Plan Overview

A Data Management Plan created using DMPonline

Title: Providing tailored, integrated palliative care for COPD patients; Standing strong together.

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Project abstract:

Nog nooit stierven er in Nederland zoveel mensen aan COPD als nu: meer dan één persoon per uur, 10.000 personen per jaar. COPD behoort daarmee tot de top vijf van ziekten met de hoogste sterfte in NL. Bij COPD is palliatieve zorg nog steeds geen ‘gebruikelijke zorg’. Patiënten hebben veel symptomen die grotendeels onbehandeld blijven, en over toekomstige wensen en behoeften wordt verder zelden (systematisch) gesproken. Veel mantelzorgers zijn daarom ook langdurig (te) zwaar belast. Het leveren van goede palliatieve zorg aan patiënten met COPD blijkt dus niet eenvoudig. Gelukkig is in de afgelopen tien jaar in Nederland en in het buitenland veel ervaring opgedaan met verscheidende programma’s en interventies om palliatieve COPD zorg te verbeteren. Deze kennis wordt in dit project benut om te komen tot een solide integrale aanpak voor palliatieve COPD zorg, bestaande uit een toolkit met interventies zoals Advance Care Planning, “the problem square” en een patiënt identificatie tool. Het project voorziet ook in het ontwikkelen van een training voor patiënten, mantelzorgers en zorgverleners omtrent het gebruik van deze toolkit.

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Providing tailored, integrated palliative care for COPD patients; Standing strong together. - Data management ZonMw (English version)

1. General features of the project and data collection

1.1 Project leader contact details

Question not answered.

1.2 I have composed my DMP with the assistance of a data management expert. List his or her name, function, organisation/department, phone number and email address.

Question not answered.

1.3 In collecting data for my project, I will do the following:

Question not answered.

1.4 In my research, I will use:

Question not answered.

1.5 I will be reusing or combining existing data, and I have the owner's permission for using or combining their data.

Question not answered.

1.6 In collecting new data, I will be collaborating with other parties.

Question not answered.

1.7 I am a member of a consortium of 2 or more partners. Clear arrangements have been made regarding data management and intellectual property. (also consider the possible effect of changes within the consortium on issues of data management and intellectual property)

Question not answered.

1.8 I can give an estimate of the size of the data collection; specifically, the number of participants or subjects (“n=”) in the collection and its size in GB/TB

Question not answered.

1.9 The following end products I will make available for further research and verification (please elaborate briefly)

Question not answered.

1.10 During the project, I will have access to sufficient storage capacity and sites, and a backup of my data will be available. (please elaborate briefly)

Question not answered.

2. Legislation (including privacy)

2.1 I will be doing research involving human subjects, and I am aware of and compliant with laws and regulations concerning privacy sensitive data.

Question not answered.

2.2 I will be doing research involving human subjects, and I have (a form of) informed consent from the participants for collecting their data.

Question not answered.

2.3 I will be doing research involving human subjects, and I will anonymise or pseudonymise any privacy sensitive data.

Question not answered.

2.4 I will stick to the privacy regulations of my organisation

Question not answered.

3. Making data findable

3.1 The data collection of my project will be findable for subsequent research (note: this is a key item, which you should report to ZonMw at the end of your project).

Question not answered.

3.2 I will use a metadata scheme for the description of my data collection.

Question not answered.

3.3 I will be using a persistent identifier as a permanent link to my data collection (note: this is a key item, which you should report to ZonMw at the conclusion of your project).

Question not answered.

4. Making data accessible

4.1 Once the project has ended, my data will be accessible for further research and verification.

Question not answered.

4.2 Once the project has ended, my data collection will be publicly accessible, without any restrictions (open access).

Question not answered.

4.3 I have a set of terms of use available to me, which I will use to define the requirements of access to my data collection once the project has ended (please provide a link or persistent identifier; also note that this is a key item, which you should report to ZonMw at the conclusion of your project).

Question not answered.

4.4 In the terms of use restricting access to my data, I have included at least the following:

Question not answered.

5. Making data interoperable

5.1 I will select a machine actionable data format, which will allow other researchers and their computers to read my data collection.

Question not answered.

5.2 I will select a metadata standard to allow my data collection to be linked to other collections (note: this is a key item, which you should report to ZonMw at the conclusion of your project).

Question not answered.

5.3 I will be doing research involving human subjects, and I have taken into account the reuse of data and the potential combination with other data sets when taking privacy protection measurements.

Question not answered.

6. Making data reusable

6.1 I will ensure that the data and their documentation will be of sufficient quality to allow other researchers to interpret and reuse them (in a replication package).

Question not answered.

6.2 I have a number of selection criteria, which will allow me to determine which part of the data should be preserved once the project has ended. (see also question 1.9)

Question not answered.

6.3 Once the project has ended and the data has been selected, I can make an estimate of the size of the data collection (in GB/TB) to be preserved for long-term storage or archival.

Question not answered.

6.4 I will select an archive or repository for (certified) long-term archiving of my data collection once the project has ended. (note: this is a key item, which you should report to ZonMw at the conclusion of your project)

Question not answered.

6.5 Once the project has ended, I will uphold the recommended data preservation period of at least 10 years.

Question not answered.

6.6 Data management costs during the project and preparations for archival can be included in the project budget. These costs are:

Question not answered.

6.7 The costs of archiving the data set once the project has ended are covered.

Question not answered.