

Researchers' Perspective on the Publication of Research Data: Semi-structured Interviews from Germany

Interview: os_010 – Translation

1	Interviewer: Then I thank you again, that we can hold the interview. This is very, very interesting for me. And at the beginning I would like to ask you to tell me in which field you do research, what you are doing.
2	Researcher: Well, I'm in emergency and acute medicine here in the research team and we mainly do care research. So we... collect patient data, erm... do also interviews. Qualitative, quantitative analysis in order to improve the supply situation in the emergency rooms. Exactly and yes... before that I was in [another field] and did more basic research, that means laboratory... erm... collected related data. Animal experiments, etc.
3	I: And how long have you been in research altogether now?
4	R: Since... well, does the doctoral thesis count as well?
5	I: I think so, yes.
6	R: Well then since 2005.
7	I: Quite a long time already. Very good. So you've already mentioned some research data that you're working with directly. Is there more or more specific what kind of research data this is? So can you go into that a little bit?
8	R: Yes, these are just... now at the moment these are routine data, these are data that are actually collected for another purpose - for the documentation in the daily clinic routine. And we make use of it in order to analyse this specifically in the context of research questions for the supply situation. And then there are also the primary data that we have, that is the data that is generated through interviews and questionnaires and then prior to this, I also have been working with gene analysis... like gene fingerprints or whatever it was termed. Exactly. So already a relatively broad mass of data forms.
9	I: And have you ever already published your research data?
10	R: No.
11	I: And why not?
12	R: Erm... Well that's... that's more an actual thing right now... so it will come into the public



	domain; people talk about it in general. Erm. I never really thought about it until then, so... Although no, I also did snip analysis once. You look at altered genes and see if they for example have an influence on the development of diabetes. And there I did indeed carry out a meta-analysis on data stored in databases, but that is so long ago that it was very poor in terms of quality and comparability. And we ourselves also never brought into it our own data.
13	I: And what stopped you from doing so?
14	R: Hm... Well, that the benefit simply wasn't clear, that you could... yes also possibly... well, as I said: One didn't really think about this at all, erm. That's just coming up now and then perhaps in the next course is the problem of data interpretation maybe, that can then perhaps be carried out by those who can use the data then and what is perhaps not in the sense of what one has requested oneself or actually wants to show wanted to show or//or, right? Now, these health care research stories also have a lot of political potential and you have to make sure that the interpretation... somehow you can always all lay it out, so that in the end that comes out what you want to say. Well not exactly like that. So it is not really like that, we want to create extra data so that you get an unguided impression, but it can, it's possible.
15	I: And you also work with... or a lot with personal data and also sensitive data, right? If you would like to publish the data now, would you know how to deal with it?
16	R: No.
17	I: So you have never done anything like this before?
18	R: No, I've never done that before.
19	I: And would you think of anything that would help you to publish such data? So whether this would have to be any information or what in general could help you to publish your research data?
20	R: Well, first of all I think the benefit for yourself and the research group would probably have to emerge out of it, because otherwise you probably won't be able to legitimize it to your boss in any way, that you want to put the data there somewhere. And then of course it would have to be ensured that the//that the data is handled according to the... well that it is handled the way you would expect it to be for such data. Exactly. And this I do not know, how transparent that really has to be and whether the platforms are already so far to provide these securities, but I also have never looked into such platforms.
20	I: Erm... I just had a question, just a moment.
21	R: And we had, we had for example for the project what I am doing now, the big health care research project, we already had to fight enormously for the data protection. To get it through, to



	just get it... running at all in Germany and even across Germany we are not allowed to do that and therefore I don't know. Probably we would have had to include this in the concepts, this integration into the data... so incorporating this into the publication of the data and I think that then it would have been.... that would have been the end of it.
22	I: Yeah. And you mentioned at the beginning that you also use data that was not actually collected for this purpose. Did you collect it yourself? Or did you, nevertheless collect it yourselves, only to another issue or is it data that you actually reuse from others?
23	R: Erm, so this is... we are... we have altogether [some] clinics in the project. So our own data, that is the data from the emergency rooms during the patient run, which are being documented. These are date of admission, sex and such things. And then correspondingly the data from the other clinics, so a total of [NUMBER]. And that's//that's the routine data, which in principle isn't actually intended to answer research questions, but which is now being used to do so. That are doing... is now a field that is getting broader and broader.
24	I: And how is it in your discipline when you publish an article that is of course somehow based on research data? There you also don't publish the data together with the article, so only the results, only the interpretation?
25	R: Exactly, exactly. According to good practice for research.
26	I: Good scientific practice.
27	R: Precisely. We keep the analysis data sets of course for the next ten years, that is being done, but we do not publish any data, so nothing. Well certainly then... the results of the analysis, but never the raw data or the processed data or whatsoever.
28	I: Okay, erm. Is it getting more or less published in other countries in your field, have you ever observed that, based on your own intuition?
29	R: Well, for sure is Germany enormously behind in terms of this routine data use. But there are now many activities in the running, so some kind of documentation standards are being tried to set up, like the medical informatics initiative, etc... There are a bunch of projects that are now also being funded. And just in order to establish standards at all so that documentation becomes uniform. Because we have now also seen, with these [emergency rooms], each of them does it differently and each of them means in the end partially different things, which actually may sound the same and there are other countries much further ahead. So I think the figurehead is Denmark as far as this is concerned or for example in Australia many, many quality indicators are also legally obliged, to report regularly from everyday clinical practice. And there is not much there yet or I also do not know what specifically is being reported, but nothing in the emergency room context.



30	I: And do you have a research data policy here at your institution? So is it regulated somewhere how you have to deal with research data, so in general?
31	R: There we had that what we had discussed in the course. Erm, I think there the documents are more and more adapted and enlarged. At the time I signed, it was... sure, it was clear that of course you handle the data well, but there was nothing yet so formally included.
32	I: And could you answer the question of who owns the research data that you collect?
33	R: [The institution]
34	I: That was a very clear answer. I find it interesting, very good. Ah, okay. Well, I think that was actually the last question. Then I would like to thank you very much again.
35	R: Gladly.

