

# Policy on data management and sharing

Parkinson's UK is committed to ensuring that the outputs of the research it funds, including research data, are managed and used in ways that maximise patient benefit. Making research data widely available to the research community in a timely and responsible manner ensures that these data can be verified, built upon and used to advance knowledge and its application to generate improvements in health.

We believe that success in maximising the value of research data depends crucially on fostering a culture in which both data generators and data users adopt good research practice, and act with integrity and transparency in managing, using and sharing research data. Researchers, research institutions, resource providers, funders and publishers all have important roles to play in helping to develop this enabling environment and in developing the resources and systems required.

There is a growing international consensus on the need to preserve and share research datasets in a manner that maximises their long-term value. This has been articulated in key documents such as the OECD Principles and Guidelines for Access to Research Data from Public Funding (2007); the Fort Lauderdale Principles (2003) and the Toronto Statement (2009).

Our policy on data management and sharing reflects the principles set out in these statements. It is consistent with the charity's position on open and unrestricted access to published research.

The policy should be read in conjunction with the associated guidance. We will keep both our policy and guidance under review.

## Policy statement

1. Parkinson's UK expects all of its funded researchers to maximise the availability of research data with as few restrictions as possible.
2. All those seeking Parkinson's UK funding should consider their approach for managing and sharing data at the research proposal stage. In cases where the proposed research is likely to generate data outputs that will hold significant value as a resource for the wider research community, applicants will be required to submit a data management and sharing plan to Parkinson's UK prior to an award being made.
3. Parkinson's UK will:
  - review data management and sharing plans, and any costs involved in delivering them, as an integral part of the funding decision
  - work with grant holders on an ongoing basis to support them in maximising the long-term value of key datasets resulting from their research

4. Parkinson's UK expects all users of research data to acknowledge the sources of their data and to abide by the terms and conditions under which they accessed the original data.
5. Parkinson's UK will foster an environment that enables researchers to maximise the value of research data. Specifically, we will work in partnership with others to:
  - ensure that key data resources are developed and maintained for use by the research community
  - recognise the contributions of researchers who generate, preserve and share key research datasets
  - develop best practice for data sharing in different fields - recognising that different data types raise distinct issues and challenges.