Phase 38 Data Directory

SECTION 17

# DMHDRU FEEDBACK POLICY

Dunedin Multidisciplinary Health & Development Research Unit

DMHDRU

DUNEDIN SCHOOL OF MEDICINE
DEPARTMENT OF PREVENTIVE & SOCIAL MEDICINE

# DMHDRU POLICY – FEEDBACK TO STUDY MEMBERS

After taking part in the Study for almost 40 years, some Study Members might think about looking at the Study's file of information about their health and development. It is very reasonable to be curious about one's own past. And how lucky for Study Members that their development has been charted over the years by scientific experts! Unfortunately, it is not possible for the Study to help with this investigation into the past for a number of practical and ethical reasons. This no-feedback policy has been in place since the beginning of the Study, for more than 38 years. We expect that the policy of no- feedback will be disappointing to some Study members, so we prepared this letter to explain the policy.

1. **The Study does not keep a paper file on each Study Member.** Instead, the data are stored electronically, as numbers. As a result, there is no physical file to look at. Each question or measurement is stored from each phase, totalling more than 25 million items of information, and one quarter of a million that relate to any particular Study Member. The bits of information are stored by question number. For example, we can determine if your answer to question 158 of the Phase 21 alcohol interview was true or false, but the electronic file does not say what question 158 asked. The data are stored in this way to keep the information about each Study Member confidential.

2. **The Study does not have specialist staff resources to provide counselling to Study Members alongside their scores**. A Study Member might have a specific question, such as "How much illegal behaviour did I report at age 15?" or "Did I have difficulty with reading at age 7?" or "What did my allergy test show at age 21?" A search might show that the Study Member's illegal behaviour score at Phase 15 was 12.5, his reading score at age 7 was 62, and his allergy scores at age 21 were 1.2, 3.1 and 2.6. Are these scores high, low or perfectly normal? Obviously, numbers mean nothing without a specialist to interpret them. Because of the breadth of research topics covered, the Study would need marriage guidance counsellors, genetic counsellors, sexual medicine counsellors, legal counsellors, specialist heart and respiratory doctors, psychologists, and more. Providing information without professional follow-up counselling to explain what it means is not ethical and doing this could risk harm to Study Members.

3. **Generally, research measurements do not meet the standards that doctors follow when giving information to an individual patient.** The data collected by the Study have a higher rate of false positives (showing illness that does not exist) and false negatives (showing health, when a person is really ill) than what is allowable for a GP to give feedback to a patient. This is because many instruments used in our research are new experimental methods, or involve innovative procedures not yet approved for doctors' clinical practice.

Our measurements are adequate for comparisons between groups of people. But our measures are not good enough to give feedback to an individual person, because the scores may be misleading.

4. **Up to Phase 15, much of the information about the Study Members was confidential information provided by their parents and teachers.** For example, mothers reported if the child had sleeping problems, and teachers reported how the child was behaving at school. The parents and teachers provided information at that time under a guarantee of confidentiality. This means that the Study is not at liberty now to show Study Members what their parents or teachers reported in the early years of the Study. (Note, any information you report about your parents is also kept strictly confidential in this way.)

Considerations like these lead to the Study's general policy not to give feedback. Nonetheless, each topic that is studied undergoes separate and individual ethical review, and where feedback is possible, and ethical, we will always try to give you feedback. At Phase 21, we gave feedback on your cholesterol scores. At Phase 26, we gave you feedback on the health status of your teeth from the dental assessment. At Phase 32, we gave you feedback in the form of a short dental report and measures of body composition, which we plan to do again at Phase 38.

We hope that this letter has been helpful. Asking for feedback seems a simple matter, but in truth it is more complex than it looks at first. We are grateful to you for being a member of the Study, even though we cannot give you feedback.

If you have questions, or would like to discuss this in more depth, please contact me directly.

Kind regards,

Sincerely,

**Professor Richie Poulton**
**Director**

PS: **There is one exception to the Study's no-feedback policy**. Feedback is given when, in the course of data collection, evidence emerges that indicates a potential threat to someone's life. In this case, the Director of the Study arranges for a feedback consultation with the Study Member and his or her GP. Examples of this would be if a Study Member told us they intended to take their own life, if a Study Member's blood lead level was found to be in the dangerous range, or if a Study Member's skin mole was judged to be a risk for cancer. This list of examples is not exhaustive, as the Study must be alert toward a variety of potential threats to life. However, such cases warranting feedback to save a life have been very rare.