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ORIGINAL ARTICLE

Experimenting with Open Innovation in Science (OIS) practices: A novel approach to co-developing research proposals

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ABSTRACT

Co-producing scientific research with those who are affected by it is an emerging phenomenon in contemporary science. This article summarizes and reflects on both the process and outcome of a novel experiment to co-develop scientific research proposals in the field of Open Innovation in Science (OIS), wherein scholars engaged in the study of open and collaborative practices collaborated with the "users" of their research, i.e., scientists who apply such practices in their own research. The resulting co-developed research proposals focus on scientific collaboration, open data, and knowledge sharing and are available as an appendix to this article.

Keywords: Open Innovation in Science (OIS); co-production of scientific research; co-development of research proposals.

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THE PURPOSE AND PROCESS OF CO-DEVELOPING RESEARCH PROPOSALS

Scientific knowledge production across all disciplines is facing a productivity crisis marked by increasing incrementalism (e.g., Chu & Evans, 2021). Meanwhile, leading publications are emphasizing the co-production of scientific research as a potentially powerful remedy to this development (*Nature* 2018, 2021, Fortunato et al. 2018, Beck et al. 2021). Co-production of scientific research refers to the joint effort of producers (i.e., academic scientists[1]) and "users" of scientific knowledge. Here, users can take diverse forms such as active peer-users like practitioners or researchers using existing studies to do further research (e.g., Rappert 1997); end-users such as patients who undergo treatment and therapies based on medical research, farmers benefiting from agricultural research, or companies from management research (e.g., Joho et al. 2010); and science hobbyists who engage with science, whether for purely intellectual reasons (e.g., Corin et al. 2017) or to make use of scientific knowledge in shaping public discourse, including as anti-science activists (e.g., Swim et al. 2014). Following the logic of use-inspired basic research (cf. Pasteur's quadrant in Stokes (1997)), the underlying rationale is that considerations of use trigger the identification of novel and relevant problems as well as potential solutions. The experiential knowledge of users may contribute unique inputs to guide future research efforts, especially when this knowledge is distant from the pool of knowledge of the scholars involved (Caron-Flinterman et al. 2005, van de Gevel et al. 2020, Guinan et al. 2013, Fleming & Sorenson 2014, Pols 2014). It is thus not surprising that in the hope of increasing the societal and scientific impact of research, policymakers, funding institutions, and advocacy groups are increasingly calling for the involvement of users of scientific research in early stages of scientific knowledge production (Beck et al. 2020, Mazzucato 2018).

As a result of these developments, we have recently seen a number of research projects and agenda-setting initiatives that emphasize the importance of engaging with the users of scientific research on equal footing to actually co-produce research (cf. Nature 2018, Arnott et al. 2020, Chambers et al. 2021). As part of the SPOMAN Open Science initiative at Aarhus University (https://spoman-os.org), for example, real-world problems and the needs of industrial enterprises have been collaboratively translated into fundamental research questions and related projects in the material sciences. But the potential gains of the co-production approach come along with high costs and failure rates (e.g., Gulati et al. 2012, Shrum et al. 2001), requiring an improved understanding of processes for and contingencies in successfully co-producing scientific research. This article adds to this understanding, by sharing insights about the process and outcome of a novel experiment used to co-produce scientific research proposals. More specifically, we explore what the design of a process for co-developing research proposals involving scholars and users of knowledge in a specific scientific research discipline can look like, and what challenges arise when doing so. By answering this research question, we shed light on the organization of scientific knowledge production and contribute to the science of science field.

The development of a well-constructed research proposal is often a critical early step in the research process and can determine to what extent scientific knowledge and the knowledge frontier are advanced (e.g., Punch 2000). Research proposals typically comprise a problem that should be investigated and a related research question that links this problem to somebody of existing knowledge, as well as outlining a research design that will allow investigators to answer the research question raised or test related hypotheses (Krathwohl & Smith 2005). For scientists, a research proposal is an important tool used to systematically outline their research ideas and, by doing so, to obtain feedback from their scientific communities and/or convince funding organizations of the scientific merit and societal impact of turning their ideas into actual research projects.

The experiment resulting in this article started at the annual international Open Innovation in Science (OIS) Research, which took place online due to the COVID-19 pandemic (see Figure 1 for an outline of the process). The conference aims to bring together OIS scholars, i.e., scholars who are interested in better understanding whether, how, and under what conditions openness and collaboration influence the novelty, efficiency, and/or impact of scientific research. To study the role and value of openness and collaboration in science, our community of OIS scholars is determined to "walk the talk" by experimenting with open and collaborative approaches in our own research. In an attempt to explore the value of use-inspired basic research, we invited users (in particular, end-users) of *our* research (i.e., scientists from across different fields who

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[1] In this context, we focus on scientists whose primary place of employment is an academic research organisation (i.e., universities and research institutes). We do not, in making this distinction, offer any judgment about the value or quality of the scientific knowledge produced by independent researchers or scientists employed at other types of organisations. However, we see the distinction as relevant because academic and non-academic actors are influenced by different institutional logics (e.g., importance of scientific publications for career advancement) that influence their decision-making and, in turn, their open and collaborative behaviour (Sauermann & Stephan 2013).

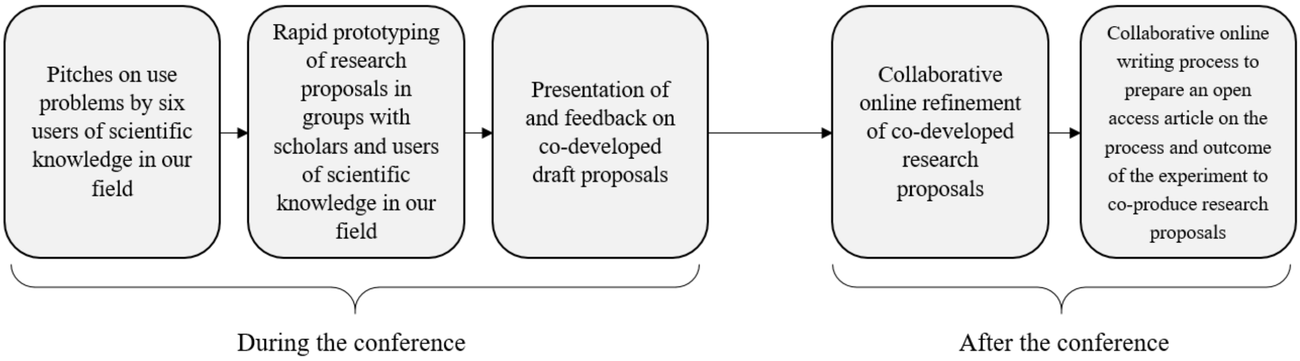

Fig. 1. Illustration of the process used to co-develop research proposals.

use open and collaborative practices in *their* research – OIS users) to 1) share their experiential knowledge on problems that they encounter when applying open and collaborative practices in their work, and 2) co-produce research proposals together with us.

In a special conference session kicking off this experiment, the six invited end-users of knowledge on the role and value of openness and collaboration in science (coming from fields as diverse as quantum physics, behavioural neuroscience, cancer research, human rights, biomedical engineering, and antimatter studies) introduced the most challenging problem that they had faced when applying various open and collaborative practices in their own research (step 1: problem pitching, 30 min). The types of problems the OIS users outlined in these introductory pitches ranged from how to involve people in positions of vulnerability as co-researchers to clarifying what influence scientific team composition has on knowledge sharing between competing groups (see next section for summaries and Appendix B for the full proposals). In step 2 (rapid prototyping of research proposals, 60 min), the OIS scholars participating in the experiment were divided into six breakout groups, together with one of the above mentioned OIS users. Each group also included a pre-assigned facilitator, selected from among the OIS scholars, who in addition to engaging in the experiment themselves was asked to keep the time, ensure that every member of the group was heard, and remind the group to document the outcome of their prototyping process. To document the outcome of the group work and guide the proposal development process, the conference organizers provided a template structured around five questions:

1. From the existing body of knowledge, what do we know and what don't we know about the problem that was pitched by the OIS users?
2. Building on this discussion, what is a novel and relevant research question?
3. If applicable: What are potential hypotheses related to this research question?
4. How can the research question be answered or the hypotheses be tested?
5. What is the title of the research proposal?

After 60 minutes of focused discussions in the breakout groups, each group was asked to present an initial draft of their research proposal so as to obtain comments from all participants (step 3: proposal presentation, 30 min). The group working on the problem of knowledge sharing between competing teams, for instance, ended up presenting "*How is seniority within the team (e.g., postdoc vs. team leader) related to perceived costs and benefits of sharing/collaboration, and how does this shape attitudes towards sharing/collaboration?*" as one of their research questions and suggested studying it through a combination of interviews and case studies. All presentations were given by one of the OIS scholars in order to facilitate knowledge integration.

After the conference, all participants engaged in a multi-step online process (step 4: collaborative online refinement, 3 months) to further refine the proposals by consulting the relevant literature, further specifying the research question and focus of the proposal, and integrating the proposals into a scientific article (this article) written collaboratively by the entire group of co-producers who engaged in the experiment (step 5: collaborative online writing; see Appendix A for a detailed description of each step).

This article makes two main contributions. First, we share insights into a novel approach to integrating relevant problem knowledge gained from the users of scientific research into the process of developing research proposals. This approach goes beyond efforts to include token contributory efforts from different stakeholders when setting research agendas and suggests that collaboratively developing research proposals has significant potential to produce problem-inspired contributions to advancing the knowledge frontiers across different scientific disciplines. Co-developing research proposals does not only involve the identification of particular problems, but also includes collaborative learning as participants spot relevant gaps in existing knowledge, define related research questions or hypotheses, and develop an appropriate research design. Second, we share the results of this process (i.e., six concrete research proposals) in an open access publication in order to invite scholars interested in studying the role and value of openness and collaboration in science to take up these proposals and, more broadly, to make needed contributions to the emerging field of Open Innovation in Science (e.g., Dahlander et al. 2021, Gkeredakis et al. 2021, Vicente-Saez et al. 2021).

In the following section we present summaries of the six co-developed research proposals. We then conclude the article with reflections on the main challenges encountered during the co-development process as well as potential remedies (section 3).

A SUMMARY OF THE CO-DEVELOPED RESEARCH PROPOSALS ON OPENNESS AND COLLABORATION IN SCIENTIFIC RESEARCH

In this section we present a brief summary of each of the six co-developed research proposals. Please see Appendix B for the full proposals.

Proposal 1: How to reach the “unreachable” in collaborative research processes? *by Rosalia Bitterl, Amelie Dorn, Riold Furtuna, Melinda Goodyear, Barbara Heinisch, and Maria-Theresa Norn*

OIS use problem: Power differentials in collaborative research with vulnerable user groups

Proposal abstract: The Austrian Village Project, a series of codesign labs intended to develop innovative service redesign and practice approaches to supporting children of parents with a mental illness (Goodyear et al. 2019), involved stakeholders representing funders, service leads, managers, services users, and a range of professionals across the psychiatric, social services, and education disciplines. Using information gleaned from this project, we sought to answer the following research question: How can vulnerable users be effectively empowered and engaged in co-creation with professional users, experts, and researchers? The study design involves developing interventions and strategies that can effectively empower and engage users that are vulnerable, hard-to-reach, and affected by stigma and power differentials in order to create more meaningful involvement in research processes. The study will develop and implement interventions, the effectiveness of which will be tested in a randomized control study.

Proposal 2: From individuals to groups: The interplay between perceived competition, open governance, and Open Innovation in Science *by Carsten Bergenholtz, Wolfgang Lukas, Gernot Pruschak, Muhammed Sameed, Henry Sauermann, Christopher L. Tucci*

OIS use problem: Tensions in knowledge sharing among competing research groups

Proposal abstract: Different research groups at CERN sometimes pursue similar research agendas. However, they do not always share their intermediary results and findings with each other. Whereas prior research on knowledge sharing has largely focused on individual scientists, we propose to investigate predictors of sharing/collaboration between research teams. First, we consider that teams are typically composed of heterogeneous members, e.g., senior and junior scientists. These members may have different perceptions of costs and benefits of sharing/collaboration, e.g., related to competitive considerations or labor market opportunities, leading to potentially conflicting attitudes towards collaboration with other teams. Second, whether and how these diverging individual attitudes shape the team’s sharing/collaboration patterns may be related to internal governance structures, i.e., the degree to which decisions are centralized versus made openly by involving all team members. The proposal outlines surveys and interviews as possible approaches to examine these mechanisms empirically.

Proposal 3: Evidence-based policy for open data sharing *by Janet Bercovitz, Tiare-Maria Brasseur, Pablo D’Este, Michael Doser, Cornelia Lawson, Yajing Li, Philipp Tuertscher, Samantha Zyontz*

OIS use problem: Costs and benefits of openly sharing and/or reusing data are unclear

Proposal abstract: Policymakers, funding agencies, and academic journals increasingly promote open data sharing in science. Despite the potential benefits, this results in complex demands on scientists with regards to appropriate data selection and making the data interpretable and usable by others (e.g., in terms of data format, documentation, appropriate infrastructure, ownership rights, and associated costs). Thus scientists may be reluctant (or unable) to share their data (Tenopir et al. 2011) or use the data of others (Wallis 2013). To resolve the tension between what is expected from scientists and what they want (or can) do, we examine three questions: (1) *Why* do policymakers require data sharing? (2) *When* do the benefits outweigh the costs of sharing?, and (3) *How* do we measure the value of data sharing and the success of data sharing policies? We propose a mixed-methods design to identify and experimentally test potential policy levers and consequently develop successful data sharing policies.

Proposal 4: Co-creation beyond dialogue: Exploring multimodal approaches to involving research participants under conditions of compound stigma *by Fabian Hans, Nóra Katona, Marcel LaFlamme, Patrick Lehner, Silvia Marchini, Marisa Ponti, Angelo Romasanta, and Alexander Ruser*

OIS use problem: Barriers from multiple sources can hamper the co-production of research with those affected by it.

Proposal abstract: Although OIS recognizes the value of engaging diverse stakeholders in the scientific research process, it can be challenging to meaningfully involve stigmatised individuals in co-creation (as seen in the "Open Research Behind Closed Doors" project). Stigma from multiple sources, such as institutionalisation and intellectual or psychosocial disabilities, prevents marginalised actors from participating in research, exacerbating existing barriers such as language, power hierarchies, and access to technology. To address this challenge, our study takes a multimodal approach to involving institutionalised individuals and their families in research co-creation. Participatory mapping will be employed to explore the capabilities afforded and denied to research participants in an inclusive format that does not rely on written or spoken language. By going beyond accepted models of dialogue, this study will contribute novel insights into how stigmatised individuals can be engaged in vital research domains such as human rights and social innovation.

Proposal 5: Leveraging lead-user ideas and co-creating with a (large) community of patients *by Alex Cayrol, Clio Dosi, Despoina Filiou, Carolin Haeussler, Olga Kokshagina, Markus Mitterhauser, Julia Suess-Reyes, and Rubén Vicente Sáez*

OIS use problem: Tensions between research requirements and patient expectations in co-created medical research

Proposal abstract: The medical ecosystem is complex, highly regulated, cost-intense, and, because human health is involved, highly emotional. To put patients at the center, co-creation with patients has recently emerged as a promising method for developing innovative medical solutions. One of the pioneering projects is PATIO (PATient Involvement in Oncology), aiming to involve prostate cancer patients and people indirectly affected by the disease in research. Yet adequately addressing each of the co-creators' needs and expectations while running against time (the patients' average age at diagnosis is beyond 70 years) leads to critical tensions. Consequently, we ask: (1) How can we effectively involve patients in co-creation activities? (2) How can we co-design with patients to rapidly prototype and test concept ideas? (3) How can we conduct projects with communities of patients, caregivers, or relatives with different vulnerabilities in an ethical and responsible way? To tackle these questions, the proposal outlines participatory co-design methods, as the lead user method and experimental studies with different groups.

Proposal 6: Fair to share? Patients' returned value from data sharing: Accelerate science by enabling data sharing by design *by Agnes Effert, Christoph Grimpe, Harald Kleinberger-Pierer, Hila Lifshitz-Assaf, Francesco Moscato, Markus Nordberg, Janet Rafner, and Matteo Vignoli*

OIS use problem: Distribution of value between scientists, companies, and patients in the development of novel medical devices

Proposal abstract: When it comes to clinical research and development of new medical devices, patients are usually very keen to contribute with their data, as well as firsthand experiences, suggestions for improvements, and even a clear definition of current limitations of available solutions. Researchers and industry usually do not provide compensation (beyond sometimes remuneration for participation) for this involvement, as patients already typically feel rewarded by contributing to the improvement of therapies. However, with patients becoming more involved in the co-development and improvement of devices - often providing important insights, e.g., about product usability and design requirements and therefore leading to better products - questions have begun to arise as to whether and how their contributions should be rewarded. Consequently, we aim to study a novel model for a flexible and transparent "fair share" or return value for the input of patients, participants, and other actors involved in health care co-development activities.

REFLECTIONS ON THE PROCESS AND OUTCOME OF CO-DEVELOPING RESEARCH PROPOSALS

"For me it is interesting to see how people who have never met before, who have met online for an hour for the first time and come from different backgrounds, manage to put together this proposal." – Participant in the co-development process

The experiences of this co-development experiment involving both "end-users" and "producers" of knowledge on the role and value of openness and collaboration in scientific research (i.e., OIS users and scholars) bring to light a number of important benefits, while at the same time identifying several procedural challenges and potential remedies to them. In this section, we share our reflections on this process and its subsequent outcome in the hope that our efforts may inspire future attempts to co-develop research proposals in different scientific disciplines.[2] While a number of our experiences merit future discussion, we chose to focus in this article on two challenges that may be generally relevant to other efforts to co-develop research proposals: 1) the diversity of collaborators' backgrounds, including the knowledge that

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[2] We collected these reflections continuously during and after the experiment. Each individual and each group could share their thoughts and experiences either anonymously or by revealing their names. If relevant for the point made, we asked contributors to reveal their role (e.g., facilitator, OIS user, or OIS scholar).

actors bring into the co-development process and 2) the co-development process itself.

First, because diverse backgrounds are a key reason for the potentially powerful outcomes that co-developed proposals yield, this experiment purposefully sought to create diverse group compositions that included collaborators from "*different disciplinary backgrounds, bringing different but necessary pieces to develop the proposal"* (italicized quotes in this section drawn from participant feedback). Such diversity can also be at the root of several challenges, however, including issues related to the coordination of knowledge inputs and discrepancies in the expected and desired outcomes of the proposal development process. Regarding inputs, some participants noted that the OIS users (i.e., those scientists who pitched the problems they encountered when applying open and collaborative practices in their own research) "*inspired*" and "*stimulated*" the discussion, but also found it challenging to "*contribute if you don't know what is already known/not known*" about the OIS practice being discussed. OIS scholars stressed that this challenge could be overcome by not only listening to the "users" but also engaging with what they were saying, noting that "*'users' seem to have certain assumptions/prior beliefs about both the problem and the causes or potential solutions. [The] job of the team is to unearth implicit assumptions and question them.*" To what extent group members can put their diverse knowledge inputs to use therefore strongly depends on participants' engagement, i.e., their willingness and capacity to actively listen and, at times, to challenge others' statements, particularly when it comes to pre-existing assumptions about solutions to the problem. This requires a setup that encourages participants to contribute, regardless of their individual background, while catering to the different levels at which they want to, are able to, or feel comfortable with contributing (e.g., by letting people choose the topic to which they want to contribute).

As for the expected outcomes of the co-development process, we observed a tension between the desire to engage in immediate problem-solving (often by the "users") and a focus on identifying relevant underlying research gaps that could inspire the definition of new problem spaces and, thereby, accrue value in the academic credit system *("could this be published in a management journal")*. Balancing these priorities, as one participant noted, proved difficult: "*At about the halfway point, I was concerned that our group had focused too much on solving the problem at hand using (open and collaborative) methods with which we were already familiar and had not talked much about the OIS research gap that we hoped to close. Therefore, I made an effort to refocus our conversation in that direction.*" Others noted that some of these tensions arose because "*'users' often have ideas about potential solutions"* and that to better balance the different foci the group needed to *"take those [ideas] and think about the underlying assumptions: what construct does the 'user' focus on, what assumptions does s/he have about underlying mechanisms? Then brainstorm in the team what research has to say about these and where the open questions emerge.*" Similarly, several groups identified that it was important to "*listen carefully to the OIS user. Identify and question underlying assumptions or beliefs, as well as differing incentives for the OIS user and the OIS researchers.*" Predictably, the proposals emerging from this intricate process (see Appendix B) have a wide range of equally valuable outcomes on a spectrum ranging from basic to applied research (Stokes 1997, see also Schauz 2014 on the uncertain status of this distinction).

A second set of challenges related to the co-development process itself, particularly with respect to the decision-making process and the maintenance of participant motivation over the post-conference period—both of which were further exacerbated in an online setting. As one collaborator noted, "*Creating a proposal with a group of people you have never worked with before, and that has not yet gone through the typical phases of team development (forming - storming - norming - performing), seems challenging at the beginning. Doing so in an online context adds additional complexity.*" To overcome this challenge in the early stages of proposal development, participants emphasized that the facilitator played a critical role during the rapid prototyping of their proposal drafts at the conference. They valued the facilitator's capacity to structure and aggregate thoughts, particularly after the brainstorming session, and to transfer them into the proposal template.

Facilitators may also be a particularly strong asset when granted authority by group members to act as de facto decision-makers. One of the most challenging decisions to be made in the groups, for example, was which inputs to keep for the proposal: "*We collected all ideas as we aimed at coming up with as many aspects as possible. We discussed them also but we did not reject/delete any ideas as each of them might be valuable in the upcoming process.*" In addition to the facilitator, other approaches to achieving group decisions include providing structure through guiding questions and templates or setting time constraints; however, such measures may also reduce the group's potential to capture value from highly diverse backgrounds and knowledge assets at this early stage. One contributor found that a "*time constraint helped focus but also left little time to explore more angles and think more deeply*."

During later stages of the proposal development process, maintaining high levels of engagement became a significant challenge. As one group experienced, "*[the] kick-off at the conference went really well… The whole group engaged enthusiastically in co-developing the research proposal. The refinement of the research proposal also went really well with nearly all group members adding their thoughts to the document in the aftermath of the conference. However, the engagement level dropped drastically afterwards."* This was a particularly difficult challenge to overcome for groups that left important questions unanswered after the first stage, leading one contributor to observe that "*as long as the cornerstones of the conception have not been worked out, it is difficult to move to a pure working paper phase in which members individually and separately - without group consent - add in their thoughts.*" Some participants suggested that maintaining momentum and fostering a successful co-creation environment could be achieved by organizing regular (virtual) group meetings to further align thoughts through ongoing discussion. This approach allowed some groups to capture more diverse and novel ideas, while at the same time avoiding "*uncertainty as to whether the additions and changes* [made individually] *are in the best interest of the other members*". Ideally, the date(s) for these follow-up meetings could already be set during the initial event, for instance by "*scheduling a dedicated workday six weeks later, so that people could get it on their calendars.*"

In the process of overcoming these challenges, participants also observed a number of significant benefits both during their own group's collaboration and throughout the process of learning about the other co-developed proposals while writing this article. The first and perhaps most important of these emerges from the exposure that OIS scholars get to problems experienced by the end-users of their research. Despite - or maybe even as a result of - the fact that their research focuses on the antecedents, contingencies, and consequences of openness and collaboration in science, use problems may sometimes go overlooked. Exposure to challenges faced by OIS users can thus shift the perceived importance of one's own research focus and inspire entirely new directions that persist well beyond the completion of the group proposal. Second, collaboratively writing this article enabled all contributing co-authors to focus not just on their own proposals, but also to contribute to proposals from other groups through reviewing and commenting rounds (see Appendix A for an overview on the detailed process steps). This exchange proved to be particularly useful in the later stages of the co-development process, as two groups recognized the need to further specify their position in a common problem space and two others realized the complementary nature of their proposals. Future research should examine opportunities to scale this process up. Lastly, the societal implications encountered during this experiment would also merit further study. Despite inviting end-users who faced real-world problems within their particular fields to co-develop the proposals, there was no pre-defined connection to societal implications or benefits. Focusing specifically on societal problems, however, could make the co-development process a powerful tool to develop research proposals that better address societal challenges. In the future, this type of experimentation process could be carried out in creative multi-disciplinary spaces (e.g., CERN IdeaSquare, Living Labs, Design Factories). Such innovation spaces could lead to exciting use-inspired research proposals that pave the way for scientific breakthroughs and unexpected innovations. The fact that such creative spaces are also inhabited by students and young researchers could lead to interesting opportunities to further develop the resulting research proposals into actual projects. Linking co-development of research challenges with users working toward particular Sustainable Development Goals (i.e., SDGs) is already being tested at IdeaSquare and at the Aalto Design Factory as part of the ATTRACT initiative (Wareham et al. 2021, ATTRACT student projects, 2021). Another option would be to implement the co-development process in PhD training programs. For example, senior scholars could be engaged as mentors with students working toward particular SDGs as well as potential users. Such efforts can further extend pioneering projects that are already taking place as Challenge-Based Innovation student projects at CERN and at sites like the Aalto Design Factory (Product Development Project 2021).

In conclusion, even if co-developing scientific research proposals is not free of challenges, this experiment demonstrated that it is feasible to do so and to create direct value for both the producers and the users of scientific research. None of the groups involved in the experiment failed to produce a research proposal, and all participants followed through on their commitment to openly share the experiment's outcome as a publication. Hence, with remedies at hand such as skilled facilitators, a concise and engaging process, and a committed team, co-development can lay the groundwork for setting research agendas that trigger use-inspired research projects that both address relevant questions and advance theory. By sharing the purpose, process, outcome, and reflections on this experimental approach to co-developing scientific research proposals, we hope to encourage future co-development endeavours for the sake of producing more novel and impactful research across different scientific disciplines. Likewise, we hope to encourage future researchers interested in the co-production of scientific knowledge to address the limitations of our experiment, for example by empirically assessing and comparing the quality of the resulting proposals with others developed through a conventional process. Last but not least, we hope to encourage scientists who did not take part in this experiment but are interested in the problems outlined in the proposals (see Appendix B) to reach out to the co-authors, get involved in a project, and thereby contribute to the co-production of scientific knowledge about open and collaborative research.

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APPENDIX

Appendix A: Steps in the iterative refinement process of finalizing the research proposals.

The collaborative process is structured as follows:

Step description	Time horizon
Problem pitches by six "end-users" of OIS, i.e., scientists with different disciplinary backgrounds who have experienced OIS challenges in their work.	Each 3 minutes
Work in six groups, each of which includes one "end-user" of OIS and one facilitator, to co-develop OIS research proposals and present first research proposal ideas (5 min each).	2 hours
Refinement of research proposals by the six groups and writing of reflection notes on the collaborative process as it was experienced.	2 weeks
Critical and constructive review by the larger group of authors (i.e., participants in this OIS experimentation session).	2 weeks
Second round of proposal refinement by groups to address comments, write text, and shorten if necessary to meet requirements.	3.5 weeks
Finalizing the proposals; in parallel, drafting section 1 of the article (purpose and process of co-developing research proposals)	5 weeks
Critical and constructive review and revision of the first draft of section 1 (purpose and process) and collection of input for section 3 (reflections on the process and outcome) by the entire group of co-authors.	3.5 weeks
In parallel to the previous step: each group writes a 250 word abstracts of their proposal for the main body of the article – the full proposals are made available as an appendix.	3.5 weeks
Finalizing section 1 and synthesizing content for section 3. Coordinators reach out to individual contributors to resolve final comments.	1 week
Language and style editing.	2.5 weeks
Last review round by all co-authors.	1 week
Resolving remaining comments and preparing manuscript for submission to CERN IdeaSquare Journal of Experimental Innovation (CIJ).	2 weeks

Appendix B: Full research proposals.

Overview of proposals and authors:

Proposal and Title	Authors (alphabetical order)
Proposal 1: How to reach the "unreachable" in collaborative research processes?	***Rosalia Bitterl, Amelie Dorn, Riold Furtuna, Melinda Goodyear, Barbara Heinisch, and Maria-Theresa Norn*** (incl. 1 behavioral neuroscientist (user) and 5 OIS scholars)
Proposal 2: From individuals to groups: The interplay between perceived competition, open governance, and Open Innovation in Science	***Carsten Bergenholtz, Wolfgang Lukas, Gernot Pruschak, Muhammed Sameed, Henry Sauermann, and Christopher L. Tucci*** (incl. 1 quantum physicist (user) and 5 OIS scholars)
Proposal 3: Evidence-based policy for open data sharing	***Janet Bercovitz, Tiare-Maria Brasseur, Pablo D'Este, Michael Doser, Cornelia Lawson, Yajing Li, Philipp Tuertscher, and Samantha Zyontz*** (incl. 1 antimatter physicist (user) and 7 OIS scholars
Proposal 4: Co-creation beyond dialogue: Exploring multimodal approaches to involving research participants under conditions of compound stigma	***Fabian Hans, Nóra Katona, Marcel LaFlamme, Patrick Lehner, Silvia Marchini, Marisa Ponti, Angelo Romasanta, and Alexander Ruser*** (incl. 1 human rights scholar (user) and 7 OIS scholars)
Proposal 5: Leveraging lead-user ideas and co-creating with a (large) community of patients	***Alex Cayrol, Clio Dosi, Despoina Filiou, Carolin Haeussler, Olga Kokshagina, Markus Mitterhauser, Julia Suess-Reyes, and Rubén Vicente Sáez*** (incl. 1 cancer researcher (user) and 7 OIS scholars)
Proposal 6: Fair to share? Patients' returned value from data sharing: Accelerate science by enabling data sharing by design	***Agnes Effert, Christoph Grimpe, Harald Kleinberger-Pierer, Hila Lifshitz-Assaf, Francesco Moscato, Markus Nordberg, Janet Rafner, and Matteo Vignoli*** (incl. 1 biomedical engineer (user) and 7 OIS scholars)

Please see the full proposals below.

PROPOSAL 1: HOW TO REACH THE "UNREACHABLE" IN COLLABORATIVE RESEARCH PROCESSES? *BY ROSALIA BITTERL, AMELIE DORN, RIOLD FURTUNA, MELINDA GOODYEAR, BARBARA HEINISCH, AND MARIA-THERESA NORN*

OIS challenge: The challenge presented to the conference audience concerned the codesign process previously undertaken in the Austrian Village Project (Christiansen et al. 2019). The Village Project is funded as an Open Innovation in Science research project to codesign, implement and test new practice approaches to help address the needs of children of parents with a mental illness (Goodyear et al. 2019). Using OIS principles, the project undertook a significant process of codesign with stakeholders representing funders, service leads, managers, services users, a range of professionals across the psychiatric disciplines, social services, and education. This Village Project is coordinated by an interdisciplinary group of researchers with the support of a competence group consisting of young people with their own lived experience of growing up with a parent with a mental illness. A core dilemma throughout this process of codesign and the implementation of open innovation methods was in managing and creating the conditions for meaningful participation of all engaged stakeholders. Meaningful participation was important to ensure the codesign process was open and not driven by those more likely to hold the 'power' in this process, while also achieving a design outcome within the time limited project. The challenge is to achieve an open process alongside the 'power differentials' that arise when working with people with lived experience who might experience disadvantage, or the hierarchical differences that emerge across professions, sectors, and levels of seniority.

Research Question Development

What do we know about that OIS challenge from existing literature?

From existing literature, we know that involving users of research can be worthwhile and even necessary, for instance in order to access key insights needed in the research process and to increase the likelihood of uptake and diffusion of outcomes (Olmos-Peñuela et al. 2015, 2016).

A stream of research has focused on benefits and challenges of involving users in health and social care research (e.g. Wright et al. 2007, Barber et al. 2011, Domecq et al. 2014). Here users may be defined narrowly as patients or service users and their carers, or more broadly as possible patients, relevant community organizations and the like, health professionals, members of the general public, etc. (Wright et al. 2007).

Benefits of user involvement include, e.g., increasing the range of research topics, focusing research on issues that are important to users, more effective dissemination of findings, an accelerated uptake of research, more effective and 'user-friendly' trials and interventions, and more use-informed interpretations of evidence (Trivedi & Wykes 2002, McLaughlin 2010, Barber et al. 2011).

Effectively involving users in research processes is, however, no trivial task. Engaging users can raise a series of, e.g., legal, ethical, and practical issues which must be addressed by researchers (Beresford 2013). Others have pointed to the risk of user involvement in research taking on a tokenistic nature or being seen as a solution to all ailments (McLaughlin 2010). Moreover, involving users in research can challenge the autonomy of researchers and standard practices in the research process (Wright et al. 2007, Barber et al. 2011). Finally, there are also potential downsides for users, including for instance a risk of feeling exploited by the research process (McLaughlin 2010).

What don't we know about that OIS challenge from existing literature?

Another stream of literature has focused on a particular subset of health and social service users, namely vulnerable users. This stream of literature, e.g., describes key characteristics of vulnerable users, discusses ethical issues in research on vulnerable populations, and provides guidelines for undertaking research *on* and engaging *with* vulnerable or disadvantaged participants.

However, to the best of our knowledge, there have been limited efforts in the literature on user involvement to specifically address how vulnerable users may be involved as active participants in research processes. Vulnerable users are particularly likely to be at risk of negative experiences when being involved in research. Some vulnerable users, e.g., from low-income backgrounds, may be particularly lacking in prerequisites for contributing to academic research processes. Moreover, vulnerable users who participate in research processes may have to interact with professional users with whom they interact on a day-to-day basis, in a situation characterized by power differentials. Finally, vulnerable users are particularly difficult to reach and engage in research processes and may be negatively affected by stigma, perhaps associated with some of the very traits that make them relevant users to involve in a study.

Building on this, our research question is: How can vulnerable users be effectively empowered and engaged in co-creation with professional users, experts, and researchers?

Thus the aim of the study is to build insight into how users that are vulnerable, hard-to-reach, and affected by stigma and power differentials can be involved in research processes. In addition, the study has a particular interest in how different groups of users - including both vulnerable users and, e.g., professional users - can be brought into meaningful, effective interaction as co-producers in a research project.

How can the research question be answered (or the hypotheses tested)?

The setting for this study is a research project aimed at co-creating an approach to building child-centered support systems around children of parents with mental illness. One of the main challenges in this study is that developing such support systems requires not only fundamental changes to the healthcare system, and thus the involvement of experts and professional users, but that it also requires meaningful involvement of vulnerable or disadvantaged participants (parents with mental illness and their children who are at high risk of developing mental illness). For the project to succeed, these vulnerable participants must be encouraged to participate in the study and supported if they are to contribute effectively to the aims of the project. They must do so in collaboration with experts and professional users and thus in a context of substantial power differentials, which may negatively impact their collaborative and open participation.

The aim of the proposed study is therefore to develop, carry out, and test the effects of interventions aimed at:

1) EMPOWERING vulnerable participants to strengthen their self-efficacy and other factors that facilitate the desire to participate in the co-creation processes with experts and professional users by:
    (a) Addressing differences in prerequisites for participation and power differentials among, e.g., parents and children
    (b) Encouraging participation that builds a sense of reward
    (c) Helping vulnerable participants feel ‘safe’ enough to participate effectively

The focus here will be on providing vulnerable participants with the tools needed to engage in dialogue with professional users.

2) ENGAGING vulnerable participants themselves in the co-creation processes, exploring ways to increase their actual contribution to ongoing processes, and decreasing any passivity caused by hierarchical hurdles. In this way we can support productive interaction among vulnerable citizens and professional users while mitigating the negative effects of real and perceived power differentials.

The study is therefore designed as an intervention study, where vulnerable participants in each of the two elements of the study will be randomly allocated into either a treatment group (which will be subjected to the intervention) or a control group (i.e., waiting list control group) which will be subjected to the intervention after the post-test measurement.

This research project will be undertaken as a series of stages:

1) A series of interviews and co-design workshops will be run with the Austrian Village researchers, participants, and key stakeholders to develop the interventions for empowering and engaging vulnerable participants who might be involved in a codesign process. The advantage of utilising this group is that the project has used OIS principles which utilise a lead user approach, crowdsource-generated research questions, and an open codesign process to develop, implement, and test new innovations using transdisciplinary research practices and citizen science.
2) Development of an implementation guide to assist with delivery of the engaging and empowering interventions as part of a research process.
3) Testing and documenting the implementation of these strategies and the impact on the meaningful participation of different user groups in the mental health research field.

In addition, ethical concerns will be addressed with regards to the involvement of vulnerable participants and potential power imbalances embedded in the participation process.

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PROPOSAL 2: FROM INDIVIDUALS TO GROUPS: THE INTERPLAY BETWEEN PERCEIVED COMPETITION, OPEN GOVERNANCE, AND OPEN INNOVATION IN SCIENCE *BY CARSTEN BERGENHOLTZ, WOLFGANG LUKAS, GERNOT PRUSCHAK, MUHAMMED SAMEED, HENRY SAUERMANN, AND CHRISTOPHER L. TUCCI*

Research Question Development

OIS Challenge description and interpretation by the group: There are several large research groups ("experiments") at CERN (see Tuertscher et al. 2014). Some of these groups work in related research areas but do not share knowledge with each other. The Problem Pitcher believes that knowledge sharing would save time and resources, e.g., by avoiding duplication of research efforts.

Currently, decisions about the strategic direction of research groups and collaboration with other groups are made by project leaders. The pitcher believes that involving a broader range of group members (including junior members such as postdocs) would lead to more support for openness, e.g., because junior members are less concerned about competition between groups or may even see personal benefits from collaboration and sharing.

Based on the Problem Pitcher's statement and suggested solution, our team identified the first research question of interest (RQ1): *Does open governance within research teams (i.e., involvement of both senior and junior members) lead to more openness and more collaboration with other teams?*

When discussing this relationship, an important underlying assumption became clear: Team members differ in their attitudes toward sharing and collaboration, with junior members favoring openness more strongly than project leaders. Without this assumption, i.e., if all team members agree, open governance may not lead to different decisions than the traditional approach. This led to RQ2 (see Fig. 1): *Is the effect of open governance on sharing/collaboration moderated by the diversity in attitudes towards sharing/collaboration within the team?*

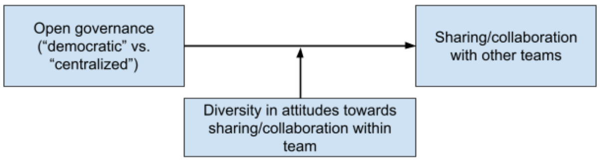

Fig. 1. Open governance, sharing/collaboration, and the moderating role of team diversity at the team level

Some of our team members challenged the underlying assumption of the Problem Pitcher, suggesting that it is not at all clear that junior members would favor openness more strongly than project leaders. For example, while junior members may see certain personal benefits from sharing/collaboration (such as opportunities for permanent employment positions), they may also see greater costs and risks (such as greater career risk if competing teams make discoveries first). This led to the more general RQ3: *How is seniority within the team (e.g., postdoc vs. team leader) related to perceived costs and benefits of sharing/collaboration, and how does this shape attitudes towards sharing/collaboration?* Fig. 2 illustrates potential relationships between these constructs as the basis for future conceptual and empirical work.

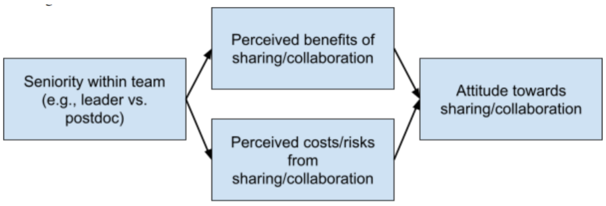

Fig. 2. Potential relationships between seniority, perceived costs/benefits and attitude towards sharing/collaboration at the individual level

What do we know about that OIS challenge from existing literature?

Our team identified several strands of literature that could inform a more detailed discussion of the relationships of interest:

Research on the organization of research teams and team governance. This literature distinguishes between conceptual and empirical research activities and shows that there is a division of labor between team members depending on factors such as coordination costs and team members' access to information and relevant knowledge (Walsh & Lee 2015, Shibayama et al. 2015, Haeussler & Sauermann 2020). A related strand of literature studies different governance designs and examines the factors that facilitate participatory decision making (Paulus et al. 2009, Schrotta 2011).

Research on openness and knowledge exchange between individuals and organizations in the sciences. This work examines the costs and benefits of knowledge sharing and openness at the level of both individuals and organizations (Haeussler et al. 2014, Keating 2018). This literature also documents the important role of both formal and informal knowledge sharing mechanisms (Schrader 1991, Bouty 2000, Tsai 2002). A key insight from this literature is that the level of sharing and collaboration will depend on perceived competition (MacAulay et al. 2020, Walsh et al. 2007).

Research on science and engineering career paths and labor markets. This work discusses the competitive nature of scientific labor markets, incentives and constraints that scientists face, and potential incentive conflicts between junior and senior scientists (Stephan 2012, Freeman 2001, Sauermann & Roach 2016). This work may help develop more specific predictions regarding how the perceived benefits and costs of sharing/collaboration may differ between junior and senior scientists.

What don't we know about that OIS challenge from existing literature?

Our reading of the literature cited above suggests important gaps. First, research on the organization of research teams has focused on the division of labor with respect to knowledge production, but says little about optimal decision making in scientific teams (perhaps reflecting long-standing norms that decisions are made by principal investigators). Second, most of the literature on knowledge sharing has discussed costs and benefits from the perspective of a single actor - either individual scientists or aggregate organizations. Apart from the literature on informal knowledge trading, there is little discussion of potential disagreements within organizations about optimal sharing/collaboration, and whether such disagreements can be addressed through open governance mechanisms. Finally, the literature on science and engineering careers focuses on the incentives and rewards for scientists as individuals. Although this literature has also discussed potential incentive conflicts between junior and senior scientists (e.g., with respect to authorship or the division of labor), it has not investigated whether career considerations may lead to conflicting attitudes towards openness and collaboration.

How can the research question be answered (or the hypotheses tested)?

RQ1 and RQ2 concern the team level of analysis. As such, quantitative analysis would require data on a large number of teams, using measures of governance, team diversity, and observed knowledge sharing and collaboration behaviors (see Fig. 1). At CERN, the number of research groups is limited, but each group is very large. This context may be more amenable for qualitative research into decision making processes within research groups and interactions between groups. This research could also gather rich qualitative insights into the perspectives of junior and senior members. It would be particularly interesting to compare governance and decision making processes across groups that seem to exhibit different levels of openness and collaboration. Archival data on knowledge exchange (e.g., meeting records) and on collaborations (e.g., co-authored articles) would also be valuable.

RQ3 concerns the individual level of analysis. If conceptual work based on existing theories does not lead to clear predictions regarding the relationships in Fig. 2, qualitative work (e.g., interviews and case studies) could be useful to build a stronger theory. If predictions are sufficiently strong, a survey of both junior and senior scientists could be used to test predictions. Among other findings, such a survey could collect data on individual status within the team (e.g., junior vs. senior), perceptions of different types of costs and benefits from knowledge sharing and collaboration, perceptions of governance, and realized sharing and collaborative behaviors. Having data from multiple members of the same team could be used to examine not only the consistency of perceptions, but also potential conflicts and disagreements. Measures of team size and scientific field should be collected as controls and could also serve to explore contingency factors.

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PROPOSAL 3: EVIDENCE-BASED POLICY FOR OPEN DATA SHARING *BY JANET BERCOVITZ, TIARE-MARIA BRASSEUR, PABLO D'ESTE, MICHAEL DOSER, CORNELIA LAWSON, YAJING LI, PHILIPP TUERTSCHER, AND SAMANTHA ZYONTZ*

OIS Challenge: In a context of increasing pressure on scientists to make their data publicly available, it is critical to clarify the evidence that would justify corresponding policies, to establish indicators to evaluate whether the expected policy outcomes are being achieved, to examine the benefits and drawbacks, and to make explicit the costs to the involved parties.

Research Question Development

What do we know about that OIS challenge from existing literature?

Recently, policy-makers, funding agencies, and academic journals have increased their pressure on scientists to share their scientific data (Borgman 2012, European Commission 2020a,b, Nature 2021, Wiley 2021). Policy-makers expect that the emerging norm of open data sharing in science will promote various benefits, including enhanced reproducibility, resource efficiency, new research and innovation, and opportunities for collaboration (Pasquetto et al. 2017).

However, there seems to be a gap between such open data policies for authors and the actual accessibility of data in some fields (Zenk-Möltgen et al. 2018). Furthermore, tension exists between what is expected from scientists and what they want (or are able) to do themselves (Fecher et al. 2015).

Despite its potential benefits, sharing data is difficult and costly. Allowing others to access and reuse data requires the originating scientist to consider the nature of the data, incentives, rewards, and ownership issues (Borgman 2012) when deciding what and how to share. Moreover, some types of data may not be relevant to others (e.g., Czarnitzki et al. 2015) and a lot of shared data is not used (Science 2011, Wallis 2013). There is also an increasing need for auxiliary metadata and tools, as data alone is not always valuable (Borgman 2012). The costs of data sharing efforts are a major reason for reluctance to share (Tenopir et al. 2011).

Overall, research highlights the need to "match" the great expectations of emerging data infrastructures and regulations with a better understanding of the actual gains and costs associated with open data sharing.

What <u>don't</u> we know about that OIS challenge from existing literature?

Several aspects of open data sharing remain unclear. First, there is no consensus on how to measure the *value* of data sharing. Some authors have used citation-based measures (e.g., Reichmann et al. 2011), but these "ignore" the value derived from making the data available to the *public* (Pasquetto et al. 2017). This triggers a debate about the *particular* value of data sharing (Borgman 2012). What is the benefit for the scientists that share the data, for the public that accesses it, and for society as a whole?

Second, several *costs* to data sharing require investigation. For instance, scientists have reported that time, effort, and costs involved are obstacles to sharing data (Campbell et al. 2002). Another potential cost is the risk of misuse or "research parasites" (Fecher & Wagner 2016, Greene et al. 2017). Third, since data sharing and curation are expensive, more needs to be known about the potential uses and users of scientific data - specifically, how the cost of *sharing* data compares with the cost of *reproducing* it. Depending on the field and project, a difference in costs may incentivize different sharing strategies among scientists (Campbell et al. 2002, Tenopir et al. 2011).

Finally, without sufficient data management and curation, and without institutional capabilities and expertise, open data sharing may not lead to data *use*. A systematic understanding of what data might be shared, by whom, with whom, under what conditions, why, at what cost, and with what consequences is still lacking (Borgman 2012).

Building on this, our research questions are: First, *why* do policy-makers require data sharing and what do they hope their policies will achieve? Second, *when* do the benefits outweigh the costs of data sharing? Third, *how* do we measure the value of data sharing and what would be considered a successful policy? Developing evidence-based open data sharing policies requires answering these questions.

Hypotheses related to your research question?

H1: The costs of data sharing are *underestimated* by policy-makers, especially since they do not often bear the burdens of producing or maintaining the data (Borgman 2012, Campbell et al. 2002, Tenopir 2011).

H2: Conversely, the benefits of open data sharing are *overestimated* by policy-makers because of the more visible perceived upsides.

H3: Taking a contingency perspective, data sharing may be more relevant for specific types of data than for others (Czarnitzki et al. 2015).

H4: A systematic evaluation of the usefulness of open data sharing is *not* part of policy-makers' considerations. A lack of metadata on policy decisions on data sharing limits our understanding of the impact of data sharing (Reichmann et al. 2011).

How can the research question be answered (or the hypotheses tested)?

To address the above questions and develop evidence-based open sharing policies, we propose a mixed-method study. The first phase will consist of discussions (workshops or interviews) with *funding institutions* and *policy-makers* and separately with *scientists* in different fields. Conversations will focus on the perceived benefits and costs of open data sharing. Additionally, funding institutions and policy-makers will be questioned about what outcomes they hope to achieve so as to identify potential measures of success. Scientists will further be asked about which data types are best for sharing and what obstacles they have encountered. Both groups will be asked about how they believe the current data sharing policies address the expectations of the *public*. The results will be used to highlight any mismatches between policy-makers' expectations and researchers' reality.

The second phase will be an empirical study on the impact of current data sharing policies. We will use *matched samples* or *natural experiments* to study the role of data sharing policies in shaping new research, innovation, and other measures of success. For example, we can develop a matched sample of research projects or collaborations that share data and compare their success and productivity over time (see Christensen et al. 2019 and Zhang & Ma 2021 for similar approaches). Specifically, we aim to test a range of fields, outcomes, and levels of data sharing in order to gain insights into the process of determining what policies have been most successful.

The third phase would be to partner with data sharing policy organizations to develop and run a set of randomized controlled trial (RCT) experiments. The first two phases will identify potential policy levers and measures of success that can be experimentally tested in the RCT. This last phase will allow us to more precisely develop successful data sharing policies for different fields and desired outcomes.

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PROPOSAL 4: CO-CREATION BEYOND DIALOGUE: EXPLORING MULTIMODAL APPROACHES TO INVOLVING RESEARCH PARTICIPANTS UNDER CONDITIONS OF COMPOUND STIGMA *BY FABIAN HANS, NÓRA KATONA, MARCEL LAFLAMME, PATRICK LEHNER, SILVIA MARCHINI, MARISA PONTI, ANGELO ROMASANTA, AND ALEXANDER RUSER*

OIS Challenge: Experience gained through the "Open Research behind Closed Doors" project at the Ludwig Boltzmann Institute of Fundamental and Human Rights (https://bit.ly/Openresearchbehindcloseddoors) showed that while it is simple to identify relevant stakeholders when engaging in OIS projects involving persons in positions of vulnerability, the question of how to involve them meaningfully in the research process can be challenging. This is especially true for persons facing multiple stigmatisation, for example those both living with an intellectual or psychosocial disability and deprived of their liberty as a result of criminal behavior and/or exemption from criminal responsibility. This compound stigma can also affect persons in close relation with the stigmatised person, including family and friends. These social realities exacerbate existing barriers to research participation such as language barriers, power hierarchies, and inequalities in access to consumer technology, suggesting the need for creative approaches that extend beyond models of dialogue and deliberation centring on written or spoken language.

Research Question Development

What do we know about this OIS challenge from existing literature?

1) The importance of participatory research methods in the context of health-related stigma

Stigma is a well-documented phenomenon that prevents marginalized people from seeking help and accessing care (Stangl et al. 2019). When researchers engage with communities facing health-related stigma, they increasingly turn to participatory methods in order to center community perspectives and to unlearn conventional research practices that reinforce social distance (Wallerstein & Duran 2017). In particular, there is some existing scholarship on the suitability of different tools and methods when it comes to the involvement of persons with intellectual disabilities in research (see Nind 2008). For instance, this body of work addresses issues around how to convey information (Andre-Barron et al. 2008) and gauge benefits (McDonald et al. 2016).

2) The value of co-creation for health care and social innovation

More generally, researchers have explored the value of co-creation in health care services, including the use of online communities to promote transparency, health literacy, social support, and patient empowerment

(Rezaei Aghdam et al. 2020). In contrast to the conventional focus in business innovation on the development of profitable and scalable products or services, social innovation emphasizes “the creation of long-lasting outcomes that aim to address societal needs by fundamentally changing the relationships, positions, and rules between the involved stakeholders, through an open process of participation, exchange, and collaboration with relevant stakeholders” (Voorberg et al. 2015: 1334).

3) Multimodal research approaches and methods

Broadly speaking, the term *multimodality* refers to the transmission and construction of meaning through different and often overlapping modalities of communication, including textual, auditory, linguistic, spatial, and visual (Jewitt et al. 2016). Multimodality plays a significant role in enabling the exchange of thoughts, beliefs, and emotions, and can be particularly important in contexts where linguistic communication is difficult or impossible (e.g., Pierce et al. 2019). Some researchers have explored prospects for participatory research using arts-based methodologies, arguing for the integration of practices like photography, dance, and filmmaking into research processes as a way to understand lived experiences that might otherwise be inaccessible (e.g., Lenette 2019).

Building on this, our research questions are:

RQ1: To what extent are multimodal approaches to co-creation suitable to reach and meaningfully involve institutionalized individuals with intellectual and psychosocial disabilities and their families in applied social research?

RQ2: How can multimodal approaches be used to involve the relevant stakeholders, and what kinds of insight can such approaches surface from different groups of stakeholders and at different stages of the research process?

How can the research question be answered?

While previous research has established the suitability of various multimodal research methods for use with persons with intellectual disabilities (e.g., Povee et al. 2014), this study employs *participatory mapping* to explore the capabilities afforded and denied to institutionalized individuals with intellectual and psychosocial disabilities and their families. Defined as “a process in which community members, writ large, contribute their own experiences, relationships, information, and ideas about a place to the creation of a map” (Cochrane & Corbett 2020: 706), the technique of participatory mapping is especially relevant to our research context because it stands to shed light on spatial dynamics of access/exclusion and empowerment/deprivation that arise in the context of detainment. Used previously to draw out the perspectives of people with intellectual disabilities (e.g., Robinson et al. 2020), the technique is extended here to elicit and compare maps created by a range of stakeholders, including human rights advocates and representatives of detention facilities.

In consultation with a stakeholder advisory group, the research team will define an orienting set of locations and themes for each research participant to explore in the map that the participant creates: one place to start would be inside vs. outside the facility (including relevant community institutions), along with barriers encountered or expected and the feelings or sense memories associated with them. Each participant will be given standard instructions and supplied with drawing materials, as well as access to communication partners as needed. Then, either in a synchronous workshop setting or an asynchronous digital format, participants will be invited to engage with each others’ maps, responding to the representations of others through communication channels including but not limited to language (e.g., drawn annotation). The shared or divergent understandings that surface can then be triangulated with other research data to identify areas for service improvement or more robust oversight.

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PROPOSAL 5: LEVERAGING LEAD-USER IDEAS AND CO-CREATING WITH A (LARGE) COMMUNITY OF PATIENTS *BY ALEX CAYROL, CLIO DOSI, DESPOINA FILIOU, CAROLIN HAEUSSLER, OLGA KOKSHAGINA, MARKUS MITTERHAUSER, JULIA SUESS-REYES, AND RUBÉN VICENTE SÁEZ*

OIS Challenge: The medical ecosystem is complex, highly-regulated, cost intensive, and, because human health is involved, highly emotional. Healthcare is unique in that it is mostly a "need" rather than a "want" service (Berry 2019). A variety of different stakeholders, such as political leaders, staff, taxpayers, regulatory bodies, and suppliers, often have conflicting goals and requirements (Moorhead et al. 2013). With the overall goal of a healthcare system being to deliver quality health-care outcomes to patients, individual stakeholders are motivated by their own goals and business logics (Guercini et al. 2020, Kokshagina & Keränen 2021, Schiavone & Simoni 2019). Co-creation can be an efficient way to integrate various stakeholders when developing innovative products and services. But how can these stakeholders be leveraged and integrated in a meaningful way? This research project explores how (former) prostate cancer patients, their caregivers, and their relatives can work together to facilitate improvements to the lives of patients with prostate cancer. By integrating various OIS approaches, this research explores methods for efficiently co-designing with patients.

Research Question Development

What do we know about that OIS challenge from existing literature?

Various approaches to leverage ideas from the periphery have been developed. In this proposal we built on several existing works: *Lead User Approach* (von Hippel 1986), *Crowdsourcing Approach* (Piezunka & Dahlander 2015), and *Transdisciplinary Research practices and citizen science* (Franzoni & Sauermann 2014).

Lead user approach: The lead user approach was developed as a market research tool to identify pioneering ideas and solutions from direct users. Lead users have user experience and product-related knowledge (Bilgram et al. 2008). They face needs that can become dominant in a marketplace (von Hippel 1986). Thus lead users have high expected benefits due to a perceived dissatisfaction with a certain product or service (Bilgram et al. 2008).

Crowdsourcing approach: Crowdsourcing refers to outsourcing a certain task to a "crowd" in an open call, rather than delegating it to a specific "agent" (Howe 2006, 2008, Jeppesen & Lakhani 2010). The expected benefits of doing so are reduced costs, scalability, quality, flexibility, speed, and diversity (Buettner 2015, Prpić et al. 2015, Wimbauer et al. 2019). Recently researchers and practitioners alike have become increasingly interested in leveraging crowds and collaborative communities to deal with complex societal problems (e.g., Chesbrough & Di Minin 2014, Kokshagina 2021). They often discuss these problems in the context of social innovation, as the value created directly benefits society instead of individual actors (Kohler & Chesbrough 2019, Phills et al. 2008).

Transdisciplinary research practices and citizen science: Transdisciplinary research means crossing the frontiers of the science system to collaborate with non-scientific actors, e.g., citizens, firms, or policymakers (Beck et al. 2020). Citizen science has recently gained particular importance in this context (e.g., Hakley et al. 2021), and the degree of involvement can range from tasks such as data collection to full involvement in research design (Sauermann et al. 2020, Franzoni & Sauermann 2014). There are two specific approaches or views explaining the rationale of engaging with citizens in scientific research (Sauermann et al. 2020): According to the "productivity view", citizens can help to scale up and/or improve the scientific output. Additionally, the "democratization view" considers non-scientific goals, e.g., democratization of science and making science more responsive to citizens' needs (e.g., Irwin 1995).

Co-creation with patients in science - patient innovation

While there are numerous studies on patients participating in scientific studies as testers (Kanstrup et al. 2015), literature on patients acting as innovators and co-designers is scarce (Bélanger et al. 2012). Yet patients and their caregivers trying to solve their needs and to improve their living conditions hold a tremendous potential as a source of innovation and can enhance the care of others who are similarly affected (Oliveira et al. 2014). Recent initiatives showcase the value of patients as active innovators (i.e., https://patient-innovation.com). These initiatives provide evidence of how patients can play a leading role in innovating healthcare service delivery. Despite this, patients are not sufficiently seen as co-creators (Elg et al. 2012). Furthermore, when involving patients in co-design, important regulatory, ethical, and social concerns can be raised. Studies should therefore be carefully designed (Heiss & Kokshagina 2021).

What don't we know about that OIS challenge from existing literature?

1) So far, *most approaches focus on idea generation and ignore the influence on later development stages, rapid diffusion, and applicability*. However, this speed is critical for patients who, while participating as co-designers anticipate a faster time-to-market and personal benefits from the outcomes. Thus in addition to increasing the quality of innovation and reducing development risks, OIS approaches can be used to generate ideas and tools to speed up availability and scaling. Crowd funding by patients, for example, may lead to more rapid production and market availability (Snyder et al. 2020, Young & Scheinberg 2017). This is particularly relevant in areas where patient innovators are racing against time.

2) The approaches described above have so far mostly been studied *in isolation*. A study *linking lead user, crowd/citizen science, and patient co-creation is largely missing*. We anticipate that OIS methods will generate more value by linking different practices along the development and production process. To date, however, this is rarely applied or empirically investigated.

3) *Co-creation with patients requires a careful and ethical way to approach problems*. We argue that capability development for patient involvement is required for all parties involved. Furthermore, patient expectations and value creation should be well-managed. We need to carefully examine our OIS tools so that they reflect the complexity of and the need for patient engagement.

Building on this, our research questions are:

- How can we effectively approach and involve patients in co-creation activities?
- How can we co-design with patients to rapidly prototype and test concept ideas?
- How can we design and implement projects with communities of patients, caregivers, and relatives with different vulnerabilities in an ethical and responsible way?

How can the research question be answered?

Participatory co-design project with patients, relatives, and caregivers

We leverage participatory design methods along several phases of development, testing, and implementation of new products and services.

- Phase 0: Understand the needs of different stakeholders, develop ethical and inclusive guidelines for participation, and set up a research project. By doing so build on prior literature.
- Phase 1: Start with a number of (rough) solution concepts, leveraging various sources of ideation (e.g., Lead Users, ideas from affected individuals, ideas from researchers/practitioners, ideas from a group of students who do a guided brainstorming, etc.).
- Phase 2: Identify patients, caregivers, and relatives, select their most promising ideas, and enter a co-creation test stage for those ideas. Partner with patients associations to represent the interests of patients and their families in preparing for Phase 3.
- Phase 3: Recruit patients, their relatives, and their caregivers for the main project stage (i.e., by using a flyer) and co-create with them through an online platform and/or through workshops.

- Phase 4: Evaluate the final results based on continuous evaluation and validation throughout all project stages (ideas selection, ideas definition, ideas development) and by taking into account created value in terms of needs and wants (KPIs such as speed, value creation for patients, healthcare system, match with patient needs).

Experimental studies with different groups/ interaction forms

- In Phase 2 select different groups of patients to further explore knowledge gaps; e.g., groups of patients with either low and high vulnerabilities.
- In Phase 3 activate different modes of interaction with patients; e.g., interaction through digital platforms vs. interaction in person.

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Proposal 6: Fair to share? Patients' returned value from data sharing: Accelerate science by enabling data sharing by design *by AGNES EFFERT, CHRISTOPH GRIMPE, HARALD KLEINBERGER-PIERER, HILA LIFSHITZ-ASSAF, FRANCESCO MOSCATO, MARKUS NORDBERG, JANET RAFNER, AND MATTEO VIGNOLI*

OIS Challenge: When it comes to clinical research and development of new medical devices, patients are usually very keen to contribute with their data, "first-hand" experiences, suggestions for improvements, and even with a clear definition of current limitations of available solutions. Researchers and industry usually do not provide compensation (beyond remuneration for participation) for this involvement, as patients already typically feel rewarded by contributing to the improvement in therapy. But with patients getting more involved in the development and improvement of devices, often providing important insights into product usability and design requirements and therefore leading to better products, questions have begun to arise as to whether and how their contribution should be rewarded.

Research Question Development

Health services in many countries collect and provide medical data. In most cases, however, there is no specific *Return Value* defined for patients taking part in research and surveys (participants) and providing data. For example, the National Health Service (NHS) in the U.K. doesn't focus on the individual value for patients who are taking part in research and surveys, but emphasizes a centralized model of "public value". Data collected in the NHS model informs improvements to the public health system, the NHS provides guidelines on how to share these data with the public and private sector. Usually the financial value of these data is not unrecognized, but public value is treated with higher priority (Wilson et al. 2020). Other countries have different approaches, including granting access to data to private sector companies or decentralizing access and storage.

Different types of *sharing economies* and frameworks provide various opportunities, but also raise questions about the ethical usage of data and its reuse in research and development (see, for example, Courbier et al. (2019), who provide an overview on risks and potentials as well as recommendations for sharing and protecting health data). Open access to data might undermine participants' trust that their data are handled with care. In this scenario, readiness to provide data or to take part in studies might be limited. A model of full commercialization of data might have similar effects for studies and surveys that see patients and participants only as data bonanzas. On the other hand, commercialization and privately driven research and development will ultimately provide better medical devices and treatments, in spite of all reservations. Even a public approach or emphasis on public value is not the answer to all questions. The study of Courbier et al. (2019) shows that the majority of rare disease patients are willing to share their data in the hopes that this will help to develop new treatments, improve diagnosis, and better understand causes and mechanisms of the disease. Thus restrictive data sharing rules might also cause patients and participants to re-think their attitudes towards sharing data when therapeutic progress and health care improvements are not happening fast enough (see Foege et al. (2019) for similar issues in crowdsourcing).

In the practice of conducting clinical trials, financial *remuneration for participants* might be an additional motivating factor for taking part in studies. In general, remuneration is primarily intended to compensate participants for working time, traveling, invested resources, etc. (see for example the 2019 Guideline from the European Federation of Pharmaceutical Industries and Associations (EFPIA 2019) on “Working together with patients”). This is typically a one-time payment though. A second approach to encouraging data sharing is to provide prioritized access to medical technology or therapies (when available) for individual patients and participants who previously shared data for the study. But it might also raise ethical concerns if access to scarce technology or therapies is not primarily based on the medical needs of the patients.

In practice there are limits to both the methods of efficient data collection and to the motivation that financial incentives can provide to patients and participants. Patients who are ready to contribute receive a reward that is primarily *non-monetary* (beyond remuneration). In addition, they contribute to research projects that are risky and could fail and therefore might not even be rewarded at all. At the same time, patients are deeply emotionally connected to the specific research project they seek to contribute to. These factors contribute to the same power and knowledge asymmetry between patients and health companies that exists between patients and public health care providers. A flexible, transparent model for a “Fair Share” or return value for the input of patients, participants, and other actors involved is necessary in these times of proliferating health care and medical data.

Building on this, our research questions are descriptive and explanatory: First, we seek to investigate which models of value distribution currently exist between patients, researchers, universities, and companies, how they are used, and in which context. Second, we seek to understand how particular arrangements for the distribution of value are associated with individual sharing behavior. Third, we aim to define the main design principles of a novel model of flexible and transparent value distribution among every stakeholder that is participating (also with their data) in the co-development effort.

How can the research question be answered?

In order to address our first research question, we propose conducting multiple case studies in different settings with various stakeholders, including patients and patient organizations, company representatives, hospital personnel, and scientists. Via observations and interviews, we want to identify how value is distributed between the different actors and how they capture value under different conditions in different contexts.

Building on the findings from the case studies and in order to shed more light on our second research question aiming to identify under which conditions individuals engage in sharing behaviour, we propose an experimental research design. Thereby we can test the effects of different conditions - e.g., increased transparency - on the data sharing behaviour of patients and the willingness of companies to make more ethical decisions and share more of their returns with patients. Moreover, scenario-based experiments could be helpful in order to elucidate the conditions under which patients would be willing to share their data.

Answers to the descriptive and explanatory research questions will then also inform considerations regarding the normative aspects of patient data sharing. For example, we might gain insights into how the opportunistic behavior of companies vis-à-vis patients can be avoided and what the “right” model of value distribution should be. Moreover, we might learn what considerations of fairness should be made with respect to who benefits from the research.

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