MAT Medicine Anthropology Theory

FIELD NOTES

# Doing Health in the Clinical Research Centre

## Care Work in Choreographies of Data Production

Nolwenn Bühler

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## Abstract

Health examinations are an essential part of cohort studies: questionnaires are filled in, biological samples drawn, bodies weighed and measured, their capacities and functions tested. Drawing on an ethnography of these clinical encounters, in the context of a population-based environmental health cohort in Switzerland, I describe the choreography of data production and how it blurs the boundary between healthcare and scientific research. In contrast to the notion of clinical labour, which describes logics of objectification and extraction, this Field Note paints a more nuanced and sensitive picture, in which care work performed by nurses, the active role played by participants, and the materialities around them, come together and move apart. These fragile choreographies point to the importance of care work as a form of expertise necessary for data production.

## Keywords

Care, Choreography, Datafication, Cohort studies, Environmental health.

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## Introduction

The examination room is quiet. It is early morning and Sara, the nurse, is checking that everything is ready for the first participant: the right tubes sorted by colour, with the correct barcodes for labs they will go to for analysis, the testing devices or glycemia and cholesterol, the window open for some fresh air, the computer switched on.[1] Sara sits at her desk and verifies that the cohort participant's identification code matches that in the research project database. She quickly reads through his questionnaires to check they are complete. She looks at the gauges on a little shelf and is typing the room's temperature and atmospheric pressure into the computer when her phone rings.

It is the participant. Lost in the corridors. Sara regrets signage is not better: it would make the room more accessible. A few minutes later, a tall old man arrives, a little out of breath. Sara sanitises her hands and welcomes him warmly, inviting him to sit and making sure he feels comfortable. After checking his identity, she thanks him for completing the lengthy questionnaires. She asks if he has any questions about the consent form he has already signed. He does not, so she goes on to describe all the steps of the health visit. He says with humour that he is used to clinical examinations and is a regular customer of the hospital across the road. Even though he has never participated in cohort studies, he has no worries.

Later, Sara asks him to remove his belt, shoes, and heavy clothes. She takes him to the bioimpedance machine. She stresses the importance of gripping the handles tightly and firmly placing his feet on the scale. The machine is slow and not working as usual. While she tries to solve the issue, she apologises for wasting his time. He says it's no problem, laughing: 'I'm your guinea pig, I'm at your disposal!' She looks at him, half-amused, half-alarmed: 'No, that's horrible, you can't say that, you're not a guinea pig, I'm a nurse!'

A guinea pig and a nurse. The participant manifesting his goodwill, his time and cooperation, trying to reassure the nurse about the technical inconvenience. The nurse, sensitive to the patient's self-animalisation, and its corollary, the almighty role of the scientist experimenting on weak, passive animals he attributes to her. Two roles, one pertaining to research, the other to healthcare. Two worlds which are kept distinct by ethical and institutional boundaries which, in practice, are not so clearly defined, are blurred, negotiated and arranged in many different ways, especially with the rise of personalised health (Meier-Abt et al. 2018). These data-driven initiatives are transforming public health research practices (Hoeyer 2016; 2019). To understand these shifts, I conducted an ethnography of the pilot phase of a cohort study investigating environmental exposures. In this Field Note, I focus

[1] The text is anonymised, and Sara is a pseudonym.

on clinical encounters taking place during health examinations as sites at the intersection of healthcare and scientific research, which play a key role in the datafication of health.

Health examinations are an essential part of cohort studies, as spaces for producing ‘good quality’ data and samples. This requires important ‘clinical labour’ from participants. This concept (Mitchell and Waldby 2010) was proposed to describe bodily work done for free by research participants, whose data and samples are stored in biobanks and serve global tissue economies. Having followed debates around biobanking in Switzerland (Bühler, Barazzetti, and Kaufmann 2018), I was aware that this concept carries a critique about the objectification and exploitation of cohort participants caught in asymmetrical research relations. Yet, as I attended health examinations, following their delicate choreography over and over again, a more sensitive and nuanced picture emerged.

Thompson (2005, 10) states that ‘ontological choreography involves the physical places and configuration in which the instruments and body parts touch. It also involves the coordinating, grafting, and often expanding of the very properties and processes that make up things’. It allows the complicating of binary narratives of power relations and dualisms such as subjectification-objectification, or human-technologies, by insisting on their interdependencies and intermingling. Drawing on these insights, I scrutinise choreographies of data production to describe the sociomaterial configuration of health examinations, the cooperation and agency of devices, instruments, bodies, subjectivities, and temporalities necessary for data to be produced. I will shed light on the importance of care work performed by nurses as the art of arranging and animating the relations of the choreography, as they care for participants, as humans with concerns, aches, families, and life histories, but also for data, samples, and devices, in a way which blurs the boundaries between healthcare and research. I especially show how care, as something that is done, but also as an attention (Laugier 2015), is a form of expertise and art which is crucial for datafication but often remains overlooked.

## The memory work of tracing exposures

Having verified an elderly male participant’s identity, Sara takes him through the exposure questionnaire, which is considered too hard for participants to answer by themselves. It situates various kinds of chemicals exposures in occupational settings and daily life: gas, solvent vapours, rayons, polycarbonates contained in plastic, dust, ski wax, supermarket receipts. The duration, frequency, quantity, and modalities of exposure must be as detailed as possible. She asks him first about gas. He seems lost, likely to answer negatively. Sara provides an example of a

situation and suddenly he remembers. He says that he worked on a farm as a teenager, driving a tractor. ‘Eight hours a day,’ he recounts. ‘I had difficulty breathing, my eyes itched. I had asthma as a child too. Actually, it was much more polluted in the past.’

Next, Sara asks him about solvents. He seems lost again. Thinking back, he recalls the stencils and white spirit he used as a schoolchild, which generated alcohol vapours. ‘There were no photocopiers at that time,’ he smiles. ‘There was also an oil heater in my classroom.’ I observe that the nurse stops insisting on the substances themselves and encourages him to speak about his personal and professional life. This prompts him to remember a security job in an industrial zone. He did night shifts and was probably exposed to plastics and resins. ‘How much time? Were the windows open?’ asks Sara.

He hesitates. ‘Perhaps a few minutes per night?’ The question of pesticides is easier: ‘We didn’t know at that time. We used fertilisers, pesticides, there were suspicious products everywhere, when I think back. It was probably RoundUp, but not like where they showered trees.’ He laughs. ‘Those farmers are probably already dead! I never use them nowadays; we eat organic food and I don’t put any chemicals in my garden.’

Listening to his stories, I realise that he nuances his answers, depending on whether the experience seems serious to him or not. He insists that his colleagues were more exposed than him, that ski waxing was only done outside. Sara carefully records his answers on the computer, patiently helping him retrieve his memories. This cohort aimed to capture low-dose, chronic exposure to a variety of substances, a kind of invisible daily life threat, where chemicals imperceptibly enter bodies and alter biologies. As I attended repetitive examinations, similar scenarios occurred. Participants just did not know how to answer the exposure questions. The substances named sounded strange to them, as did the situations and modalities of exposure. Although environmental concerns were often a reason for participating in this study (Bühler et al. 2023), I observed that participants downplayed the seriousness of their exposure. It was only the nurse’s careful listening, attention, and sensitive guidance to extract recollections that rendered details perceptible. By enshrining abstract chemicals into the flesh and emotions of life experiences, by caring for data and the participant at the same time, exposure became visible, tangible, and questionnaires could actually be filled with precision.

## Working and learning with machines

Sara invites a middle-aged female participant to sit. She sanitises a device that looks like a Ventolin asthma inhaler, consisting of a tube with two plastic nozzles. I learn that it is a spirometer to measure lung capacity. Sara carefully explains she will have to put a nose clip on to block the nostrils. Then she will ask the participant to take a deep breath and fill her lungs with as much air as she can. When Sara gives a signal, she should forcefully blow into the mouthpiece, until her lungs are empty. Sarah warns that the process is difficult. The participant says she is not afraid, she knows how to breathe! Sara reassures her that she can take her time to complete the test well. Then she asks her to breathe normally into the tube. Her respiration appears as a curve on the computer screen, which they both look at. The machine beeps regularly. Seated in a corner, I find the noise disturbing and admire Sara's calm. The woman breathes normally, then inhales deeply. Sara tells her to blow. They look at the screen; the test has failed. The inhalation was not strong enough. The machine continues beeping. 'Breathing is so normal, you never think about it,' says the participant. The nurse agrees, adding that we often breathe badly. The computer loses connection with the device and the test is interrupted. They have to start again. They repeat the process five times. The curves are inadequate and the tests are not good enough to be recorded. The blow is timed too early or too late, or is too weak. The participant seems discouraged: 'I'll never succeed, I don't know how to breathe! The machine is never happy'.

The nurse speaks to the device: 'You will exhaust us!' Then, to the patient, 'It's a very sensitive machine and a very difficult exercise, don't worry.'

The participant gathers her strength. 'I'm going to make it understand!' Sara says they can go up to eight attempts. They try again. Between attempts, she lets the participant regain her breath. In the end, three attempts are registered as good enough for the test.

While observing the participant and Sara struggling with the spirometer, what struck me was how learning the machine functioning and translating its instructions, was needed to perform the test and produce good data. First the nurse explains exactly what to do, the machine's role, how it will react, what it will reveal, what it expects. She also explains what is expected from the participant, what they have to do, when, and how. But giving oral instructions is not sufficient. There is bodily learning that can only be acquired by passing the test, by doing the spirometry, failing, and starting again. A bodily activity which is unnoticed most of the time—breathing—needs to be focused on, and its dynamic embodied movement understood sufficiently to be directed and coordinated with the device.

From the outside, it seemed so easy to follow the nurse's instructions. But as I saw many participants, of different ages and physical condition, fail the test repeatedly, I started to understand how the cooperation between bodies and devices was crucial. It involved not only respiration, but the whole body. A participant's position on the chair, their mental effort telling the lungs what to do. The concentration required to perform the test was palpable. What appeared easy was in fact an arduous and gruelling exercise. Without the nurse's caring encouragement, kind guidance through several attempts, and reassurance about its difficulty, but also without the participants' willingness, perseverance, and their bodily learning, as well as technical cooperation from the all-powerful device dictating which breaths were 'good enough' to be recorded, the choreography of data production could not succeed.

## Taming and timing blood draws

'Do you want a glass of water?' asks Sara.

'Yes please,' answers the participant, an elegant woman in her late thirties. Sara goes to fetch a glass, asking her to sit in a chair next to a small metal trolley on which lies a plastic bag containing blood collection tubes. While the participant drinks, Sara takes the tubes out of the plastic and arranges them in a specific order. She asks the participant to roll up her sleeve, disinfects her hands and a small cotton pad. She puts on protective gloves, tightens the tourniquet and starts palpating her inner arm. The veins are not visible. They seem very thin. The woman says it is usually hard to draw her blood. The scene takes me back to when I was working as a nurse and how stressful it could be.

Sara stays focused. I admire her peaceful expression. Softly tapping the veins to activate circulation, she says, 'Come on, be good.' She inserts the needle into a vein. No blood appears. The woman seems stressed. Sara carefully moves the needle. No blood. The butterfly line remains transparent. 'I don't want to harm you, tell me if it hurts,' she says, looking the participant straight in the eyes. After what seems a very long moment, she removes the needle and says she will try the other arm, if the woman agrees.

The participant nods her head. She apologises with a kind of desperate smile. 'My veins are not very cooperative.' Sara has to change the position of the trolley and the participant's chair. She takes another needle out of the sterile protection bag and starts the operation again. She is luckier this time. Blood runs slowly into the line. She swiftly connects one of the tubes and, as soon as that is full, connects another one. She is focused; nobody speaks. Only the soft sounds of Sara handling the tubes break the silence. The blood flows slowly, and it takes time to reach a thin mark indicating the required level in each tube. Feeling that there will

not be enough blood for all, I see Sara prioritise some tubes over others. Two are only half-filled. She says she hopes the lab will be able to do something with them. She removes the tourniquet and puts a small plaster over the vein. She then rushes to the phone and calls the courier to pick up the tubes and take them to the lab across the road.

After that, Sara scans the tube barcodes to register them in the software that follows each one from blood collection to the centralised biobank. Once that is done, she offers some fruit juice and biscuits, which the woman welcomes. Sara tidies up the material and prints out results from the whole examination. She frequently checks the clock. The courier should already be here. She is getting irritated. She explains that the blood needs to be in the lab in less than twenty minutes, and that timing is vital for quality. Finally, he knocks on the door. Sara gives him the tubes and reminds him of their destination. There are several labs; she wants to prevent any possible mistake. ‘A job well done!’ She smiles, relieved.

Collecting blood is a daily routine in healthcare practices. Yet it remains challenging when a body does not cooperate, in spite of the participant’s goodwill and patience; when the participant is only there once; when so many tubes are to be filled; when there is insufficient blood; when it must be rapidly decided which analyses to prioritise; when there is the risk of a tube being wrongly scanned, or forgotten; when there is time pressure, the urgency of getting samples to the lab before four o’clock. The possibility of failing the choreography is hidden in these many details, in the mutual cooperation of several human and non-human actors. When the choreography succeeds, that data of good quality is collected and the participant feels well, the care work needed for its success is made invisible, it is naturalised, and assumed to be the normal standard. Observing health examinations and these sensitive choreographies might remind us that, in the entire enterprise of producing data for research, there are divisions and hierarchies of work, and the caring necessary to produce data is not ‘normal’, peripheric, or noise that needs to be cleansed later. It is central, an invisible art of bringing things, bodies, and subjects together, of putting them in motion, and of being put in motion by them.

## Conclusion

The boundary between research and healthcare matters. It stems from a history of medical abuses done in the name of science, which justified the institutionalisation of research ethics. Yet one main reason people take part in cohort studies is to get a ‘free’ medical check-up, which might be especially important in the Swiss healthcare system where some individuals rarely see their doctor to avoid paying high insurance deductible. There is little visible difference

between research health examinations and ordinary clinical spaces. Yet there is more time allocated for research examinations, than in the daily routines of hospital wards. Moreover, I could see that participants were pleased to get their results, to see their bodily functions evaluated, quantified, datafied. They looked forward to receiving more results. Nurses, while playing a central role in producing quality data for research, also used the examinations to promote health. They made their possible to personalise results and render them meaningful relating to participants' biographies, bodies and biologies. They could differentiate a slightly 'out of range' number from a serious deviation and valorised participants' ability to know what is best for them based on how they feel and not on abstract figures or normative public health recommendations.

The personalised care and attention the nurses gave the participants contributed to producing good data for both research and participants, giving them something in return for their clinical labour. In contrast to this notion, describing logics of objectification and extraction, this Field Note paints a more nuanced picture. The sensitive choreographies described are fragile. There are so many little procedures and details to pay attention to. The cooperation between subjects and things is always amenable to frictions. They expose the importance of caring in the datafication of health. This caring is a form of undervalued expertise and art which is necessary for quality data production. Beyond the promissory horizon of data-driven public health, this Field Note reveals how the data gathered from a cohort was not simply given, but produced through small gestures of care. Datafication proceeds through an invisibilisation, an extraction, of the 'worldliness' of these choreographies, through incremental operation of data purification and cleansing. But, to obtain quality data and samples, first must comes the quality of care work which holds and moves the choreography together.

## Authorship statement

The author, Nolwenn Bühler, conceptualised the project, conducted research, made the analyses and wrote the fieldnote. Her findings were discussed in internal meetings with other members of the SNSF Sinergia project, which provided funding to explore the Development of Personalized Health in Switzerland with Social Science Perspectives (DoPHiS, n°CRSII5_180350).

## Ethics statement

The research project, on which this Field Note is based, respected the ethical requirements in force in Switzerland. The proposal was examined by the Ethical Commission of the Canton of Vaud (Req-2019-01305).

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## About the author

*Nolwenn Bühler* is an anthropologist of biomedicine and health whose work lies at the intersection of Science and Technology Studies (STS) and Gender Studies. Her expertise is in the field of reproduction studies, (post)genomics, and environment-health relations. She currently works at Unisanté, a University Center of General Medicine and Public Health.

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