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SPECIAL ISSUE • Opening up evidence-based policy: exploring citizen and service user expertise

research

Walking the (argumentative) talk using citizen science: involving young people in a critical policy analysis of vaccination policy in Austria

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Background: Vaccination policy has grown increasingly polarised, and concerns about vaccination practices are often articulated jointly with fears over declining trust in scientific expertise and the demise of evidence-based policy. This has led to a discursive deadlock in which *evidence* comes to denote something that is crafted and monopolised by a trained élite, with no role to play for the workings of democracy. Our own methodologies tend to accentuate this epistemic hierarchy, for much qualitative research relies on élite interviews with officials and scientific experts. The introduction of the vaccine against Human Papilloma Virus (HPV), on which we report in this paper, is a case in point.

Objectives and methods: With this study, we intervene in this discursive and methodological deadlock using unconventional methods: inspired by the participatory spirit of the 'argumentative turn' in policy analysis, we experimented with citizen science to produce critical knowledge about HPV policy in Austria and simultaneously intervene in this expert-driven policy discourse. Specifically, we involved adolescents in analysing HPV policy discourse using press releases and a combination of inductive and deductive textual coding.

Findings and conclusions: Our results point to the sidelining of sexuality and gender in the presentation of scientific evidence on HPV in press releases, and highlight the dominance of the pharmaceutical industry in shaping the political-administrative decision to offer the HPV vaccine to all children in 2014. Our study points to ways of integrating citizen science in the social sciences and contributes to a rethinking of methodologies in qualitative policy analysis.

Key words evidence-based policy • vaccination • citizen science • knowledge

Key messages

- Social science research methods risk reifying the expert-entered nature of policy making.
- Citizen science methods can be used to enhance the democratic nature of policy making.
- Contemporary vaccination policy requires a rethinking of evidence-based policy making.

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Introduction: the trouble with vaccination

Concerns regarding vaccine hesitancy (Larson et al, 2018) currently feature prominently on political agendas throughout Europe and beyond. Against this background, policy makers frequently mobilise the language of evidence and facts to counter anti-vaccine narratives, yet despite such appeals to knowledge, rationality and trust (in science, experts, and so on), vaccine hesitancy continues to gain political significance (Yaquub et al, 2014; Petrelli et al, 2018). In parallel, declining vaccination rates and the rise of populist movements, such as the Italian Five Star Movement, which promotes a strongly anti-institutionalist and anti-public health stance (Pavolini et al, 2018), make for an increasingly polarised policy area. Policy officials are increasingly concerned that value judgements could come to replace the factual judgements made by experts and scientists. They are thus inclined to protect vaccination policy discourse as a matter for experts, and to forgo public participation. Yet non-scientific contributions to the debate do not necessarily contradict scientific contributions – rather, they are situated differently and are therefore not grounded in shared norms and practices (Peschard, 2007). This means that the co-production of knowledge for policy is a challenging task (Peschard, 2007) and has led to what effectively amounts to a discursive deadlock in which *evidence* comes to denote something that is crafted and monopolised by a trained élite, with no role to play for the workings of democracy.

This paper opens up the notion of *evidence* by reporting on a citizen science case study of a particularly polarising vaccine: the vaccine against Human Papillomavirus (HPV). We present a study of its introduction in Austria, where it was met with resistance and criticism in 2008, but was eventually included in the national immunisation programme in 2013 (see Table 1). This paper explores the HPV debate by analysing press releases issued by a range of policy actors. While the HPV debate has been the subject of a host of social science research, including the Austrian case (for example, Stöckl, 2010; Lindén and Busse, 2017; Paul, 2016), existing research on the HPV vaccine controversy frequently relied on élite interviews or policy documents, as most qualitative policy research does. As a result of this, policy analysis has unintentionally risked reproducing the technocratic nature of much ‘evidence-based policy making’, whereby the focus on (scientific) evidence alone tends to reduce political problems to technical ones (Saarni and Gylling, 2004; Greenhalgh and Russell, 2009). In the present study, we seek not only to generate knowledge about the policy process, but also to experiment with a specific mode of analysis, inspired by, first, citizen science methodology and, second, calls for more participatory forms of policy analysis, which have been increasing ever since the argumentative turn (Fischer and Forrester, 1993).

In an attempt to intervene in what appears to be an important intersection between the political and the methodological, our aims were thus at once experimental, instrumental, and interventionist. First, we wanted to test the possibility of using citizen science methods in policy analysis. While citizen science feeds into policy making in important ways – specifically in environmental policy (Irwin, 2002; Greenwood, 2017), it has not yet been used to generate knowledge *about* the policy process. Second, the instrumental purpose of our study was to complement and enhance our knowledge about a specific policy process that we had previously studied using conventional qualitative methods: the incremental introduction of the HPV vaccine in Austria. Third, our study represents a political intervention in a policy discourse that is dominated by medical experts and where there has been virtually no room for involving the wider public.

This study asks: How, and based on what arguments, did expert institutions – including policy actors, scientists, and commercial actors – shape HPV policy discourse in Austria? To analyse the role of expert institutions, we used their press releases as a proxy for their stance on the HPV vaccine, assuming that these press releases were fairly representative of the stance that they took in policy negotiations behind closed doors. Using press releases as data sources allowed us to identify shifts in the debate over time. This did mean using material that inevitably frames scientific evidence in a particular way, but it also provided a temporary remedy for our dilemma: how can we, as policy analysts, intervene in a policy area that is heavily dominated by experts, but also legitimately relies on them for input? Using press releases, and an online platform designed as part of the project, enabled us to create a greater distance from experts than, for instance, interviews and observations would have done. Overall, we find that the tradition of citizen science has much to offer in formulating alternative approaches that are more in line with Bourdieu's call to move beyond the 'scholastic perspective' (Bourdieu, 2000; cited in Kenway and McLeod, 2004).

This paper is structured as follows: first, we will map out the Austrian HPV policy debate. We will then reflect on our experiences with elite interviews in this policy area, since these inform our current critique of that method. Subsequently, we will make a case for the potential of citizen science in innovating policy analysis and enhancing reflexivity. In the results section, we will report on a school-based citizen science project in which we sought to empower the target group for the vaccine to engage with the political controversy in Austria by analysing the debate. Finally, we extrapolate from these findings to make a call for a reframing of what has become known as 'evidence-based policy'.

Background: evidence and expertise in vaccination policy making

The HPV controversy in Austria

In the early 2000s, medical researchers saw the development of a new vaccine against some strains of the carcinogenic Human Papillomavirus (HPV) as a real breakthrough. Gynaecologists, in particular, imagined that the vaccine could replace the Pap smear test – a cervical cancer screening method which had been in use for decades but had many drawbacks and weaknesses, including false positive results and the associated physical, emotional, social, and financial costs. Yet these hopes proved not only premature but highly contested, as sociologists have documented extensively (cf. Casper and Carpenter,

2008; Epstein, 2010) and as recent controversies surrounding HPV research indicate (Jørgensen et al, 2018). When the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA) approved two vaccines against HPV in 2006 and 2007, most countries in the EU and beyond began to include the vaccine in their own national immunisation programmes. In this respect, Austria was something of an outlier and therefore represents a particularly interesting case. Elsewhere, public health officials were quickly persuaded by the early licensing of the vaccine and embraced what they understood to be a breakthrough in women's health (Lindén and Busse, 2017; Paul et al, 2018). Austrian officials, conversely, were much more hesitant and rejected the vaccine based on arguments of cost-effectiveness. Specifically, the Minister of Health at the time – a Christian Democrat – rejected the vaccine based on arguments relating to cost, uncertainty, and – more implicitly – ethical objections to vaccinating children and adolescents (particularly girls) against a sexually transmitted virus. The vaccine did, however, become available immediately on the free market, at a cost of approximately €600 in total for three doses.

However, this policy stance shifted fundamentally over time, as we show in Table 1 below. Initially framed as a 'girls' vaccine', it was transformed into a 'gender-neutral' vaccine within a period of five years, and one that was intended to 'save children's lives', as the Minister of Health at the time announced at a press conference in the summer of 2013. The vaccine was then made available free at the point of care as part of the national immunisation programme for nine-year-old children – significantly earlier than in other European countries. This policy shift came suddenly to many observers, including the first author of this paper, who had been following the debate closely. Policy analysts would typically choose process-tracing methodologies (Collier, 2011) or elite interviews to explore policy changes of this kind, and indeed, existing research on HPV policy – both in policy analysis and science and technology studies (STS) – relies on such methods, including the first author's previous research (Paul, 2016). Below, we report on why and how we decided to depart from these methods.

Table 1: Brief account of HPV policy in Austria

Year	Evolution
2006	USA Food and Drug Administration approves two licensed vaccines against HPV
2007	European Medicines Agency approves vaccines for girls and boys starting age 9
2007–2010	Several EU member states introduce HPV vaccine for girls only (age 12–13)
09/2007	Austrian Supreme Health Board approves of vaccine and recommends inclusion in national immunisation program (NIP) for girls and boys; this is rejected by Minister of Health (Andrea Kdolsky) based on concerns about cost-effectiveness and safety (following incidental death of young girl post-vaccination)
12/2007	First Austrian health technology assessment (HTA) leads to decision not to include HPV vaccine in NIP
2007–2013	Vaccine is available at 600 EUR for three doses, out of pocket.
2007–2013	HPV research progress and indicates effectiveness of vaccines in protecting against additional HPV strains (causing genital warts and cancers that affect men)
2012	Vaccine relicensed for use with two doses only (rather than three); this reduces costs and improves likelihood of completion.
08/2013	Minister of Health (Alois Stöger) announces introduction of HPV vaccines for girls and boys at age 9, free at the point of care

Towards reflexivity: from technocracy to greater democracy in research

Three reasons inspired our move towards citizen science, and thus a more participatory methodology. To begin with, the first author of the present paper had spent nearly two years in the field, interviewing experts and conducting participatory observations at public events relating to vaccination. Yet her reliance on experts in this very politicised and top-down policy area was limiting the ‘interactional expertise’ (Collins and Evans, 2002) that she had hoped for. The policy area was also so polarised that interview partners were keen to vet her stance on the vaccine before or during interviews, often complicating the interview process and testing the limits of snowball interviewing, since there was a risk that she would be dismissed as ‘biased’ by further respondents. She reflected on this risk in her write-up of the qualitative analysis (Paul, 2016), but as yet, her approach did not go beyond the well-established tradition of acknowledging one’s presence, impact, and role in (re)producing particular interpretations. As Kenway and McLeod (2004) point out, this almost conventional, and by definition individualistic form of reflexivity has become common practice, if not *doxa*, in qualitative research, where researchers employ the term reflexivity to denote the “effect of their presence on the conduct and interpretation of the research” (Kenway and McLeod, 2004: 527). Our citizen science project sought to move beyond this methodological stance and towards research that is more in line with Bourdieu’s call for a *reflexive sociology* (Bourdieu, 2000: 121; cited in Kenway and McLeod, 2004).

A second and related driver of the current research project relates to a concrete, yet no less reflexive experience. Policy networks in the Austrian context are tightly-knit, and the researcher soon felt that she had become too closely associated with it. There was a clear risk that relying on experts’ accounts would not only limit her research results, but also the potential impact of that research. In her effort to understand formal experts (policy officials, clinical practitioners, action groups), she had focused solely on them and their interactions in a conflict-laden policy area. This virtually blinded her to those excluded from these circles, creating what Labaree (2002) labels an ‘insider/outsider dilemma’.

A third, more practical, reason was a unique a window of opportunity: The funder that had also supported our earlier research on HPV policy issued a call for proposals that would integrate a citizen science perspective into existing research, with a specific focus on younger citizens. For the present project, we chose to work with the target group of the vaccine, adolescents, since they had been spoken *of* so much, but never spoken *with* in the context of the HPV debate. Notwithstanding our desire to rethink what participation could mean in relation to policy analysis, some of our considerations were more pragmatic and reflect the project-based nature of much contemporary social science. As early-career researchers, we were reliant on external funding, and thus our project proposal aimed to ‘tick as many boxes’ as possible in the funder’s call for proposals: the call encouraged the inclusion of under-researched segments of the population, including young adults. Moreover, choosing a school-based approach meant reducing some of the risks we faced regarding recruitment. At the same time, this inevitably limited the extent and nature of participation that we were able to inspire and experiment with.

Despite these limitations, we sought to give this under-heard group an opportunity to engage with, analyse, and critique other actors’ views on the HPV vaccine. Our citizen science project offered opportunities to translate their experiential knowledge (as a target group) into ‘credential knowledge’ (as active contributors to the analysis of discourse) (Rabeharisoa et al, 2014). Using this experimental research methodology,

we engaged with the HPV controversy from a different vantage point and also made our own knowledge claims regarding the controversy more transparent (Whatmore, 2009). As this paper seeks to show, this reframing of expertise does not conflict with, but could, in fact, contribute to an extension of evidence-based policy.

Participatory policy analysis after the argumentative turn

The rise of what appears to be an increasingly critical citizenry has been a particular challenge for both policy makers and critical policy scholars (Strassheim, 2017). Policy makers have responded predominantly by insisting on the integrity of facts, calling for a ‘better education of the public’ and ‘more effective communication of scientific facts’. Conversely, particularly since the argumentative turn, critical policy scholars have called for a deliberative engagement with policy actors (Fischer and Forester, 1993; Metze, 2018), including the target groups of particular policies.

Participatory and deliberative policy analysts have since increased their use of collaborative methods, such as in planning (Healey, 2006; Innes and Booher, 2010) and more recently in public administration (Bartels, 2018). Yet this scholarship tends to maintain a clear division between the roles of researcher and participant – even if participants are credited with policy innovations or ideas in many cases. Scholars of health care and environmental policy have made the value of ‘lay knowledge’ more explicit, such as when determining health needs (Popay et al, 1998). In parallel, sociologists such as Phil Brown (1992) have explored community resistance to exposure to toxic waste, activities he termed ‘popular epidemiology’. Similarly, Popay and Williams (1994) studied residents’ action on water contamination, and Wynne (1992) famously revealed the power of farmers’ knowledge in documenting the effects of the Chernobyl disaster. Across this scholarship, participants are more than just vessels or carriers of data, then; they are active producers of knowledge. In policy analysis, however, experiential knowledge is only rarely valued in the production or analysis of data – and in policy making, this knowledge is often dismissed, at times to catastrophic effect, such as in the case of reports preceding the Grenfell Tower fire in 2017 (Popay, 2018).

Overall, interpretive policy analysts have largely held on to conventional notions of knowledge production, thus implicitly upholding the epistemic hierarchy between trained scientists and affected citizens as untrained experts. Citizen science methodologies, by contrast, offer the prospect of moving towards a truly co-productive mode of knowledge production, which is more in line with the democratic and reflexive ethos of interpretive policy analysis. Ideally, participation in knowledge production should take place at the very heart of the scientific endeavour: discussing what is at stake, and negotiating the relevance of relevant data and sources, and how these should be interpreted (Peschard, 2007). By acknowledging the value of different forms of knowledge, interpretive policy scholars have made clear steps towards more collaborative forms of analysis (Fischer and Forester, 1993; Yanow, 1996; Wagenaar, 2011). However, the close focus on observing policy practice has also been criticised (Stewart, 2014) and may indeed have stood in the way of a more radical overhaul of our policy-analytical toolbox towards a more participatory mode of analysis. How can we overcome this bias in favour of knowledge produced by trained experts, and what kind of interventions does the current resurgence of the paradigm of evidence-based policy (Strassheim and Kettunen, 2014; Saltelli and

Giampietro, 2015; Newman, 2017; Parkhurst, 2017) entail or require? Building on the discourses that have sprung up around the interpretive turn and raised some pressing issues in health policy, in the following section, we will recount our findings and experiences in the context of a citizen science project regarding the HPV vaccine in Austria.

Methods: introducing citizen science into policy analysis

Social science and citizen science

Social scientists have long been aware of the performative and political nature of their research methods (Law, 2004), as evidenced in the history of innovative methods such as ‘action research’ (Kindon et al, 2007; Bartels and Wittmayer, 2018). Action research and interpretive policy analysis share the aim of facilitating learning for policy actors, particularly in relation to addressing the complex problems at hand (Wagenaar, 2011; Bonetti and Villa, 2014), often in interaction with practitioners and affected communities. Our research design was inspired in part by this movement, and in part by the challenges experienced in our earlier research, as discussed above. Citizen science offered a way to overcome some of these issues while intervening in the policy area at the same time.

More generally, citizen science offers the opportunity to engage non-experts in the scientific process, enhance their understanding of scientific work, and carry out research that would otherwise not be possible (Silvertown, 2009). This means that participation goes beyond simply communicating research results to the public; it should enable direct interaction between scientists and non-scientists during the research process. Ideally, this interaction should establish a new scientific practice, whereby both citizens and scientists are accountable for what they do and what they say based on a shared set of norms (Peschard, 2007).

But while citizen science also responds to normative demands, such as calls for the democratisation of science, it has primarily been used in the natural sciences. There, technical infrastructure for quantitative observations is often more readily available, and add-on functions that facilitate citizen participation (to deliver additional data) can be developed in a comparatively straightforward fashion. This means citizen science differs from action research inasmuch as it traditionally draws primarily on ‘laypeople’ to provide additional data, such as counting and reporting bird numbers, and does not usually involve direct intervention in the field. As such, citizen science does not contest the epistemic authority of science but provides new routes to participation (Del Savio et al, 2016) and is associated with ‘learning’ (Bonney et al, 2014). Mobilising citizen science for the sake of policy analysis therefore has two potential benefits: first, its scientific orientation fits neatly into the language of evidence-based policy; and second, the active participation of citizens in research facilitates the extension of that expertise within a scientific framework.

With the growing availability and use of the internet, the past decade has seen a remarkable increase in successful web-based citizen science projects (for example, FoldIt, GalaxyZoo, PatientsLikeMe), and the potential of these approaches has been clearly demonstrated. While these projects have highlighted the advantages of citizen involvement in science, they have also triggered debate (Riesch and Potter, 2014). Legal and ethical questions have been raised regarding data security (Kaye et al, 2012),

the risk of harm to participating citizens (Vayena and Tasioulas, 2013) or their use as ‘free labour’ for scientific research projects.

Importantly, our project did not merely view participants in citizen science as collectors or carriers of data, which is typically the case in social–scientific survey-based research. Informed by the lessons learned in participatory action research regarding the extractive nature of some methods (Kindon et al, 2007), we considered participants as ‘untrained experts’ in their own right (Collins and Evans, 2002). Their experiences as part of the target group for the vaccine, we believed, would provide them with specific experiential knowledge – a different reading of events. We sought to mobilise and explore this particular resource, and to transform this into skills akin to ‘credential knowledge’ (Rabeharisoa et al, 2014), for the purpose of producing knowledge about the HPV policy debate in Austria.

Our own journey – from planning a research project from within the safety of our own office walls to seeing participation unfold in practice – offers insights into both project planning and research design. While in traditional scientific projects, planning and research are usually seen as one and the same thing, with only few contingencies, this is not necessarily the case when working with untrained experts. As Peschard (2007) points out, the accepted norms of science are less universally accepted outside the scientific community, and some of them may well be challenged in participatory projects, as we experienced ourselves. To cope with both the milestone-driven logic of contemporary research funding and the scientific needs of the project, we developed an online platform for the purpose of jointly analyzing material, and also enabled direct *in situ* exchange with participants through a series of workshops. The web tool was designed to enable continuous – but flexible – participation, focusing on the collection and interpretation of data. The workshops, on the other hand, provided the opportunity to discuss and present the current status of the project, to reflect on preliminary results and to define and solve problems.

Aims and mode of participation

Given the limited prior application of citizen science in the social sciences, the project reported on here is fairly experimental in nature. The project sought to involve adolescents in our analysis of the HPV debate. To this end, we decided to use press releases as data that could serve as a proxy for political discourse (for a more detailed discussion on press releases and their discursive functions, see Lassen, 2006; Sleurs et al, 2003). Press releases also have a fairly standardised format and length compared to, say, newspaper articles – and we were seeking to use sources that summarised the stance of social and political agents in the HPV debate rather than that of particular newspapers. The press releases were made available to us through an agreement between our university library and the Austrian Press Agency.

To this end, we partnered with a local middle school to assess the suitability of web-based citizen science in a controlled setting. Informed by social science protocol, we obtained written informed consent from our participants and their parents or caregivers. In addition, to avoid any ethical challenges, we used no financial incentives, but rather informed participants about the nature of the exercise, its potential educational value to them, and their valuable role in this research project.

We recruited three cohorts of 16-year old pupils – 75 in total – to study and analyse a dataset of over 400 press releases issued between 2007 and 2014. We downloaded

press releases issued via the Austrian Press Agency (APA) using a keyword search (*HPV*). The press releases were manually categorised according to their sender (actor category), as this was considered important for further analysis. We differentiated between the following actor categories: politics (for example, political parties, Ministry of Health), industry, research, media, NGOs, and other (for example, health awareness associations or women's groups). This was to allow for a comparative analysis of content across actor categories.

The question that we sought to answer was: how, and based on what arguments, did expert institutions – including policy actors, scientists, and commercial actors – shape the policy discourse through the media? The idea was to address this guiding research question by coding the press releases in order to trace shifts and continuities in the political debate. Before discussing the results in detail, which we will do below, we will first discuss our methodological concerns and the research design.

Designing citizen participation

To allow for effective sharing and archiving of our project, and in line with recent developments in citizen science, we opted for an online platform for use in classrooms. In our corpus of press releases, we wanted participants to be able to assign text passages to particular predefined codes (deductive coding) listed in the application. In addition, we wanted participants to be able to create new codes based on text passages to allow scope for inductive coding.

The existing codes were derived from an earlier research project (Paul, 2016) and were listed in pop-up windows containing short single-sentence narrative explanations. These codes were, in essence, statements about the text, that could be rated as absent (red button) or present (green button). For instance, participants could assess whether the sexually transmitted nature of HPV was mentioned in a given press release – thus helping to identify at which moments, and by which actors, sexuality was bracketed out. The existing codes were simplified in order to function in a classroom setting and were formulated as follows:

- the HPV vaccine is for girls
- the HPV vaccine is for girls and boys
- the HPV vaccine is for children
- HPV is sexually transmitted
- the HPV vaccine is free of charge
- the HPV vaccine is for the benefit of society: women's health requires screening and prevention
- the HPV vaccine is criticised (in this text)

The number of text passages assigned was limited to three, and so was the number of possible new codes – initially at least. Indeed, at our first introductory session with the participants, they immediately questioned our restrictions, particularly those concerning the creative parts of their analysis – the inductive coding. We subsequently reprogrammed our online tool to enable a more dynamic mode of analysis, allowing an infinite number of new codes. This modification of the tool is a good example of how we involved participants in improving the coding application, thus promoting relational learning. As researchers, we were aware of the top-down nature of our

approach, and keen to make participants feel valued and to give them a say in the design of the project. What we found was that the top-down approach makes it difficult to develop shared norms and practices, but simplifies processes from a project management perspective. We assume that this effect would be further exacerbated in purely digital research projects, with no scope for offline interaction and contact between trained and untrained researchers. But even when there was direct interaction, it was difficult to implement major adaptations beyond those mentioned, due to the constraints of the project.

Another way in which participants intervened in, or even contested our research design related to the codes that we provided. In the case of the code ‘the HPV vaccine is criticised’, participants did not mark press releases in which the vaccine itself (or its effectiveness) was criticised, but in which the *actors* were criticised. For example, the Social Democrats criticised the government at the time for the delay in introducing the vaccine. While we did not follow up on this effect any further, we interpreted it as an effect of the politicisation of vaccination policy: the polarised debate led to a situation in which the controversy was more about policy actors (either in favour of or opposed to the vaccine), rather than the vaccine itself. While, first and foremost, we aimed to produce knowledge *about* the policy process, this finding may also be valuable knowledge *for* policy, and thus an expression of the ‘credential knowledge’ we sought to generate in this project.

Challenges along the way

The research project lasted from September 2016 to June 2017. We introduced our participants to the online platform at a three-hour workshop at the partner school and held a total of nine workshops, in addition to a number of walk-in Q&A sessions. At these workshops, we familiarised the students with citizen science more generally, the rationale behind the research project, our research design, and the web application. We found that we were able to instruct our participants in basic coding very effectively, not least because they felt involved and valued as critical readers of texts that related to a prominent area of political and scientific controversy.

The school setting significantly hampered the voluntary character of participation and limited our ability to depart from a top-down approach. Even though no marks were given to participants, the simple presence of a teacher in the room – who helped us engage with the students in a pedagogically sound manner – induced a relationship of hierarchy. The receptiveness of students to our instructions was nonetheless astonishing – and at the same time, their ability to question our authority remained intact. For instance, at our first session, a participant raised the question of whether, perhaps, their role was simply to supply free labour for our scientific project. We responded to this by setting aside time in a plenary discussion to discuss this concern and by offering the students opportunities to engage not only in data production, but also analysis. For instance, at regular intervals, we provided them with simple pie charts containing data on the frequency of particular codes and asked them to interpret these findings.

Moreover, we gave students the opportunity to discuss the risks and benefits of their participation, and stressed that this way of working was as new to us as it was to them – and importantly, that the project itself was much riskier than our usual research practice. Second, we admitted that we were relying on their cooperation and

reiterated that, of course, they were free to opt out at any point. A second question concerned our own interests: did we have any interest in persuading them to get vaccinated? Clearly, this was not our objective, but the fact that the question was raised reveals the complexity of the context in which we found ourselves, and the politicised nature of the subject matter.

The criticism articulated by the participants regarding the features of the online platform, in particular, provided interesting insights into the general nature of (digital) participation in science. The online tool was considered too restrictive by some participants, and they contested it right at the start of the project (partly because it was not user-friendly, from their perspective). Additionally, as we experienced ourselves, the reliance on short-term external funding and the milestone-driven logic of such research projects do not always fit neatly into the open-ended ideal of citizen science. The digital nature of participation accentuates this temporal restriction on learning.

However, we also found that participants' attitudes towards their participation changed over time. Despite their criticism of the online platform, they began to engage with the project and made suggestions for improvements that would enhance both the definition of shared goals and the methodological implementation (for example, allowing peer validation of selected codes). In this process, our research participants revealed that the use of online tools can reproduce existing hierarchies and patterns of thinking, and that, in truly participatory research, walking the (argumentative) talk requires more than merely discussing reflexivity as an epistemological principle.

Findings

General quality

While we facilitated and assisted in the school-based coding sessions, participants were largely autonomous when it came to interpreting the texts. This was useful and necessary for the experimental nature of our project, but it also led to diverging interpretations. In our overall analysis using Stata 11.2, we aggregated these interpretations to obtain more general conclusions.

To begin with, participants were able to dismiss (or rather, skip) press releases which they deemed irrelevant for the purpose of answering our research questions. Over 120 press releases were coherently assessed as irrelevant, and over 90 of those had been issued by members of the pharmaceutical and research industry (announcements of new products that built on HPV research, for instance). This reduced the relevant corpus to 353 press releases in total. The consistency of these interpretations indicates the overall internal validity of the results. In addition, a research assistant validated over 10% of the coded press releases.

Where deductive coding results diverged, we aggregated them as follows: if two participants had suggested that particular codes were absent, but an equal or higher number of participants had indicated them to be present *and* had assigned specific text passages to them, we assumed the latter to be a valid assessment. Overall, this aggregation of results was particularly relevant to the press releases issued by the industry. We assume that these press releases were often more difficult to understand because they included more technical information based on emerging biomedical HPV research. In future projects of this kind, a peer validation mechanism and an annotation tool would most likely be included in order to increase the interaction

between participants and enhance the quality of results. Such a mechanism would also reinforce this approach to citizen science as a responsive and responsible form of interaction between trained and untrained scientists, and would enable more participation in defining what is at stake. This would be particularly relevant when applying citizen science to policy analysis, where scholars often stress the need for the joint articulation of meanings – and thus defining the political contours of policy issues. Since we did not have this enhanced function, however, we relied on personal contact with participants in order to define common goals. However, relying on personal interaction would make citizen science very resource-intensive as a permanent scientific practice. Without a digital mechanism, interaction remains possible for only a limited number of participants, and for a limited period of time. Moreover, the challenges that we experienced suggest that, as a genre of texts, press releases are a more challenging type of data than, for instance, newspaper articles, because they may be directed at an expert audience.

Actor specificities

In our analysis, we focused on two specific actor categories: ‘political actors’ and ‘industry’, even though other actors were clearly involved in shaping the discourse through press releases, too. This was a pragmatic decision: not only did these two actors constitute a substantial part of the overall sample, but we also observed that participants were more keen on discussing these two actor groups. This means that we are mostly able to make valid statements about these press releases in the context of our project. In principle, it would be desirable to have a sample that is not only larger but distributed more evenly across actor categories in order to be able to make statements about all types of actors involved in the discourse. However, the analysis of these two actor categories was enough to provide a good impression of the results and possibilities of a participative discourse analysis.

The results point to two clear peaks in the press releases issued around HPV: in the year of 2007 – following the release of the vaccine and the subsequent assessment of the national vaccination committee – and in the year of 2014, shortly following the introduction of the HPV vaccine into the Austrian child immunisation programme. Industry actors issued press releases continuously throughout the relevant period (2007–2014), whereas political actors (that is, political parties, Ministry of Health, and women’s groups) were particularly active during these two peaks. The comparative silence of political decision-makers between the two peaks confirms our impression that, in Austrian politics, political actors mainly negotiate in committees behind closed doors. Both sets of actors also continuously emphasized that the HPV vaccine could not replace existing screening methods (that is, the Pap smear). This suggests a convergence in their stances towards the vaccine during this period of negotiation.

Gender and sexuality

As indicated in our brief review above, the HPV vaccine generated a range of debates concerning more or less explicitly gendered considerations linking the vaccine to particular notions of (primarily heteronormative, cf. [Epstein, 2010](#)) sexuality. Our earlier study ([Paul, 2016](#); [Paul et al, 2018](#)) also pointed to the gendering of the vaccine and showed that the introduction of the vaccine relied on the bracketing out of

sexuality. This finding corresponds with the findings of our participants: in 2007, only 4% of press releases issued by the industry were framed as gender-neutral, while 12% of political actors did away with gender categories in that same year – the first peak in the HPV debate. Similarly, members of the industry referred to the sexually transmissible nature of HPV in 33% of their 2007 press releases, while political actors only did so in 18%. These results confirm our earlier finding of a tendency to sideline sexuality, and that political (public policy) actors tend to do so more than other actors. Regarding the inclusion of boys in HPV vaccination programmes, we see a substantial increase in political actors' press releases referring to boys as possible recipients of the vaccine – from 5% in 2007 to 33% in 2014. Overall, entirely 'gender-neutral' press releases were extremely rare (26 in total, as identified by the participants). We do find a tendency for political actors to strike a more 'gender-neutral' tone in their texts, but the coding of the relevant press releases diverges substantially, making it difficult to make claims on that basis. We can, however, state that both industry and political actors released more 'gender-neutral' press releases regarding HPV over time, reaching around 10% in 2014. The political-administrative consensus on offering the HPV vaccine to all children aged nine years or above in 2014 was thus reflected in the press releases. Similarly, both sets of actors strongly communicated the supposedly 'cost-free' nature of the HPV vaccine at that time, and unsurprisingly, political actors did so more noticeably.

Regarding the inductive coding, two valuable insights emerged. We assessed the codes assigned earlier on in the project and found that participants were eager to add gender-related aspects and, at times, codes relating to age-based target groups (differentiating, for instance, between children and adolescents as target groups of the vaccine). Second, towards the end of the project, participants began to point to themes and issues that were *not* being mentioned in a particular press release. This suggests that their participation had turned them into experts not only by experience, but by *engagement* with the development of the policy debate. At least for the duration of the project, we were able to establish a framework of values that made all the actors involved (whether trained or untrained researchers) accountable to each other and to certain norms of participatory research, such as transparency, dialogue, and willingness to shift positions. Again, this points to the relevance of 'credential knowledge' as potential input for policy, specifically in policy areas where researchers may tend to adopt an 'insider' status as quasi-experts too quickly (Larabee, 2002).

Our inability to systematically allow for the highlighting of silences and blind spots was a clear limitation of our study – even if our understanding of the need for such a feature was a finding in itself. Our participants thus became genuine research partners by pointing out our own bias to us, questioning the limits of our research design, and more importantly, reminding us that critical policy analysis must not only critically engage with what is being said, but with silences and omissions, too. Similarly, any notion of evidence must also include both knowledge and an awareness of its limits and blind spots (Paul and Haddad, 2019).

Discussion

This paper has presented a novel form of participatory policy analysis in a highly politicised policy area: vaccination policy. Rather than focusing on professional communities of practice, as we had in the past, we involved adolescents in a

school-based citizen science project. We specifically chose to involve them as the target group of a hotly-debated vaccine – that against Human Papillomavirus – in an analysis of an extended policy debate in Austria. To be clear, the expertise that we assigned to participants was not that of having experienced vaccination, but having been addressed as a target group of the vaccine. This experience, we conjectured, provided those participants with a particular form of ‘credential expertise’ (Rabeharisoa et al, 2014), which allowed us to not only expand our knowledge of the policy debate – thus fulfilling our instrumental aim – but also to explore the potential of citizen science in policy analysis. It is in this sense that our study was experimental, both for us as trained researchers and for the participants. By inviting them to analyse press releases on the subject matter systematically, we not only helped them acquire new skills, as citizen science projects typically do, but also enabled them to articulate their perspectives on the policy debate and to offer their own interpretation of events. In this way, we argued for citizen science to be considered in the potential pool of methods available to counteract the technocratic nature of evidence-based policy.

For, as argued in our discussion of methods above, mobilising citizen science for the sake of policy analysis has two advantages: with its scientific systematicity, it fits neatly into the language of evidence-based policy, while it also enables the broadening of the notion of expertise by way of citizen participation. Our project was effective in mobilising participatory forms of knowledge production, yet ultimately, we, as trained researchers, held on to the task of translating ideas and data analysis into knowledge, and knowledge into evidence, particularly when it came to communicating results – such as in professional publications. For citizen science to gain more ground, the challenge is then to constantly weigh citizen participation as a value in and of itself against the aim of producing of evidence. Regarding the second benefit – that of extending expertise by way of citizen participation – our participants exceeded our expectations. Our offline interactions were particularly valuable in uncovering the capacity and expertise of these young participants. Yet our own research design, but also structural funding-related issues were in the way of truly developing new notions of expertise. Based on our experience, we would thus recommend a two-tiered approach for future projects, featuring both offline and digital components, and a greater variety of material than merely press releases. Finally, the restricted resources at our disposal meant that our ability to interact with participants in workshops was limited, and the hierarchically-informed school-based setting likely hampered a long-lasting broadening of the notion of expertise.

These results and our joint experiences in the project speak to several timely issues, tied to various levels of the project. First, we argued for the need to rethink our methods at a time when trained experts are increasingly being challenged in their role of speaking ‘truth to power’ (Nichols, 2017). Citizen science offers ways to reframe the very notion of expertise in that it enables the citizens involved, or in our case, the target group of a new medical technology, to act as credential experts (Rabeharisoa et al, 2014) and to expand our own view beyond what Bourdieu (2000, cited in Kenway and McLeod, 2004) referred to as the ‘scholastic perspective’. If active participation is to become common practice, particularly at the science-policy nexus, citizen science projects must be designed to allow more space for a common understanding of issues to emerge, and to formulate and resolve (scientific) problems jointly (Peschard, 2007).

Second, the results of this project suggest that, particularly in politicised policy areas, affected citizens can be activated as research participants fairly easily. Our experience may thus be relevant in other instances of (evidence-based) policy making. Perhaps, if citizens were to be more involved in collecting, assembling, but also framing, testing and contesting evidence in a particular policy area – whether through sensors or through their smart phones (Newman et al, 2012) – their active contribution could not only strengthen the evidence base for particular decisions, but also improve the democratic nature of policy making as a whole. Beyond producing knowledge for policy, as they would do by collecting data on, say, pollution or their experience of a particular technology, citizen scientists can and should produce knowledge *about* particular policies. While, in the current study, we foregrounded this *instrumental* aspect of knowledge production, this collective critical reading of policy discourse also amounted to a political *intervention*. In politicised and controversial fields, in which experts also have fundamental internal disagreements, participating citizens could then take on the role of the friendly critic, opening up space for deliberative engagement with actors in a contested policy field. To ensure that instrumental aims would not sideline the political aspects of such a project, care must be taken to ensure that all the parties involved are aware of their respective roles. The potential risks and limits of participation should be made clear from the outset, in order to minimise the risk of undermining the desired effects (Liabo et al, 2018).

The novel and experimental nature of this project proved challenging – not least because of the need to involve seemingly disparate social worlds, including teachers, programmers, social scientists and adolescents. Having participants read and interpret materials with a ‘fresh pair of eyes’ substantially improved our own understanding of the subject matter at hand and enabled us to fine-tune our earlier findings. For example, we are now able to empirically point to the tendency of public policy actors to bracket out sexuality in the context of the HPV vaccine at particular points in time – a discursive turn that allowed for the effective introduction of the vaccine in 2014. In addition to its scientific value, this actor-specific finding provides more effective feedback for policy makers regarding their communication around new medical technologies, particularly in an era when scientific evidence is frequently contested. Overall, the study shows that, for the purpose of mapping controversies (Whatmore, 2009), participatory methods may be just as suitable as expert-centred methods, but with the additional advantage of potentially counteracting the technocratic nature of health policy making *and* our own analysis.

Finally, the feedback we received from participants – who pointed out omissions and aspects that were *not* mentioned in certain press releases – offers a new angle for considering the politics of evidence as politics of knowledge practices more broadly. McGoey (2012) has pointed out the importance of what she terms ‘strategic ignorance’, first and foremost by critically assessing the ways in which the pharmaceutical industry compiles evidence selectively. We propose a reconsideration of evidence-based policy both in terms of what knowledge it promises and yields, but also which inevitable knowledge gaps feed into policy (Paul and Haddad, 2019). In other words, policy analysis – and our joint efforts to contribute to democratic and symmetric evidence-based forms of policy – must approach knowledge practices as involving the production of both ignorance *and* knowledge alike.

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Authors’ contributions

The literature review and background discussion draw on Paul (2016) and Paul et al (2018). The project reported on in this paper was presented in its more technical features in Paul (2018). The corresponding author led the project, formulated the main arguments, and wrote the first draft. The second author assisted with data analysis using Stata and the final write-up. Both authors read and approved the final manuscript.

Conflict of interest

The authors declare that there is no conflict of interest.

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