Response to: Science as a public enterprise: the case for open data.

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Boulton and colleagues (1) make out a strong case for sharing of research data. A surprisingly topical development (2), which is indeed inevitable. If we want to maximise the value of data sharing, the issues raised certainly need to be solved. This includes how to win over researchers to this cause: it would be disappointing if the promising development of open sharing of data would lead to no more than scientists piling their data in fairly unsearchable data repositories, only because they are forced to by journal editors or funders. Dutch experiences with the National Care for the Elderly Programme (3), the String of Pearls Initiative (4) and the Mondriaan Project (5) show this is possible. More so, in all three initiatives researchers are leading the development. In the first programme on health care for frail older people, the joint researchers have agreed on a minimal set of baseline characteristics and outcome measures that each project (more than sixty in total) will collect (6). In the String of Pearls Initiative all eight university hospitals in the Netherlands collect and share clinical data and biomaterial on nine different diseases. The Mondriaan Project aims to optimize the use of routine health care data for pharmacoepidemiologic research. However, the development takes time, money, effort and expertise. Therefore, the aim of data sharing would benefit from the establishment of an international research-network to support the exchange of best practices and experiences and to produce international consensus guidelines on the subject.

Reference List


