Longitudinal studies and the Research Data Lifecycle: Application of the Data Documentation Initiative

McMahon [1], Christiana; Dezateux[1], Carol; Kehoe[2], Dennis; Alexandrakis[1], Stelios; Castillo[1], Tito
[1] MRC Centre of Epidemiology for Child Health, University College London
[2] AIMES Grid Services

Introduction

- Longitudinal studies of population cohorts are vital if researchers are to better understand life course influences and developmental origins of health both now and in the future.
- However, development of models to gain enduring consent often proves problematic and efforts are hindered by limited access to pre-existing documents.

Background

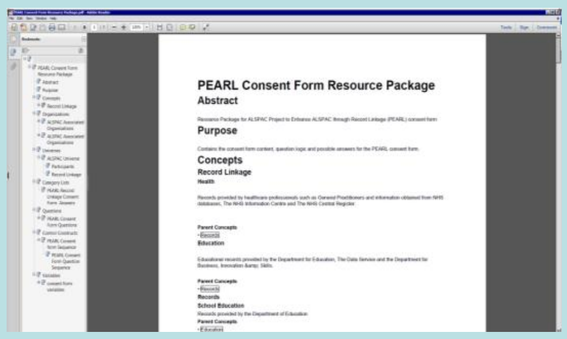
- Metadata is data about data.
- Metadata standards help to ensure quality, completeness and promote uniform management and analysis of resulting datasets.
- The Data Documentation Initiative (DDI) [1] has two forms:
  - Codebook (DDI-C) - facilitates metadata markup post study completion
  - Lifecycle (DDI-L) - enables continuous metadata annotation.
- DDI is an internationally recognised metadata standard and supports the creation and management of searchable and comparable reference documentation.
- DDI is widely used for social sciences research data but its use in epidemiological research is rare.

Method

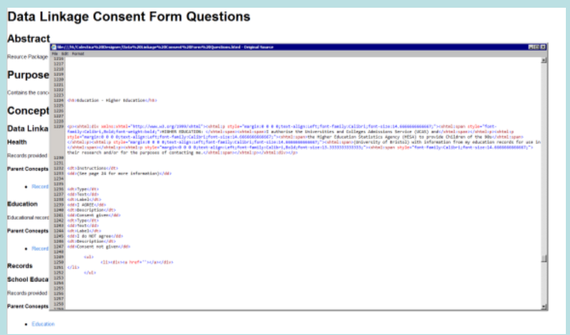
- Permission was obtained from the study data manager to use the consent form prior to record creation.
- The logical sub-elements were developed separately until content had been finalised.
- Use of Colectica Designer [3] enabled automatic generation of DDI compliant XML syntax and exportable HTML, PDF and XML files.

Initial Results

DDI to PDF

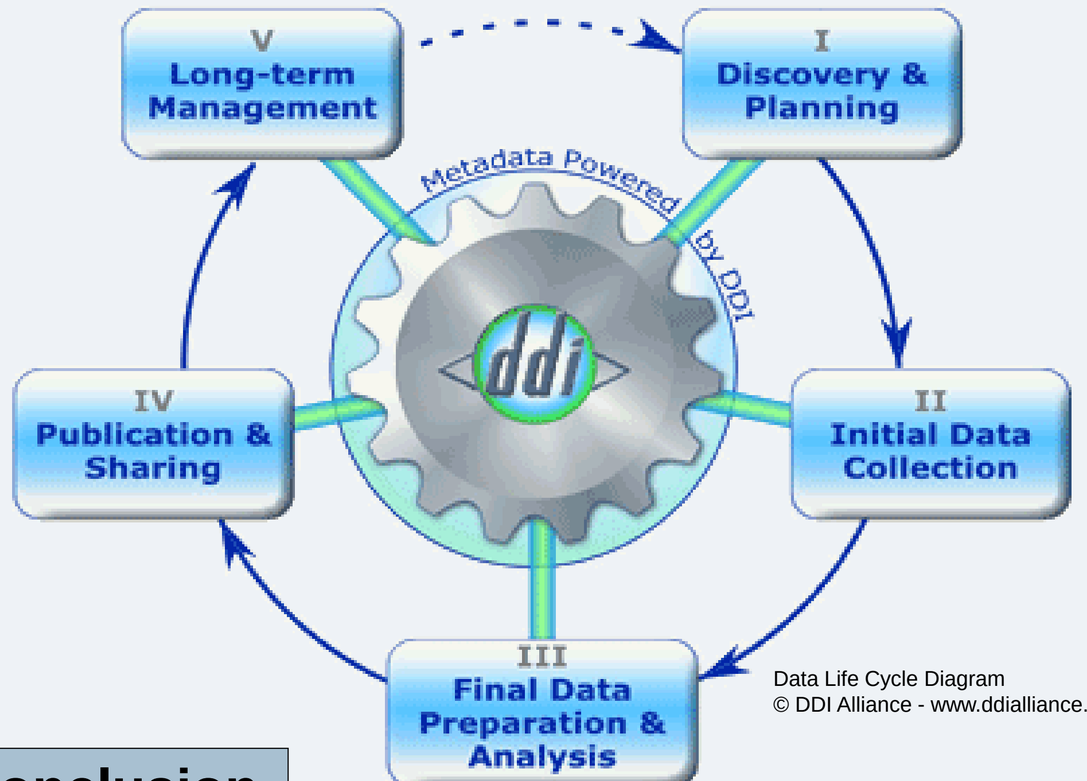


DDI to HTML



Aim

- Assess application of DDI-L in epidemiological research to document consent forms for inclusion within a searchable catalogue system in support of the research data lifecycle.
- Development of this catalogue will support the establishment of best practice and dissemination of the judgements of ethical committees.
- It is aimed at those in Life Study [2] and other such researchers requiring access to pre-existing, standardised survey documentation.



Data Life Cycle Diagram
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Conclusion

- Design of DDI-L supports versioning of elements, encourages metadata annotation throughout the research process and complements the research data lifecycle.
- Use of DDI-L compliant catalogue promotes data discovery/sharing and increases study design documentation availability.
- All XML and document production processes were automatically managed by Colectica Designer[3]
- Work to date serves as a proof of concept - application of DDI-L to epidemiological research can successfully standardise consent form metadata of a longitudinal study and promote a continuous approach to its management.
- Future work will focus upon expanding the catalogue through an exploration of DDI-L's use of object-oriented formalisms and organise focus groups with potential users.

References

1. *Data Documentation Initiative*. 2011 2011 June 8 [cited 2012 September 10]; Available from: http://www.ddialliance.org/
2. *Life Study*. 2012 [cited 2012 October 26]; Available from: http://www.lifestudy.ac.uk/homepage
3. *Colectica*. 2012 [cited 2012 October 19]; Available from: http://www.colectica.com/

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MRC Centre of Epidemiology for Child Health
30 Guilford Street, London, WC1N 1EH
christiana.mcmahon.11@ucl.ac.uk