

# Decision tree for the scientific reuse of personal identifying information

This decision tree is the basis for the 'existing data' procedure in the review system for the Ethics Review Board of the Faculty of Social Sciences.

## Legal limitations

While the concept of 'data ownership' does not exist under Dutch law, there may be restrictions stemming from signed agreements with partners, or things like intellectual property or copyright. Review this or consult the legal department.

## Respect these restrictions

If participants were initially told data would not be shared with other researchers, kept confidential or would not be used for any other purpose than the current research, then no other use is (ethically) permitted. If it does allow reuse under certain conditions, proceed under 'no' but keep in mind these restrictions.

The ethical board may decide on whether reuse after anonymization is still permissible in light of explicit restrictions.

## GDPR not applicable

Data can be shared or published without restrictions. When dealing with sensitive information, it is vital to be certain the data is anonymous. When in doubt, contact research support or your local privacy officer.

Remember, anonymization may not always be possible. In addition, there may be ethical restrictions in reusing the anonymous data when participants were explicitly told nothing would be shared during the initial data collection.

**In Opinion 05/2014 of the Article 29 Working Party on Anonymisation Techniques, the Working Party stated:**  
*"The Working Party considers that anonymisation as an instance of further processing of personal data can be considered to be compatible with the original purposes of the processing but only on condition the anonymisation process is such as to reliably produce anonymised information in the sense described in this paper."*

**Article 5.1(b)** contains an exception for scientific research, wherein secondary scientific processing of personal data (in accordance with **Article 89**) is always considered compatible with the original purposes.  
 However, **5.1(a)** states that personal data shall be processed lawfully, **fairly** and in a transparent manner in relation to the data subject ('lawfulness, fairness and transparency');  
 It would not be 'fair' to ignore conditions stipulated in a previous agreement with the participants.

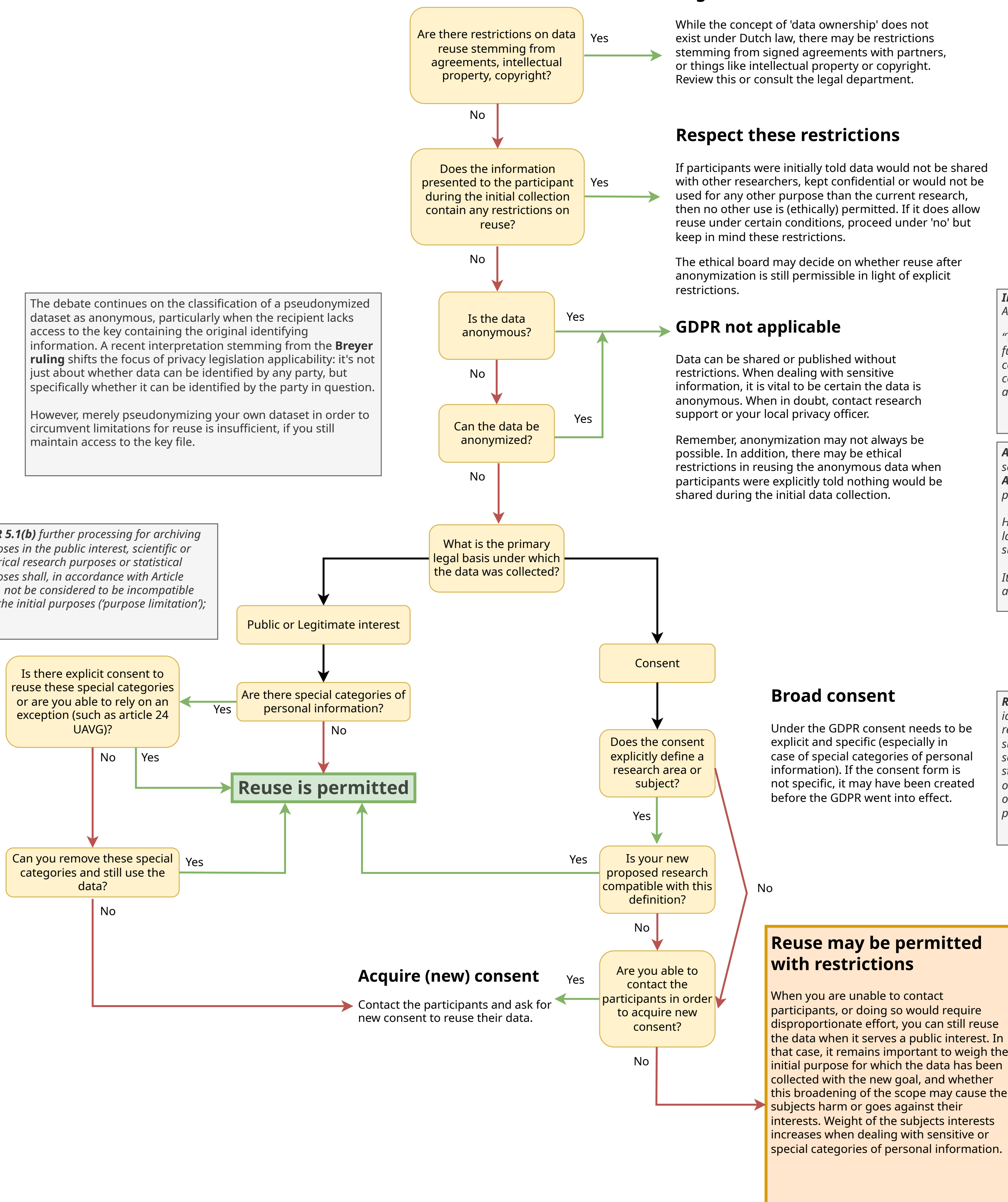
**Recital 33** of the GDPR states that it is often not possible to fully identify the purpose of personal data processing for scientific research purposes at the time of data collection. Therefore, data subjects should be allowed to give their consent to certain areas of scientific research when in keeping with recognised ethical standards for scientific research. Data subjects should have the opportunity to give their consent only to certain areas of research or parts of research projects to the extent allowed by the intended purpose.

The processing of special categories of personal information is allowed when it is deemed necessary for the purpose of scientific or historical research or statistical purposes in accordance with **Article 89** of the GDPR, this research serves a public interest; requesting explicit consent proves impossible or requires a disproportionate effort; and the implementation is provided with such safeguards that the personal privacy of the data subject is not disproportionately harmed (Article 9(2)(j) of the GDPR in conjunction with **Article 24** of the UAVG). This necessity also provides the basis for the public interest under **Article 6.1(e)**.  
 Furthermore, Gedragscode Gezondheidsonderzoek **COREON 2022, 5.4**, clarifies what constitutes as 'impossible or disproportionate': There are challenges in updating contact information for research participants, making contact with a large group is impractical, there's a risk of uncorrectable bias in the research results, contacting participants for consent could be excessively burdensome, and there's a need to ensure privacy in communication with potential participants.

The debate continues on the classification of a pseudonymized dataset as anonymous, particularly when the recipient lacks access to the key containing the original identifying information. A recent interpretation stemming from the **Breyer ruling** shifts the focus of privacy legislation applicability: it's not just about whether data can be identified by any party, but specifically whether it can be identified by the party in question.  
 However, merely pseudonymizing your own dataset in order to circumvent limitations for reuse is insufficient, if you still maintain access to the key file.

**GDPR 5.1(b)** further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes ('purpose limitation');

**GDPR 9(1)** states that processing of special categories of personal information is prohibited, unless there is explicit consent **9(2)(a)** (among other exceptions). In addition, there is art. 24 UAVG which states that according to **9(2)(j)** of the regulation, processing is also allowed if it's necessary for scientific, historical research, or statistical purposes as per Article 89(1), serves the public interest, consent is impractical or too burdensome to obtain, and adequate privacy protections are in place.



**Broad consent**  
 Under the GDPR consent needs to be explicit and specific (especially in case of special categories of personal information). If the consent form is not specific, it may have been created before the GDPR went into effect.

**Reuse may be permitted with restrictions**  
 When you are unable to contact participants, or doing so would require disproportionate effort, you can still reuse the data when it serves a public interest. In that case, it remains important to weigh the initial purpose for which the data has been collected with the new goal, and whether this broadening of the scope may cause the subjects harm or goes against their interests. Weight of the subjects interests increases when dealing with sensitive or special categories of personal information.