This document was translated from English by machine and may contain mistakes. The English original is at https://www.novaracg.com/2026/11/17/he-had-to-fight-for-the-data-from-his-own-brain-signers-cannot-even-find-theirs/.

He Had to Fight for the Data From His Own Brain. Signers Cannot Even Find Theirs.

Heather Grizzle · November 17, 2026

A brain implant patient was told his own neural data was not his. The interpreters inside sign language AI were never even told they are in the data.

Conteúdo

1. The form that answered the question
2. Nobody asked, so nobody built it
3. A man who knew where his data was
4. The interpreter in the corner of the screen
5. Same argument, different body
6. What NCG has asked, and of whom
7. What a signers′ version would say
8. A partner, not a source
9. Referências

A paralyzed man in California let a university put six chips in his brain, then learned from a consent form that what came out of it was no longer his. His fight is now in The New York Times. The people whose hands and faces built sign language AI have the same problem with one more layer on top: most of them have never been told they are in the data at all.

EM RESUMO

- A 70-year-old participant in a Caltech and USC brain implant trial asked for a copy of his own neural data and was refused. A revised consent form settled it in the institution's favor, and his lab sessions are paused while the universities work out an answer.
- He knew where his data was, who held it and which document governed it. He had a review board to write to, lawyers and a coalition of fellow implant users behind him. A signer in a sign language AI corpus usually has none of those things.
- The largest British Sign Language corpus, BOBSL, is about 1,400 hours of BBC programmes signed by 39 interpreters. The only permission form the BBC publishes for it is for the researchers who download it. The BBC says it owns and controls the dataset and every use of it.
- The licence is non-commercial, and at release the BBC said it hoped academic work would inspire commercial companies to invest. Whether the line between the two has held cannot be seen from outside, so NCG has put Freedom of Information requests to the BBC, Oxford, Surrey, UCL, UK Research and Innovation, the Information Commissioner's Office and four publicly owned train operators.
- Buckwalter's coalition wrote its own statement of participant rights. Signers need one of their own, and buyers of sign language AI can write its terms into their contracts now.

The form that answered the question

J. Galen Buckwalter is 70 and has been paralyzed from the chest down since a diving accident in his teens. In January 2024 he had six chips implanted in his brain for a brain-computer interface trial run by Caltech and the University of Southern California, and for two years he has gone to the lab twice a week so researchers can record his neurons. He joined to help people with spinal cord injuries who come after him, and because, as a former research scientist, he wanted to learn from the data. When he asked for a copy of it, the researchers said no. The Times tells his story in full, and it is worth reading there[1].

The short version is that a form settled the question. Buckwalter asked in writing for the right to copy, use and share his own data. The answer came in March as a revised consent form, which told him "the data will no longer belong to you" and that anyone with concerns should not take part. Leaving the trial would mean another surgery to remove the chips. He found lawyers, they wrote to the review boards of both universities in October, and Caltech paused his lab sessions until a consent form is signed or a new one agreed. Caltech's review board chair told the Times the university wants to find a way to share the data and hopes to settle it within the coming year[1].

THE DATA FROM ONE MAN'S BRAIN

January 2024
Six chips implanted
A Caltech and USC brain-computer interface trial.

March 2026
The revised consent form
The data is the investigators', and no longer his.

outubro de 2026
Review boards asked, sessions paused
Lawyers write to both universities. Caltech pauses his sessions.

November 2026
Participants publish their own rights
The BCI Pioneers Coalition releases its recommendations.

Nobody asked, so nobody built it

The most useful line in the whole story is the review board chair's account of how Caltech got here. Few participants had ever asked for their data, he said, so the university had seen little reason to hand it over, and the risks of leaks or misuse looked larger than the benefit. Under that sits a legal gap. American law does not clearly say who owns clinical trial data, so the institution's consent form decides, and the forms differ from one study to the next. Francis Shen, a University of Minnesota law professor, told the Times the law is settled, and settled in a way he considers a problem[1].

Put those two facts together and you get a rule that reaches far beyond brain implants. A right that only appears when somebody asks for it is a right that only exists for peo-

ple who know there is something to ask about. Buckwalter knew. He had sat in the lab and watched his own neurons on a monitor. The people this piece is really about have never seen the room where their data is kept.

A man who knew where his data was

None of this makes Buckwalter's position a good one. A man who gave his skull to science is being told by a form that the output of his own brain belongs to someone else, and his reward for objecting is an empty calendar. But look at what he has to work with. He knows the data exists. He knows who holds it and which document governs it, because he signed that document. He has a named investigator to write to and two review boards with a legal duty to protect him. He has lawyers, a coalition of people in the same position and a reporter from The New York Times. Every one of those is a lever, and he is pulling all of them.

> A right that only appears when somebody asks for it is a right that only exists for people who know there is something to ask about.
>
> NCG

Now picture a different person. She is a British Sign Language interpreter, and some years ago she stood in the corner of the screen on a BBC programme and signed it for Deaf viewers. She was paid to interpret a broadcast. She went home. She has no chips in her head, no consent form, no investigator and no review board. If she is one of 39 particular interpreters, her signing is training data.

The interpreter in the corner of the screen

The BBC signs a share of its programmes with an interpreter in vision. Working with Oxford's Visual Geometry Group, BBC Research and Development turned that archive into the BBC-Oxford British Sign Language dataset, known as BOBSL, and released it in 2021. It holds 1,962 episodes, about 1,400 hours of signed BBC footage with the subtitles aligned to the signing. Its makers describe it as the work of 39 signers, all of them interpreters, and they split it by signer so that a model can be tested on faces it has never seen[2].

BOBSL IN FOUR NUMBERS

1,962
BBC episodes in the dataset

1,400
hours of signed footage, approximately

39
signers, all of them interpreters

12
months a researcher's permission lasts before renewal

Source: Albanie et al. (2021); BBC Research and Development, BOBSL dataset page

The BBC's own page for the dataset is short and firm. It says the dataset contains clips of sign language translators within BBC programme content, that it is for strictly non-commercial academic research, and that the BBC fully owns and controls the dataset and any use of it. Companies and independent researchers may not use it. A university

researcher who wants it must apply with an official academic email address, keep it secure, share it with nobody, and come back for renewal after twelve months[3].

The application form has a title worth reading twice. It is called the Permission to Use for Participants. The participants it means are the researchers. Nothing on the page speaks to the 39 people whose faces and hands make up every one of those 1,400 hours, and NCG has not found a published document, from the BBC, from Oxford or from anyone else, in which those interpreters agreed to have their signing used to train systems that recognize or generate British Sign Language. If such documents exist, NCG would be glad to see them and to say so. They are among the records NCG has now asked for.

This is not a new observation on this site. In September, The Corpus Question set out how the documented sign language corpora were assembled and what each method means for consent, payment and withdrawal. Its finding on BOBSL was plain. The interpreters were paid to interpret, not to supply a corpus, and the dataset's deletion obligation runs from the broadcaster to the researchers, not from the interpreters to anyone[5]. Buckwalter at least has a form with his name on it. The interpreter's name is on no form at all.

What each person can do about their own data

Questão	Galen Buckwalter (brain implant trial)	Interpreter in BOBSL	Signer in a corpus scraped from public video
Knows the recording exists	Sim	Knows the broadcast exists. Use in BOBSL not documented	Knows the video exists. Inclusion in a dataset not documented
Signed a document about this use	Yes. The trial's consent form	No published document found	No. Platform terms only
Has somebody to ask	The lead investigator and two review boards	No published route	No published route
Can get a copy	Refused so far. Caltech says it is working on it	No published route	Holds the original upload only
Can stop future use	Only by leaving the trial	No. Deletion runs from the BBC to researchers	Deleting the video stops new downloads only
Can come out of a trained model	Não abordado	No mechanism	No mechanism
Has a group speaking for them	The BCI Pioneers Coalition	None named	None named

Source: NCG, from Wang (2026), the BBC's BOBSL dataset page and Albanie et al. (2021)

Same argument, different body

Brain data and signing data are not the same thing, and it would be lazy to pretend otherwise. Buckwalter wants access and a share in what his brain produces. The interpreters in BOBSL, as far as anyone knows, have never asked for anything, because nobody told them there was anything to ask about. But the two cases rest on the same three facts, and each of them is sharper for signers.

The first is that the data is the person. A recording of Buckwalter's neurons is a record of how one particular man thinks and moves. A recording of signing is a record of one particular face and body, because a signed language is produced there. The eyebrows mark a question, the mouth separates one sign from another, the gaze and the tilt of the head carry the grammar. Blur the face and you have not anonymized the language, you have broken it. A model trained on 39 interpreters has learned from 39 specific faces, in a community small enough that Deaf viewers can often name them[5].

The second is that the form decides and the law stays quiet. Buckwalter's rights are whatever Caltech's consent form says they are. In sign language AI the governing document is an agreement between the BBC and the researchers, and the people on screen are not a party to it. Biometric privacy law does not obviously fill the gap. The strictest of those laws are written around processing a face to identify who it belongs to, and a sign language model processes the face for its grammar, which can leave the most detailed computational use of a face in ordinary commerce outside the protections written for faces[5].

The third is money. Buckwalter is told he may not commercialize the data from his own brain while the institution keeps it for future research. The interpreters are not trying to commercialize anything. The question is whether anybody else is. When the BBC released BOBSL, its research blog said that although the data was limited to non-commercial use, the BBC hoped academic researchers would prove such systems viable and so inspire commercial companies to invest in the field[4]. That is a reasonable hope for a public service broadcaster to hold. It also describes a road that runs from a non-commercial dataset to commercial products, and on that road somebody has to hold the line the licence draws. From the outside, nobody can see whether anyone has.

What NCG has asked, and of whom

So NCG asked. Under the Freedom of Information Act 2000, NCG wrote to the BBC on 30 October and to the University of Oxford, which has acknowledged the request. On 12 November NCG wrote to the University of Surrey, University College London, UK Research and Innovation (including Innovate UK and the Engineering and Physical Sciences Research Council), the Information Commissioner's Office and four publicly owned train operators. The requests ask, in different forms for different bodies, what records exist on whether BOBSL, or BBC sign language footage like it, has been used to build commercial sign language AI, what each body checked, and what it was told. Several also ask about Signapse, the UK company whose AI signing NCG has written about before. The Act gives public bodies twenty working days to respond.

NCG makes no allegation against any of them. Asking is the point. A licence nobody can check is a promise, and the 39 people the promise is supposed to protect have no way to check it themselves.

WHERE AN INTERPRETER'S SIGNING CAN TRAVEL

Interpreter signs a BBC programme
Paid to interpret a broadcast for Deaf viewers.

→ BBC archive

BBC archive
Signed programmes kept by the broadcaster.

→ BOBSL dataset

BOBSL dataset
About 1,400 hours from 39 interpreters, released for non-commercial research, twelve months at a time.

→ University research

University research



Does it stay in non-commercial research? Nobody outside can see. NCG's requests ask.

Yes → Inside the licence No → Outside the licence, and invisible to the 39

What a signers' version would say

The most hopeful part of Buckwalter's story is not the lawyers. It is the coalition. About a dozen people with spinal cord injuries and brain implants, the BCI Pioneers Coalition, wrote their own statement of the rights of people in brain-computer interface research and published it in November. At Buckwalter's request it treats brain data as the participant's personal information, with researchers as stewards rather than owners[1]. The people the research is done on wrote the rules they want it done by.

Signers need their own version, and it should be written by Deaf signers and interpreters, not by vendors, not by researchers and not by NCG. In NCG's view it would need to cover at least these six things.

1. Notice. Every signer in a training corpus is told that they are in it and what it is used for.
2. Consent that names the use. Agreeing to be broadcast is not agreeing to be a training corpus, and agreeing to sign recognition is not agreeing to generation, which teaches a machine to produce faces learned from yours.
3. Payment as a contributor, not as a research subject and not as nobody.
4. A copy, on request, of the recordings held about you.
5. Withdrawal that reaches the model. A trained model cannot forget one person, so the commitment has to be that the signer is left out of the next training run.
6. Representation. A Deaf-led body with standing to ask on signers' behalf, so that rights do not depend on each person finding out alone.

Buyers do not have to wait for that statement to be written. A council, a rail operator, an airport or a hospital buying sign language AI can put these terms into a contract tomorrow. They can ask the five written questions The Corpus Question set out before signature, require the vendor to name the corpora its product was trained on and the licence each was used under, and decline any product whose answer to that question



is that the data is proprietary[5]. A buyer that asks first is doing for the 39 what Buckwalter's review board is finally doing for him.

A partner, not a source

What Buckwalter wants is not to be left alone or bought off. He wants to be a partner in what his own body produces, with a say in where it goes and his name on what comes of it. That is a modest thing to ask of the people holding your data, and it took a newspaper to get him a hearing.

Signers' bodies are already producing something new: machines that sign, with faces learned from real ones. The people whose hands and faces taught those machines are not partners in that work. Most of them have never been told. Galen Buckwalter had to fight for the data from his own brain, and it is a fight worth winning. But he at least knew where to send the letter.

Heather Grizzle-Odland is the founder of Novara Consulting Group, which works on independent governance for sign language AI. She is DeafBlind and lives in Minnesota.

Referências

1. Wang, V. (2026, November 17). Does this man have a right to the data from his own brain? The New York Times.
2. Albanie, S., Varol, G., Momeni, L., Bull, H., Afouras, T., Chowdhury, H., Fox, N., Woll, B., Cooper, R., McParland, A., and Zisserman, A. (2021). BBC-Oxford British Sign Language dataset. arXiv:2111.03635. https://arxiv.org/abs/2111.03635
3. BBC Research and Development. BBC/Oxford British Sign Language Dataset (BOBSL): dataset page and terms of access. Retrieved 17 November 2026. https://www.bbc.co.uk/rd/projects/extol-dataset
4. BBC Research and Development (2021, November). Releasing the largest British Sign Language dataset for research. https://www.bbc.co.uk/rd/blog/2021-11-british-sign-language-dataset-bobsl

5. Grizzle, H. M. (2026). The Corpus Question. Novara Consulting Group. https://doi.org/10.5281/zenodo.23003735

TIPS

Know something about a sign language AI system, or about how sign language video has been used to train one, that the public should know? Send it to tips@novaracg.com. Every tip is read by me and kept confidential. If you work in the UK, writing to us is not by itself a protected disclosure under the Public Interest Disclosure Act 1998, so before you share employer information, check your options with Protect (protect-advice.org.uk), the free whistleblowing advice line.

SUPPORT NCG

NCG does this work without vendor money, so our findings stay ours. If it has been useful to you, you can support NCG's independent work here. NCG is a for-profit company, not a charity. Contributions are not tax-deductible and buy no service or influence.

Como citar

Grizzle, H. M. (2026, November 17). He Had to Fight for the Data From His Own Brain. Signers Cannot Even Find Theirs.. Novara Consulting Group. https://www.novaracg.com/pt/2026/11/17/he-had-to-fight-for-the-data-from-his-own-brain-signers-cannot-even-find-theirs/