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Improving transparency of longitudinal health research: glossary, infographic and accessible study summaries

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Background

Longitudinal studies collect information repeatedly about the same group of people, allowing for analyses of changes over time. They are vital in mental health research, as elsewhere. As longitudinal studies rely on the participation of patients and the public, their methods, purposes and results must be transparent and accessible.

Introduction

Many UK longitudinal research studies with mental health data are indexed via the Catalogue of Mental Health Measures ('Catalogue'), and organisations including DATAMIND provide broader information about mental health data research. However, the information on such platforms is primarily researcher-oriented, creating a barrier to its transparency and accessibility. Barriers can be alleviated by providing clear definitions of specialist terms, a transparent overview of longitudinal mental health research, and 'bite-sized' summaries of the Catalogue studies.

Methods

This project was co-designed and co-created by patient/public representatives from the DATAMIND Super Research Advisory Group (SRAG) and researchers. UK Health Data Research Alliance transparency standards were followed across the delivery of three outputs. (1) To provide clear definitions of specialist terms, SRAG members and researchers collected terms commonly used longitudinal research and researchers clarified definitions. Definitions were revised by SRAG members and terms were added to an existing data science glossary. (2) To create a transparent overview of longitudinal mental health research, the patient/public involvement (PPI) lead and SRAG co-applicant proposed content for an infographic about longitudinal research. The design was discussed with a graphic designer who created the infographic, and involved the PPI lead for the UK Longitudinal Linkage Collaboration. This was then revised iteratively for clarity, accessibility and diversity. (3) To generate accessible summaries of the Catalogue studies, psychology undergraduate students drafted summaries for an initial six studies, which were reviewed via a workshop led by the SRAG. Following revisions to the content and style, summaries were created for all 55+ studies on the Catalogue. Unfamiliar terms encountered during the process were also added to the glossary.

Results

Three new resources were created. (1) We developed a glossary of terms commonly used in longitudinal studies and research, to be incorporated into the DATAMIND glossary (https://datamind.org.uk/glossary/). (2) We created an infographic 'storyboard' to show how researchers, patients and the public can work together in the creation and curation of longitudinal research. The infographic illustrates the intertwined relationships between patients and the public, providing a transparent representation of challenges such as sharing studies, data access, patient benefit, and the importance and impact of public involvement. It illustrates many ways to find out about longitudinal research. (3) Accessible and transparent short summaries were created for all longitudinal studies in the Catalogue (https://www.cataloguementalhealth.ac.uk/). These provide clear and concise overviews, enough to capture the essence of each study and inform researchers and the public quickly and easily.

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Conclusions

Co-production supports the transparency of longitudinal research, and ensures resources designed and produced for the public have public input. Two generic information resources and one specific resource are presented.

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