

Open Science for Non-Specialists: Making Open Science Meaningful Outside the Scientific Community

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Abstract

One of the major goals of the open science movement is to make more scientific information available to non-specialists, but it has been difficult to achieve that goal in a meaningful way. This paper argues for two steps to help address this weakness: (1) placing greater focus on the kinds of scientific *content* that are most relevant to non-specialist audiences; and (2) focusing more attention on “*packaging*” that content in meaningful ways for those audiences. The paper uses a case study involving a major environmental health issue (namely, widespread human exposure to PFAS pollution) to illustrate how the proponents of open science can work with groups like government agencies, nongovernmental organizations, and extension programs to implement these two steps.

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1. Introduction

The open science movement is a major trend in contemporary scientific practice. According to a report from the National Academy of Sciences, “Open science aims to ensure the free availability and usability of scholarly publications, the data that result from scholarly research, and the methodologies, including code or algorithms, that were used to generate those data” (NAS 2018, p. 1). Open science can include a wide variety of activities: making scientific data and research materials more widely available (Leonelli 2016), preregistering studies before performing them (Kupferschmidt 2018), discussing study designs and techniques with others while performing experiments (Schapira and Harding 2019), posting preprints before studies are published (Callaway 2013), making published papers freely available (Else 2018), and making peer review processes more transparent (Ross-Hellauer 2017). Major motivations for this movement include speeding scientific innovation, making scientific results more reproducible, and providing greater public access to scientific information (see e.g., NAS 2018; Royal Society 2012).

Despite the importance of this movement for the scientific community and for society at large, it has received very little attention in the philosophical literature. One of the few philosophers to focus on this topic is Sabina Leonelli, who has scrutinized open data initiatives in her book, *Data-Centric Biology: A Philosophical Study* (2016). She has also examined open science more broadly in a series of articles (e.g., Bezuidenhout et al. 2017; Leonelli et al. 2015; Levin and Leonelli 2017). One of the important themes in her work is that the goals of the open

science movement cannot be achieved solely by placing scientific information in the public domain. Rather, for scientific information to be meaningful to recipients it needs to be labeled appropriately (Leonelli 2016), and those receiving it need access to resources for interpreting it (Bezuidenhout et al. 2017). Building on this insight that open science initiatives need to be designed in ways that make information meaningful for target audiences, Kevin Elliott and David Resnik (2019) have raised the worry that most open science initiatives are designed primarily for the benefit of expert scientists rather than for non-specialist audiences.

In response to Elliott and Resnik's concerns, this paper examines how the proponents of open science can better achieve the goal of providing information in a manner that is meaningful to non-specialists. Section 2 argues for two steps: (1) placing greater focus on the kinds of scientific *content* that are most relevant for non-specialist audiences; and (2) focusing more attention on "*packaging*" that information in a manner that is meaningful to those audiences. Section 3 examines a case study about the emerging human health hazards associated with per- and polyfluorinated alkyl substances (PFAS) in order to illustrate some of the measures that could be taken to implement these two steps. The case study shows that the proponents of open science can advance their goals of making scientific information available and meaningful for non-specialists by working strategically with organizations like government agencies, nongovernmental organizations (NGOs), and extension programs.

2. Open Science for Non-Specialists

One of the significant limitations of the open science movement is that even though its proponents emphasize the goal of making information available to non-specialists, the major

initiatives associated with the movement are not well designed for achieving that goal in a meaningful way (Elliott and Resnik 2019). As emphasized by a European Commission-funded research project called FOSTER Plus, the two open science initiatives that receive the most focus are open data (i.e., making the data underlying publications publicly available) and open access to scientific publications (i.e., making publications available without “paywalls”; de la Fuente n.d.). It is fairly obvious, however, that open data are of little use to most non-specialists because most people have very limited abilities to understand or make use of large, complex scientific databases. Making scientific publications freely available is somewhat more useful, but most people are still unlikely to be able to understand the details of those publications. Other initiatives that are commonly discussed as part of the open science movement (e.g., preprint servers, registries of trials, open lab notebooks, and open peer-review processes; Brock 2021) are similarly opaque to most non-specialists.

One could argue, of course, that having this information openly available can help non-specialists in indirect ways. For example, making the data that underlie scientific studies publicly available could enable other researchers to scrutinize the data and identify weaknesses in those studies, thereby ultimately benefiting non-specialists. This is probably true, but it does not capture the lofty goals of many proponents of open science. In its influential overview of open science, for instance, the British Royal Society stated, “A realistic means of making data open to the wider public needs to ensure that the data that are most relevant to the public are accessible, intelligible, assessable and usable for the likely purposes of non-specialists” (Royal Society 2012, 8). This quotation clearly expresses the goal of making scientific materials like data directly usable by interested members of the public.

This paper argues for two steps that can help make open science more meaningful to non-specialists. First, the movement can place greater focus on the kinds of scientific content that are most relevant to non-specialist audiences. Second, they can focus more attention on packaging that content in meaningful ways for those audiences. This section introduces both of these steps, and the following section illustrates how the proponents of open science can potentially work with a range of organizations to help achieve them.

Content

In the course of critiquing the open science movement, Elliott and Resnik (2019) hint at a solution that could help to alleviate their worries. They clarify that most people do not care about all the details released as part of most open science initiatives; rather, people typically care about the “take-home lessons” from scientific research projects and the major value judgments associated with those lessons (Elliott and Resnik 2019, 3). Building on this point, one way to make the open science movement more relevant to non-specialists is to consider the content that is most useful and relevant to specific non-specialist audiences and develop initiatives that focus more attention on communicating that content. As a starting point, this paper focuses on two kinds of content: *important value judgments* and *personally relevant data*.

The recent philosophical literature on value judgments in science is extensive (see e.g., Brown 2020; Douglas 2009; Elliott 2017). This literature has shown that scientists make a wide array of judgments that can have important social ramifications; for example, these judgments can involve the choice of research projects, the design of studies, the development of models, the interpretation of results, the choice of standards of evidence, and the framing of scientific

findings. For non-specialists trying to make decisions that draw on scientific information, these judgments can be extremely important. For example, depending on the situation, people might want to know the major strengths and weaknesses of the available scientific information, the reasons why some studies disagree with others, the major gaps in existing evidence, or the major issues on which scientists agree and disagree. Science journalists can sometimes play an important role in making this information available to the public (Elliott 2019), but given the fragility and upheavals in contemporary journalism (Gerber 2014), it is important to consider a variety of avenues for making this content available to those who need it.

Another important kind of content that often matters to non-specialists is personally relevant data. Even though most people have little interest in all the data underlying scientific studies, they do frequently care about specific kinds of data that are relevant to their health or well-being. For example, during surges in the COVID-19 pandemic, people cared deeply about the infection rates in their states and cities, and during the water crisis in Flint, Michigan, residents wanted to know the lead levels in their drinking water. In general, people also care about their personal medical data and the ways those data could help them make better decisions about their healthcare. Of course, this data can still be difficult to digest and understand, which is part of why it is not only important to focus open science initiatives on the content that matters to people but also on the best ways of packaging that content.

Packaging

In addition to developing initiatives that focus on the content that is most relevant to specific non-specialist audiences, the open science movement can enhance its relevance by

“packaging” the information it releases in meaningful ways. The concept of packaging used in this paper is multi-faceted; it can include not only the analysis and description of scientific content but also the people or institutions who provide it. This paper’s discussion is inspired by Leonelli’s analysis of the systems used for packaging open data (see e.g., Leonelli 2016). Her starting point is the assertion that “making data available online does not automatically make them usable” (Leonelli 2016, 25). In other words, it is not enough merely to encourage or require scientists to make their data publicly available in repositories; those data need to be organized in ways that make them meaningful to others. Two of the important elements of the packaging system discussed by Leonelli are labels and curators. The creation of labels involves both the use of “bio-ontologies” (i.e., terms that refer to each entity or process under investigation) and metadata (i.e., descriptions of the conditions under which data were obtained). Database curators are in charge of “decontextualizing” data so that they can be used beyond the settings in which they were originally collected, and they also help database users to “recontextualize” the data so they can be used in new contexts (Leonelli 2016, 30-31). As Leonelli puts it, the careers of these curators “depend at least in part on their ability to identify, embrace, and constructively engage with as many epistemic cultures in biology as possible” (2016, 32).

In addition to discussing the roles played by labeling systems and curators, Leonelli (2016) also emphasizes the importance of institutions and organizations that facilitate the transfer of data from one context to another. She focuses especially on bio-ontology consortia, which are organizations that help to develop the labels and standards used by databases. These consortia, like the Open Biomedical Ontology consortium or the Gene Ontology consortium,

provide opportunities for two-way communication among data curators, data users, and those who play a regulatory role in open data initiatives (e.g., journal editors and funders). Leonelli also discusses less formal social media structures like wikis, which provide additional opportunities to crowdsource the tasks associated with curating and annotating data (Leonelli 2016, 54).

These lessons about the importance of packaging are just as relevant (if not more so) for those seeking to make scientific content available to non-specialists. For scientific information to be useful to such groups, a variety of conditions need to be met. People need to be aware of the information. They also need to have access to it (e.g., through websites or social media or newspapers or print sources). In addition, the information needs to be understandable and contextualized in a meaningful way. Significantly, just as curators need to understand different groups of scientists in order to help them decontextualize and recontextualize information for their purposes, the open science movement needs people who can play the same role for non-specialist audiences. Information that might not otherwise be particularly helpful for non-specialists (e.g., open access papers or trial registries or online databases of scientific data) can become useful if they are packaged (i.e., explained, interpreted, and contextualized) appropriately. The following section uses a concrete case study to illustrate what this packaging of relevant scientific content can look like and to explore some of the existing organizations that can help make this possible.

3. A Case Study: Communicating about PFAS Chemicals

As the open science movement strives to communicate information more effectively to non-specialist audiences, it can build on a number of initiatives that are already taking place. This section uses a case study involving toxic chemicals called PFAS to show how three kinds of organizations (government agencies, NGOs, and extension programs) can help achieve the two steps described in the previous section: (1) communicating scientific content that matters to non-specialists; and (2) packaging that content in meaningful ways. Thus, those who seek to promote open science for non-specialists can potentially collaborate with these organizations and strengthen their work.

Human exposure to PFAS is one of the most important emerging issues in contemporary environmental health research and policy (Blum et al. 2015). PFAS are organic molecules made up of chains of carbon atoms bonded to fluorine atoms and other chemical groups. They have stain- and water-repellent properties that have made them a popular component in non-stick cookware, stain-resistant carpets, water-repellent clothing, food-packaging material, and fire-fighting foams (Buck et al. 2011). Unfortunately, because of the strength of carbon-fluorine bonds, these chemicals are extremely difficult to break down, and thus they are highly persistent in the environment (Cordner et al. 2019). These chemicals also tend to bioaccumulate in living organisms, and some of them cause health problems such as high cholesterol, cancer, problems with immune function, and low infant birth weight (Blum et al. 2015). People are exposed to these chemicals through daily activities as well as through releases from contaminated sites. More than six million U.S. residents appear to be exposed to problematic levels of PFAS in their drinking water (Hu et al. 2016), and some communities (e.g., those living near military bases or airports that released fire-fighting foams into the

environment) face particularly high levels of exposure. Two of the most studied PFAS compounds, perfluorooctanoic acid (PFOA) and perfluorooctanesulfonic acid (PFOS), have been voluntarily phased out of use by industry (Cordner et al. 2019), but there are thousands of chemicals in the PFAS family, and relatively little is known about many of them. This section explores how government agencies, NGOs, and extension agencies engage in activities that proponents of open science can build on to make their work meaningful to non-specialists.

A Government Agency: The Agency for Toxic Substances and Disease Registry (ATSDR)

The ATSDR is a U.S. federal agency associated with the Centers for Disease Control (CDC). Its mission is to help communities address hazards posed by natural and human-made substances, including emergencies posed by spills or chemical releases. ATSDR's communication efforts related to PFAS illustrate not only efforts to make relevant content known to different communities but also strategic packaging of that content. First, the ATSDR provides basic information about PFAS on its website in an easy-to-understand format for members of the public who just want relatively simple information.¹ For those who want somewhat more detailed information, the ATSDR gives people advice about how to talk to their physicians about potential PFAS exposures.² This is an important step because physicians can potentially contextualize (i.e., package) scientific information about PFAS and explain it in an understandable and relevant manner that meets the needs of specific patients. To assist with

¹ <https://www.atsdr.cdc.gov/pfas/health-effects/index.html>

² <https://www.atsdr.cdc.gov/pfas/health-effects/talk-to-your-doctor.html>

this process, the ATSDR provides a fact sheet to update physicians on scientific findings about PFAS.³

The ATSDR's fact sheet for physicians provides a further illustration of how science communicators can attend both to relevant content and to the packaging of that content. With respect to content, the fact sheet not only provides an overview of animal and human studies regarding the potential health effects of PFAS, but it also highlights important value judgments that could be relevant to physicians and patients. For example, it clarifies that most of these studies identify correlations rather than establishing causal relationships, it identifies cases where different studies provide conflicting results, and it distinguishes cases where there is stronger versus weaker evidence. With respect to packaging, the fact sheet takes evidence that is already in the public domain (e.g., open access publications) and digests it in a manner that is understandable for physicians. In 2020, the ATSDR solicited guidance from a committee of the U.S. National Academy of Sciences (NAS) in order to update its fact sheet to reflect the latest evidence about PFAS.⁴ The NAS committee waded through a great deal of published information that would have been difficult for most physicians and patients to understand and evaluate. By working with the NAS, the ATSDR is packaging the available information about PFAS in a manageable format for physicians, and those physicians can in turn pass on the most relevant information in an understandable way to their patients.

An NGO: The Silent Spring Institute

³ <https://www.atsdr.cdc.gov/pfas/docs/clinical-guidance-12-20-2019.pdf>

⁴ <https://www.nationalacademies.org/our-work/guidance-on-pfas-testing-and-health-outcomes>

NGOs can also play a particularly valuable role in making information accessible and usable by non-specialists. The Silent Spring Institute is one of the NGOs that has been particularly engaged in communicating about PFAS. Silent Spring was founded in 1994 in response to community concerns about high breast cancer rates in towns on Cape Cod, Massachusetts. Since its founding, the institute has broadened its focus to include a variety of health effects related to chemical exposures. One of Silent Spring's distinctive features is its emphasis on community-engaged research projects, which provide opportunities for members of the public to collaborate with scientists on research projects that address their concerns. These projects provide unique opportunities for identifying content that matters to particular individuals or groups and packaging it in ways that are meaningful to them. For example, the institute has organized a crowd-sourced biomonitoring study that measures people's exposure to ten common toxic chemicals. Members of the public can pay to submit urine samples using kits developed by the institute, and they receive personalized reports with their results, including guidance on ways to reduce their exposure to the tested chemicals.⁵ Thus, in addition to producing general scientific knowledge about the public's chemical exposures, this project provides scientific content that matters to people (i.e., personally relevant data) and packages it in a meaningful way (namely, by contextualizing the data in a manner that enables people to alter their behaviors and enhance their health).

Silent Spring is involved in a similar community-engaged research project in the case of PFAS. The PFAS-REACH project is a collaboration between scientists at Silent Spring, Michigan State University, and Northeastern University. The project has three main goals: (1)

⁵ <https://www.silentspring.org/detoxmeactionkit/>

to assess the effects of PFAS exposures on children in two communities that have been exposed to high levels of water contamination; (2) to develop an online center (the PFAS Exchange)⁶ with information resources for contaminated communities; and (3) to conduct a social-science analysis of the effects of contamination on these communities.⁷ As part of the project, the investigators are committed to reporting back individual results to participants about their PFAS exposures, and they are designing their online information center to help the participants (and other members of the public who are tested for PFAS exposures) interpret their results. Thus, as in the case of Silent Spring's other community-engaged research projects, this project provides an excellent example of supplying relevant content (i.e., personally relevant data) and packaging it in a meaningful way.

The X University Extension Program

[NOTE: Details about the university and state where these extension activities occur are removed from this draft to facilitate blind review.] Another avenue through which publics can obtain information about PFAS is through extension programs. In the United States, the Smith-Lever Act of 1914 created a system of extension services connected to the land-grant university in each state. The goal of the Smith-Lever Act was to promote the flow of information from researchers working in these universities to farmers and other community members who could benefit from their research. Traditionally, the extension services included offices in every county of every state, and they focused particularly on food and agricultural issues. They have

⁶ <https://pfas-exchange.org/>

⁷ <https://silentspring.org/project/pfas-reach>

expanded their focus over time to include educational opportunities for both children and adults related to a range of environmental and economic topics. Some of the scientists working for extension services are county extension agents (based in local county offices), while others are extension specialists who work in departments at the land-grant universities (Bursten and Kendig 2021). This provides a unique system for communicating relevant scientific content and packaging it in ways that matter to specific non-specialist communities.

For example, in the state of X, high-levels of PFAS contamination have been identified in the waterways surrounding the now-closed X Air Force Base, where PFAS-laden fire-fighting foams were released into the environment. Another major contamination site is in X, where there is widespread PFAS contamination from waste disposal sites associated with the X company. The people living in these affected communities are highly motivated to gain greater knowledge about PFAS so they can reduce their personal exposures and engage in more effective community activism to force the clean-up of contaminated sites. X University recently created a Center for PFAS Research, which provides an excellent potential resource for these community members who want to obtain cutting-edge information from experts studying PFAS. Nevertheless, mechanisms are needed for connecting the members of affected communities with the Center and its researchers.

The X University extension service provides one avenue for creating these connections. For example, the X Center for PFAS Research includes an extension specialist. As part of their communication efforts, this specialist organized a series of meetings designed to inform county extension agents about the latest scientific information regarding PFAS.⁸ Some of those

⁸ The information in this paragraph was obtained through personal communication with X on February 11, 2021.

meetings included university researchers studying PFAS, representatives from the state task force working on PFAS, and even staff from the office of one of the state's federal senators. The extension specialist also organized "Speed Meetings" (similar to speed dating) to introduce county extension agents to university researchers working on PFAS. One of the goals of these efforts was to create a situation in which community members could reach out to their county extension agents for assistance, and those agents would be equipped to either answer questions directly or reach out to university scientists they knew who could help them identify and interpret the desired information. In this way, extension specialists and county extension agents play a role much like the curators of the databases discussed by Leonelli (2016), insofar as they link those who produce scientific content with those who need it while helping to package the content in meaningful ways.

Opportunities for the Open Science Movement

This brief examination of the PFAS case illustrates that the proponents of open science can potentially make progress in achieving the two steps described in section 2 by collaborating with organizations like government agencies, NGOs, and extension agencies and strengthening their activities that contribute to open science. For example, those seeking to promote open science could encourage government agencies to use their significant financial resources to make the scientific information at their disposal more useful to non-specialist audiences (just as the ASTDR did by convening an NAS committee to improve their fact sheet). Along these lines, the U.S. National Aeronautics and Space Administration (NASA) recently launched an excellent initiative called HAQAST. It funds university researchers to use NASA's publicly

available data to answer questions that local communities have about their air quality (Holloway et al. 2018). This is an excellent example of an effort to take openly accessible government data that would otherwise be of little use for non-specialists and packaging it (i.e., analyzing and interpreting it) in ways that matter to specific non-specialist communities.

Proponents of open science can also encourage and support the work of NGOs, which are often uniquely suited to identify scientific content that matters to non-specialist audiences and package the information in meaningful ways. Unfortunately, they often have limited funds available to do their work. Highlighting their contributions to open science could help justify additional funding for them. For example, the U.S. National Institute of Environmental Health Sciences (NIEHS) typically focuses on university research projects, but because of the Silent Spring Institute's ability to enhance the PFAS-REACH project's outreach to affected communities, the NIEHS is helping to support this NGO's work.

Proponents of open science could also help to revitalize extension programs. These programs have struggled to maintain their funding and justify their relevance in recent years (Rivera 2011; Wang 2014), resulting in lost staff and less ability to engage with community members. Nevertheless, as discussed earlier in this section, these programs could help achieve meaningful open science for non-specialist audiences. Extension programs are not only able to provide unique opportunities for two-way communication between non-specialists and university researchers, but they can also facilitate community-engaged research projects much like those organized by the Silent Spring Institute (Ryan et al. 2018; van de Gevel 2020).

4. Conclusion

This paper explored how the open science movement can become more meaningful to non-specialists. It argued for two steps: (1) placing greater focus on the kinds of scientific *content* that are most relevant to non-specialist audiences; and (2) focusing more attention on *packaging* that content in ways that are meaningful for those audiences. It used a case study involving science communication efforts about the health hazards associated with PFAS to illustrate how the proponents of open science can help achieve these steps by working strategically with organizations like government agencies, NGOs, and extension programs.

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