Appendix 1: Stakeholder categories focus group participants

Focusgroup 1

Participant no.	Stakeholder category
1.	Legal council
2.	Policymaker
3.	Scientist
4.	Data provider
5.	Scientist
6.	Scientist

Focusgroup 2

Participant no.	Stakeholder category
1.	Healthcare provider/Scientist
2.	Data provider
3.	Scientist
4.	Healthcare provider/Scientist
5.	Scientist
6.	Scientist
7.	Legal council

Appendix 2: Stakeholder categories in-depth interview participants

Participant no.	Stakeholder category
1.	Scientist
2.	Policy maker
3.	Scientist
4.	Healthcare provider
5.	Scientist
6.	Legal counsel
7.	Legal counsel
8.	Healthcare provider
9.	Legal counsel
10.	Data provider
11.	Healthcare industrialist
12.	Scientist
13.	Healthcare provider/scientist
14.	Legal counsel
15.	Data provider
16.	Scientist
17.	Scientist
18.	Healthcare provider

Appendix 3: Illustrative scenarios

Scenario 1 – Setting up new data linkage studies in a particular research area without consent for secondary processing and linkage

A physician-researcher in a UMC decides to set up a new database with patient-data for scientific studies in the field of cardiovascular disease. Subsequently, the researcher plans to link the collected patient data with data from health insurance companies for both current and future studies in the field of cardiovascular diseases. Consent for the processing of data for specific research questions of current and future studies, as well as consent for linking with external datasets by the patients involved, has not (yet) been obtained.

Scenario 2 – Enriching an existing cohort

As part of a long-term cohort study, a researcher at a UMC has been collecting a variety of patient data for years. With these data she has created a database for research on lung diseases. For the collection and processing of these data, the researcher asked permission from the patients involved at the start of the study. The results generated within the cohort provide new insights and give rise to new research questions. To answer one of these new research questions it is necessary to add health insurance data from Vektis, data from the Julius GP Network and the Dutch Central Statistics Office to the database of the cohort. However, for this new research question and for the linkage with the external databases, no informed consent has been given by the patients when they originally consented to participate in the cohort.

Scenario 3 – New research with existing databases for which consent for reuse was not sought at the time of primary data collection

A researcher from a UMC is setting up a new scientific study. For this study, the researcher wants to use patient data stored in his own patients' medical records. Subsequently, the researcher wants to link these data with data from multiple already existing databases containing health data, health insurance data, and/or demographic data. The researcher wants to be able to establish a relationship between personal characteristics from the health record and the data from the databases. Therefore, working with anonymous data is not an option. Consent for reuse of the patient data for scientific research has not been obtained during the time of collection.