DIYbio movement, at the same time they stand out as the main reasons why governments and other organizations distance themselves from further funding their activities. As a response to the report by the Woodrow Wilson International Center for Scholars, *Nature* (2013) published an Editorial where it argues on one hand, that governments should support the DIYbio movement because at the end it would provide them with more control over their work. But on the other hand, "governments, of course, cannot become more involved in supporting this movement without taking a more proactive role towards regulation. (…) The security and stability of government funds would safeguard the future of the DIYbio movement; the issue is whether the movement would accept the trade-offs that such stability would bring".

The question of funding and governance is certainly important and is being pursued by the DIYbio community. In 15 October 2013, DIYBio Europe was invited by the COST (European Cooperation in Science and Technology) office for a meeting entitled "A bottom-up approach to disseminate information for public attendance". COST's scientific members of the Trans-Domain Action were interested in knowing more possible connections to citizen science, and also more particularly on the DIYbio Code of Ethics and its implementation and interpretation at the local level. For instance, they asked questions "whether the acceptance of American military funding by La Paillasse in Paris would comply with such an ethic framework"[65]. It referred to a 7500$ grant obtained by La Paillasse from SpaceGAMBIT, funded by NASA and DARPA, to develop a low-cost and open-source bioreactor accessible to all. In the end, COST and DIYbio Europe stated their common interest in crowd sourced science, open science and effective science communication, but still more to discuss on the question: "how to combine the strive by DIYBio for independence of academia with the will to cooperate".

[63] SpotOn Editor (2012) SpotOn NYC: DIY Science – How do we make DIYBio sustainable?, 13 December. Available at: http://www.nature.com/spoton/2012/12/spoton-nyc-diy-science-how-do-we-make-diybio-sustainable/

[64] https://groups.google.com/forum/#!msg/diybio/ELrK_oF9H8U/rwbWZW605QkJ, https://groups.google.com/forum/?fromgroups=#!topic/diybio/ys_HwtaY9Pg

[65] van Boheemen, P. (2013) DIYBio Europe meets COST, 7 November 2013. Available at: http://waag.org/en/blog/diybio-europe-meets-cost

## 2.4 DIY Projects – a selection

| Name | Description | Promoter | Year |
|---|---|---|---|
| Wikihouse | Open Source construction set that allows anyone to design, download and print CNC-milled houses and components, which can be assembled with minimal formal skill or training | London (UK) as original chapter | 2011 |
| Open Source Ecology | Set of open source blueprints for industrial machines (50 most important machines that it takes for modern life to exist, from a tractor, to an oven, to a circuit maker) that can be made for a fraction of commercial costs, with online free designs | International | 2003 |
| DIY forest surveillance kit | Open source hardware and software DIY forest surveillance kit. Resulting video streams and collected data are expected to be uploaded and then become part of the online platform network for crowdsourced surveillance and artistic manipulation purposes. | Lisbon (Portugal) | 2012 |
| ECLECTIS: European Citizens' Laboratory for Empowerment | Several smart citizen laboratories, such as construction of mini foldable spectrometers and conversion of cameras to multispectral Infragram cameras to map surrounding areas | Creative Learning Lab, Waag Society (Netherlands) | 2013 |
| Apps for Climate Change | A workshop to create citizen science apps by and for local communities, for data gathering and real-time information sharing. Applications range from wildlife and habitat monitoring, to environmental measurement, to infectious disease measurement & tracking. | Mozfest, London (UK) | 2014 |
| Barrow Hacking for the Climate | A workshop for high school students to be introduced to basic skills, such as micro-controller hacking and mobile app design, and to encourage them to start their own citizen science projects | The Mobile Collective, Alaska (USA) | 2014 |
| Sensorium | Citizens recorded sensordata by using SensPods, mobile sensorkits connected to Android telephones, while walking a pre-designed route. After gathering data of levels of CO2, small particles or noise, they were asked to visualize their data in various ways: by turning their data into a soundscape opera and by making 2D and 3D maps both in paper and in lasercutted wood. | Federal University of Groningen and Sensoris (Netherlands) | 2012 |
| Mapping for Change Hackathon | A hackthon for developers to produce a new prototype of Community Maps (mapping platform that allows many to map what interests them locally), to develop ideas for integration with other platforms and to discuss ideas the next generation of participatory mapping. | University College of London (UK) | 2014 |
| Science Hack Day | A 48-hour-all-night event that brings together designers, developers, scientists and other geeks in the same physical space for a brief but intense period of collaboration, hacking, and building 'cool stuff' | International grassroots network | Since 2010 |
| OpenCube | Open Source and generic plug-and-play nanosatellite platform for research and technology demonstration missions | International | 2011 |
| Tranquility Aerospace | Vertical take-off, vertical landing, reusable rocket for the launching of payloads both suborbital and LEO from the UK | Oxford (UK) | 2013 |
| Open Bioreactor | Open-source personal desktop bioreactor that will enable anybody to grow automatically necessary | La Paillasse, Paris (France) | 2013 |

| | | | |
|---|---|---|---|
| | materials or biologically synthesize molecules, with the least amount of energy possible | | |
| Space Hacker Workshop | Introduces citizen scientists and hardware hackers to the experiment flight opportunities: microgravity and suborbital science, the XCOR Lynx spacecraft, the Lynx Cub Payload Carrier, and how to build suborbital payloads | Citizens in Space, United States Rocket Academy (USA) | 2013 |
| Hackerspace Earthship | Air-tight closed circuit system to sustain the life of a human by recycling all waste via employing cutting edge sensors, computer automated atmosphere control, and various biological systems to breakdown and transform waste back to vital nutrients, clean water, and air | USA | 2013 |
| LightSight | Open-source system for the fabrication of extremely low cost parabolic mirrors for the use in amateur telescopes | MAGLAB, Pomona (USA) | 2013 |
| Foldscope | Origami-based print-and-fold optical microscope that can be assembled from a flat sheet of paper and costs less than a dollar in parts. It provides over 2,000X magnification with sub-micron resolution (800nm), weighs less than two nickels (8.8 g), is small enough to fit in a pocket (70 × 20 × 2 mm3), and requires no external power | Stanford University (USA) | 2014 |

Looking more closely into some DIY emblematic projects, we present for instance:

**Smart Citizen Project**
http://www.smartcitizen.me/

Smart Citizen is a platform to generate participatory processes of the people in the cities. Connecting data, people and knowledge, the objective of the platform is to serve as a node for building productive open indicators and distributed tools, and thereafter the collective construction of the city for its own inhabitants. The Smart Citizen project is based on geolocation, Internet and free hardware and software for data collection and sharing, and (in a second phase) the production of objects. It connects people with their environment and their city to create more effective and optimized relationships between resources, technology, communities, services and events in the urban environment. Currently it is being deployed as initial phase in Barcelona city. The project is born within Fab Lab Barcelona at the Institute for Advanced Architecture of Catalonia.

Figure 2.1 Smart Citizen kit
Source: https://www.flickr.com/photos/99346985@N04/9424061296 (CC BY-SA 2.0)

**Open Source Beehives**
http://www.opensourcebeehives.net/

The Open Source Beehives project is a network of citizen scientists tracking bee decline. It uses sensor enhanced beehives and data science to study honeybee colonies throughout the world. The technology and methods, from the hive and sensor kit designs to the data, are documented and made openly available for anyone to use. One of the pilots is 'Barcelona Warré', tested at Valldaura Labs and Fab Lab Barcelona together with the Open Tech Collaborative in Denver Colorado. The hive is a vertical top bar type and follows a tradition of natural beekeeping methods. Either hive can be freely downloaded, installed to a CNC router machine, and cut from a standard 4x8 sheet of material, such as plywood. The project is developing a sensor kit that will allow users to monitor bee colony information and upload the data to the Smart Citizen platform. All generated data will be viewable and downloadable by anyone. Their first Alpha Kit is being developed with audio, temperature, infrared, and humidity sensors. Later versions will include VOC sensors to monitor for foreign chemicals, scales to monitor honey production, and web cameras to give visual information about the colony.

Figure 2.2 Barcelona Warré - Open Source Beehives
Source: http://www.opensourcebeehives.net 

**Balloon Mapping Workshop**

The workshop "Defiende el territorio desde el aire" took place in Castellon, Spain, in January-February 2014. Participants used balloon mapping kits, digital cameras and digital cartographies to map territories affected by Spanish real estate bubble, and thus to support ongoing local environmental struggles that were already taking place for the defense of the territory. All the information produced was licensed under free licenses and is available online. The workshop was promoted by Basurama, a nonprofit organization for discussion and reflection on trash, waste and reuse in all its formats and possible meanings, and the Public Laboratory for Open Technology and Science (PLOTS), a non-profit and a community of activists, educators, scientists, technologists, community leaders, and organizers that develop and apply open-source tools to environmental exploration and investigation.


Figure 2.3 Balloon Mapping Workshop
Source: http://publiclab.org/notes/pablo/02-12-2014/mapping-with-balloons-in-castellon-and-building-community (CC BY-SA 3.0)

**OpenROV**
[http://www.openrov.com/](http://www.openrov.com/)

OpenROV is an open-source, low-cost underwater robot for exploration and education, and its global community ranges from professional ocean engineers to hobbyists, software developers to students. It's a welcoming community and everyone's feedback and input is valued. It is capable to reach 100 meter/328 feet of seawater, more than double the depth of recreational SCUBA divers. When driving the ROV on a moderate power setting, you get 2 hours or more battery setting. The source code as well as the hardware design are open and extensible. The idea to build it wa pioneered by Eric Stackpole, an engineer at NASA at the time, David Lang, a self-taught sailor from Minnesota, and Matteo Borri, who designed and built the electronics, software and motor system for a prototype. The project started in a garage in Cupertino, California, and was funded in 2012 on Kickstarter.

Figure 2.4 OpenROV
Sources: http://www.openrov.com/ (CC BY-NC-SA 3.0)

**Glowing Plant**
[http://www.glowingplant.com/](http://www.glowingplant.com/)

The Glowing Plant project seeks to engineer a Arabidopsis thaliana plant to emit weak, green-blue light by endowing it with genetic circuitry from fireflies, though long-term ambitions include the development of glowing trees that can be used to replace street lights, reducing CO2 emissions by not requiring electricity. It was the first crowdfunding campaign for a synthetic biology application, which was launched in Kickstarter on 23rd April 2013, reached its initial funding goal of $65,000 after just three days on April 25th, and finished with $484,013 on June 7th. The project sparked controversy, under fears that distributing the plants could set a precedent for unsupervised releases of synthetic organisms, and might foster a negative public perception of synthetic biology.

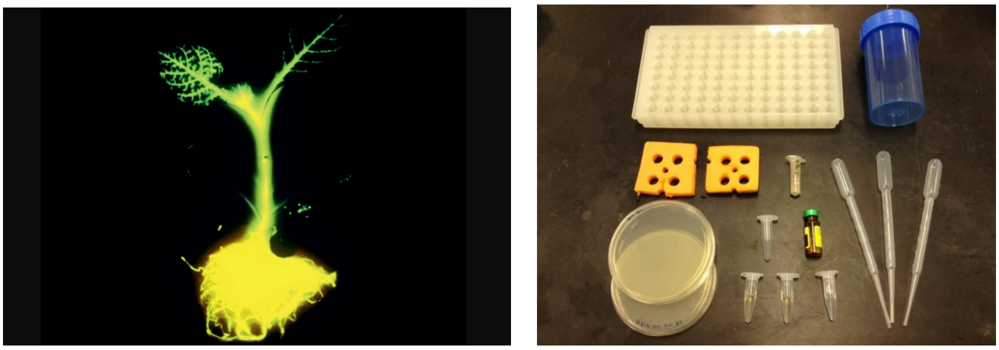

Figure 2.5 Glowing Plant and Maker kit
Sources: http://www.glowingplant.com 

## OpenPCR

OpenPCR is a project to develop open source hardware, software, and protocols to perform PCR and Real-Time PCR reactions, and a community dedicated to openness in science and applying the fundamental technologies of PCR to global problems. The device is a low-cost ($599) thermocycler you build yourself, capable of reliably controlling PCR reactions for DNA detection, sequencing, and many other applications. This is useful for example to determine whether an individual is infected with HIV or Malaria, or whether leafy vegetables are contaminated with E. Coli or Listeria. The OpenPCR project stemmed out of DIYbio in 2010 when Josh Perfetto and Tito Jankowski designed the original OpenPCR thermocycler, and the project was formally sponsored by Chai Biotechnologies in 2013, which funded the development the Open qPCR Real-Time PCR instrument.

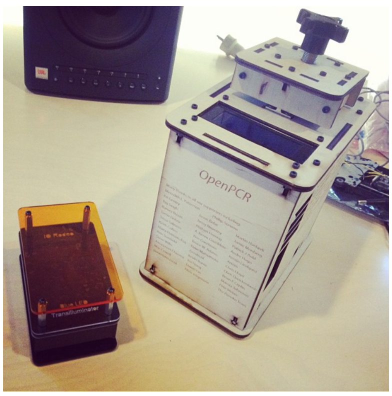


Figure 2.6 OpenPCR
Source: https://www.flickr.com/photos/wilbertbaan/8807883411 

**Amplino**
http://www.amplino.org

Amplino is a Netherlands based start-up that is developing affordable, portable diagnostics based on real time PCR technology. The team is building a device and specific cartridges to meet the need for sensitive and selective pathogen detection in the world. The name Amplino is the combination between Arduino and amplification (PCR is a method for amplifying segments of DNA). One of its projects is a low-cost malaria detection device/kit that offers the same reliability as laboratory machines, but now usable in the field for rapid diagnostic. The testing device is connected via Bluetooth to a mobile phone, making it possible to track malaria outbreaks and the spread of particular strains. The team just won 40,000 EUR ($52,000) in the 2012 Vodafone Mobile for Good competition to further develop the kit.

Figure 2.7 Amplino (prototype)
Source: https://www.flickr.com/photos/amplino/11477060514 (CC BY 2.0)

## 3. Trends and Reflections

The number of projects that invite citizens into the scientific endeavour has been growing rapidly. This is not only demonstrated by the increasing number of publications documenting the experiences of citizen science but also the increasing number of projects (with on-line presence) across a number of fields over the last decade.  The development of ICT and in particular the development of cheap Internet access, mobile and personal gadgets, development of low-cost sensors, the rise of a digital culture and an increase in literacy are all factors that contribute to voluntary engagement of citizens in the citizen science call. It is interesting to see that major institutions have now their own citizen science dedicated web pages such as *NASA* and *Nature Conservancy*, as well as journals like *Nature* or other scientific magazines like *Scientific American* which have dedicated sections only to citizen science projects.

Alain Irwin's imagination of a citizen scientist in the 1990s has been largely developed into citizens being limited to activities that feed into the scientific establishment. In other words, citizens respond to the call of scientists to engage as data collectors (sensors!), resources suppliers or players of projects that originate in the scientific community, therefore responding to questions from the scientific community, which are not necessarily the questions of (non-scientist) individuals or from the society in general. Many of these projects claim also a didactic function as well as influencing of behaviours. In Institutionally led citizen science projects, the modes of enquiry and ethics code are of course those of the scientific community. The majority of the projects we found are also "safe" to the extent that the involvement of citizens is *a priori* justified by the noble cause of scientific discovery, curiosity and knowledge sharing in issues that are likely to raise little controversy, such as space observation, biodiversity, visible pollution monitoring, etc.

However, as documented here, there is an emerging movement that instead relies on projects that are initiated and developed by individuals or groups that do not have any affiliation with the scientific establishment. Even in the cases that these individuals and groups have a scientific affiliation or background, their initiatives do not align with conventional or prescribed institutional rules. Here we described some on-going "do it yourself science" projects that somehow respond to community-based questions across several fields. They rely on personal or crowd-funding, "do it yourself", open source tools and kits, garages and "non-authorised" spaces to perform their activities. In addition their forms of enquiry and of knowing are not necessarily scientific to the extent that they recognise different ways of knowing and thus allow for more out-of-the-box thinking and experimentation. In some communities ethic codes have been developed (in the DIY biology for example); in others the discussion is mildly present (in general across the communities that develop IT gadgets).

In a critique to Cooper *et al.* (2007), Shyamal (2007b) argues that "Citizen science should ideally move away from using citizens on unequal terms and toward treating citizens as scientists on equal terms. Indeed, if anything, acts of information centralization should embrace the concepts of open access and freedom, allowing all to conduct science." As a matter of fact, our analysis of the language used reveals the well known dichotomies of experts and non-experts, reinforces the legitimacy of science as the privileged way of knowing in addition to relatively poor agency of citizens to influence the research processes they engage with.

Hence, we would like to counteract the notions of citizen science that attribute to citizens mere functional tasks in projects for which they have next to no agency or sometimes even engaged as human subjects. Instead, we see the value of projects where reciprocal social learning, where those involved share agency both on the questions asked, the framing of the research and the outcomes to be delivered. As Newman *et al.* (2012) pointed out current technologies stimulate creative endeavours for both scientists-driven and community-driven research endeavours. The co-existence of different projects is not problematic or harmful, quite the contrary. But what seems problematic to us is that citizen science as presented by many of these [useful] initiatives is represented as democratisation of expertise or citizen empowerment about societal matters where the *de facto* underlying assumptions and motivations lie with the "deficit model" and "public understanding of science". Hence Citizen Science should not be offered as a proxy, institutionally supported endeavour of some form of citizen engagement to substitute a deeper call of citizen engagement that instead recognises other legitimate forms of knowledge, voices and imaginaries of public engagement.

In fact, most of the definitions of citizen science provided by the projects we have reviewed in section 1 are akin to what Bonney (1996; 2004) had described as "citizen science", hence scientist-driven public research projects and not so much what Irwin (1995), i.e. "Citizen Science' evokes a science which assists the needs and concerns of citizens – as the apologists of science so often claim. At the same time, 'Citizen Science' implies a form of science developed and enacted by citizens themselves" (*Op. cit.).* Section 2 of this report describes projects that are more akin with this latter definition.

At the European Commission it seems to us, through many framework projects of research the endeavour of deepening the interface between science and society has been going on for sometime. The latter efforts are called "Science with and for Society"[66], Responsible Research[67] and Innovation as well as Open Science[68].

As this report is written in the context of the latter, we would like to make the following considerations:

(1) As we have discussed citizen science or DIY science are not Open Science (or Science 2.0 for that matter). But we concur that from a citizen engagement perspective, fostering the mechanisms that further *open* Open Science requires it to accommodate practices and spaces that engage citizens in the questions that need to be investigated in order to resolve societal challenges, as well as make space for different epistemologies and ontologies with regards to knowledge production, assessment and governance.

(2) Definitions of engagement of citizens in the scientific endeavour that see science as legitimating and not empowering (Irwin, 1995) are missing the point of how the digital culture in particular has been changing knowledge production, citizen agency and ultimately innovation and creativity or the very meaning of 'science'.

(3) The DIY movement in the sciences is quite powerful as we have discussed, even considering issues of quality and ethics, where the traditional means to 'control' those are no longer applicable. In addition, other understandings of quality, openness and ethics are being experimented and experienced by both developers and users.

(4) The call by the European Commission President Junckers for citizen dialogue and citizen engagement in policy making (and policy relevant science for that matter) upon the generalised crisis of trust of citizens in the European project would be fruitless if these types of movements are not only taken into account, but actually engaged with as they are happening grassroots and seem to represent now the *safe* spaces where many citizens act and walk the talk of citizen engagement in science and more generally in the societal

[66] http://ec.europa.eu/research/swafs/index.cfm?pg=home
[67] http://ec.europa.eu/programmes/horizon2020/en/h2020-section/responsible-research-innovation
[68] http://ec.europa.eu/research/consultations/science-2.0/consultation_en.htm

challenges that afflict our societies at the moment.

# 4. References & Bibliography

## 4.1 Citizen Science

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# Annex 1

## *Table A.1*

| Name | Description |
|---|---|
| Great Backyard Bird Count | The Great Backyard Bird Count is one of the largest citizen science efforts in the world. |
| Survey Katydids in Your Neighborhood | Cricket and katydid survey in the Washington DC area. |
| The Lost Ladybug Project | Help with finding out where all the ladybugs have gone so researchers can try to prevent more native species from becoming so rare. http://www.lostladybug.org/ |
| iSeahorse | Ocean creatures, add new data to science, and influence conservation policy with iSeahorse. |
| Spotted Bat Survey | Did you ever wonder if bats migrate? This citizen science project is finding out so that conservationists can protect species where they live and travel. |
| Hawaii Challenge | Keep Hawaii beautiful by locating invasive plants for the Hawaii Challenge |
| FrogWatch USA | go on a treasure hunt with FrogWatch USA to support declining amphibian populations. |
| Field Scope | This is the age of big data, but once you have all of that data, what do you do with it? If citizen scientists are gathering the data, how can they enter it quickly and easily? FieldScope answers these questions. |
| Butterflies and Moths of North America | Make natural history by submitting your butterfly and moth pics to BAMONA. |
| Horseshoe Crab Survey | The Horseshoe Crab Spawning Survey |
| Snapshot Serengeti | photo safari in the Serengeti to research carnivores & their prey |
| CondorWatch | Zooniverse's new project CondorWatch lets you do all of this at once. |
| Pika project | Pikas need to stay cool (they can die from temperatures of 78 °F or over), they will be one of the first species affected by climate change and there are already signs that they are changing their behaviour. |
| oldWeather | Voyaging with the mariners of oldWeather and improve data for climate models. |
| NestWatch* | track the reproductive success of birds and improve understanding of challenges they face with NestWatch. |
| BudBurst | record when trees bloom and wildflowers blossom to help Project BudBurst track the effects of climate change |
| Eurasian Collared Dove: Have You Seen This Bird? | Thirty years ago, non-native Eurasian collared doves were starting to show up in South Florida. Today, this species is being documented across North America. How citizen scientists help document the spread of a non-native species. |
| Monarchs Journey North | Why do monarchs migrate? How do they know when to go to Mexico? How do they know where to fly? |
| Wildlife CSI | How does the local wildlife behave around the compost heap? Wildlife CSI is on the case. Join a crack team of sleuths that includes crowbots. Yes, crowbots. |
| Microplastics Project | Have you heard of microplastics? Every time you wash your clothes, you release 2 000 into the water system. |
| Victorian Malleefowl Recovery Group | Ever heard of a malleefowl? You'll never forget it after reading about their big feet, huge nests, and chicks born fully feathered that can fly within 24 hours. |
| Penguin Watch | Contribute to science by looking at photos of adorable penguins, seriously. Give Penguin Watch a chance. |
| Floating Forests | Citizen science that protects an entire ocean ecosystem without traveling or learning to dive |
| Schaefer Prairie Preserve | Project began by volunteer in 2010 and their first report was for 2011-2012. The early years of the project provide baseline data that can be |

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|---|---|
| Citizen Science | used to track changes in the prairie over time. |
| SeaNet | Survey Atlantic beaches to help sea bird conservation with SEANET. The Seabird Ecological Assessment Network (SEANET) is a collaborative citizen science effort to identify threats to seabirds. |
| COASST | Coastal Observation and Seabird Survey Team (COASST), a partnership led by the University of Washington, is your chance to learn about the marine environment while contributing baseline data for conservation science. |
| JellyWatch | JellyWatch was launched in 2010 with the support of the Monterey Bay Aquarium Research Institute (MBARI) as a citizen science effort to improve the data on jelly populations. |
| OtterSpotter | Otter Spotter is the citizen science project of the River Otter Ecology Project (ROEP) and they need your help to learn more about North American river otters and the ecosystems that they inhabit. |
| Firely Watch | Firefly Watch is a project dedicated to finding out more about firefly populations and they need your help. |
| Butterfly BLitz | By monitoring butterflies in local areas through annual counts, over time we can learn about changes in surrounding habitats or timing of butterfly flight and how species may be expanding where they live |
| National Moth Week | The vast majority of moths are important as indicators of ecosystem health. There are between 150 000 and 500 000 species and they come in all sorts of colours, shapes and sizes. |
| Rocky Mountain Amphibian Project | A citizen science program that’s looking for amphibians in Wyoming |

### *Table A.2: Citizen science companion Apps*

| App | Purpose |
|---|---|
| Audubon Birds, iBird Pro, National Geographic Birds, Peterson Birds, and Sibley eGuide to Birds | Bird Watch |
| Secchi | Mobile interface to the Secchi Disk project, which encourages mariners to participate in a global study of the phytoplankton in the sea. Phytoplankton support the marine food chain and scientists need help understanding the effects of climate change on their habitats. |
| Wildlife tracker | Researchers use motion-detecting cameras to remotely study animal activities and behaviours. Photos taken by these cameras can help scientists understand how humans and domestic animals may be impacting wildlife. Citizen scientists can help scientists and learn about the wildlife of the Santa Cruz Mountains in particular by using the Wildlife Tracker Facebook app. |
| **mPing** | Created as part of the Precipitation Identification Near the Ground project, the mPing app asks citizen scientists to report on precipitation. The goal is to aid meteorologists at the National Severe Storms Laboratory in developing and refining algorithms that use the newly upgraded dual-polarization NEXRAD radars. |
| **What's Invasive,** IveGot1, SEEDN, Mid Atlantic Early Detection Network, EDDMapS West, Outsmart Invasive Species | Invasive species often threaten native plants and animals, and experts need to know where to find them. That's the main idea behind these Apps, which are developed for different regions in the USA. |
| **Loss of the Night, Dark Sky Meter** | For a project that measures and seeks to understand the effects of light pollution on health, environment and society. Users take part in a worldwide citizen science project—called GLOBE at Night — by mapping light pollution and star visibility. The results are added to a database that scientists use to investigate the reasons for the increasing illumination of the night, its ecological, cultural and socioeconomic effects as well as the impact on human health. |
| **Kinsey Reporter** | Global mobile survey platform for sharing anonymous data about sexual behaviours. The data collected with the app is aggregated and shared openly at KinseyReporter.org, a joint project of the Kinsey Institute for Research in Sex, Gender and Reproduction and the Center for Complex Networks and Systems Research. |
| **Marine Debris Tracker** | To find and log marine debris items on beaches or in the water. The app is a joint effort of the National Oceanic and Atmospheric Administration (NOAA, USA) Marine Debris Division and the University of Georgia's Southeast Atlantic Marine Debris Initiative. |
| Creek Watch | By monitoring the health of local waterways, including water amount and trash, participants can help watershed groups, agencies and scientists track pollution and manage resources. |
| NoiseTube | Allows citizen scientists to participate in the collective noise mapping of their city or neighborhood. NoiseTube has three features: measure noise, localize it and tag it. Tags include the level of annoyance and the source of sound, such as an airplane. The collected data is wirelessly sent to the NoiseTube server in real time. Free Univ. of Brussels and SONY. |
| Project Noah | Tool for nature enthusiasts who want to explore and document wildlife. Noah is an acronym for "networked organisms and habitats" and is designed to help labs, environmental groups and various organizations gather important data for research projects. New York, USA. |
| CoCoRaHS | It's one of the most viable, most used, most reliable, most accurate "citizen scientist' network in North America... http://cocorahs.org/ |
| Brunalab apps | Field biologists can use in their fieldwork; it includes citizen science apps. http://brunalab.org/apps/ |

## *Table A.3: Citizen science in Health*

| Project | Description | Organisation |
|---|---|---|
| Care pages | Share your story. Build your support circle CarePages.com is an online community with over a million unique visitors a month who come together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. | Care pages<br>https://www.carepages.com/<br>USA 2008 |
| CureTogether | From 2008 CureTogether is a health research project that brings patients and researchers together to find cures for chronic conditions, acquired, in 2012, by 23andME. | ,http://curetogether.com/ |
| e-patient net | The Society for Participatory Medicine is devoted to promoting the concept of *participatory medicine*, a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners. | http://participatorymedicine.org<br><br>http://e-patients.net/To encourage |
| e-patient Dave | A voice of patient engagement. | http://www.epatientdave.com/<br>USA, from 2009 |
| Doctor Chat | E-health App. created and developed by physicians for physicians (patients' data are anonymised).<br>Discussion groups and share experience, with picture and video. | http://www.doctorchat.org/#home |
| Doctor Chat | Medical advice service open to all citizen in Colombia. | Fundación Santa Fe de Bogotá<br>http://www.fsfb.org.co/?q=node/220 |
| Pazienti | Portal with forum and free Q&A, chats with specialists and video consultations. | . Pazienti.org S.r .L.<br>http://www.pazienti.it/Pazienti.it |
| OpenNotes | Patients and clinicans on the same page.The project makes accessible notes doctors write about their patients> patients become more actively involved in their care. | BethIsrael medical centre, UW Medicine<br>http://www.myopennotes.org/<br>USA 2010 |
| JGZ Kennemerland | Web community for family and children care, using different SN and media: Twitter, Facebook, Instagram, Pinterest, Skype, Tumblr<br>Crowdsourcing with immediate feedback | http://jgzkennemerland.nl/ |
| Transparency Life Sciences | Transparency Life Sciences is an open innovation drug company that crowd sources improvements to clinical trial protocols | http://transparencyls.com/ |
| Cures within Reach | The world's first open-participation research platform to explore whether drugs, devices and nutriceuticals approved for one or more human diseases can be repurposed to create "new" treatments in other diseases. | http://www.cureswithinreach.org/welcome |
| CAFEH the Community Assessment of Freeway Exposure and Health Study | Larger umbrella for five community-based participatory research (CBPR) air pollution studies. Combines community and academic resources to advance scientific understanding of the health risks of highway pollution. | Tufts University<br>http://sites.tufts.edu/cafeh/ |
| HUD Clean Air Project (CAP) | Is a sub-study of the CAFEH study being conducted in Somerville at the Mystic River Housing Development. Participants complete three surveys and attend three in-home clinicals. An in-home HEPA air filtration unit and air monitoring equipment is installed in the participant's home for a period of 6 weeks. | http://sites.tufts.edu/cafeh/project-description/hud-clean-air-project-cap/ |
| A Community-Based | This project will conduct environmental | http://www.northeastern.edu/research/ |

| | | |
|---|---|---|
| Participatory Research (CBPR) investigation of traffic pollution and cardiovascular disease (CVD) in Puerto Rican adults | monitoring using a mobile air monitoring laboratory at the homes of participants to characterize the ultrafine particulate profile (UFP), test associations between measured levels and roadway proximity and traffic density; and test associations of UFP with inflammatory markers, blood pressure, and CVD risk factors. | limitedsubmissions/nimhd-community-based-participatory-research-cbpr-initiative-in-reducing-and-eliminating-health-disparities-planning-phase-r24 |
| Community-Institutional Partnerships for Prevention Research Group | Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum presents an opportunity to explore the practice of CBPR as an innovative approach for improving health. The curriculum intends to foster critical thinking and action on issues impacting CBPR and community-institutional partnerships. | Community-Based Public Health Caucus of the American Public Health Association http://depts.washington.edu/ccph/cbpr/intro/intro.php#j |
| Gardenroots | The overall objective of *Gardenroots* was to determine whether home garden vegetables grown in Dewey-Humboldt had elevated levels of arsenic. | Dewey-Humboldt, AZ community University of Arizona ttp://www.superfund.pharmacy.arizona.edu/projects/community-engaged-research/gardenroots/home |
| Step Up. Step Out! | Step Up. Step Out! Began as a research study conducted by the University of South Carolina's Prevention Research Center in partnership with Sumter County Active Lifestyles and the Sumter County Recreation and Parks Department. As a result of the program, the participants who stayed in the program for 24 weeks increased their level of moderate or vigorous intensity physical activity by 40 minutes a day. Now, Step Up. Step Out! is available to everyone! | University of South Carolina Sumter County Active Lifestyles and the Sumter County Recreation and Parks Department http://www.sumtercountyactivelifestyles.org/StepUpStepOut/ |
| Milwaukee Consortium for Hmong Health | The goal of this pilot project is to increase rates of breast and cervical cancer screening and reduce cancer morbidity and mortality among Milwaukee Hmong women through development and implementation of culturally - appropriate lay health education and peer mentoring programs | http://www.mkehmonghealth.org/Projects/Current/?lg=en |
| TransPulse | The Trans PULSE Project is a community-based research (CBR) project that is investigating the impact of social exclusion and discrimination on the health of trans people in Ontario, Canada. | http://transpulseproject.ca/ |
| Gateway project | The Gateway Project is recruiting participants on the autistic spectrum and participants with and without disabilities for a series of continuing Internet-based research studies on topics such as health care, well-being, and problem solving. | AASPIRE http://thegatewayproject.org/ |

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