

Improving Transparency of Longitudinal Health Research: Glossary, Infographics and Accessible Study Summaries

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Our aim was to create transparent, transferable, and accessible materials for longitudinal health research. This involved developing an inclusive glossary of frequently used terms, infographics to visually explain aspects of patient and public involvement (PPI), and engagement in the research, and plain language summaries of studies on the Catalogue of Mental Health Measures. Through our projects, we brought all the HDRUK Transparency Standards to life. They were the drivers of our aims and impacts. Scan the QR code for the full list of standards ➡



INFOGRAPHICS

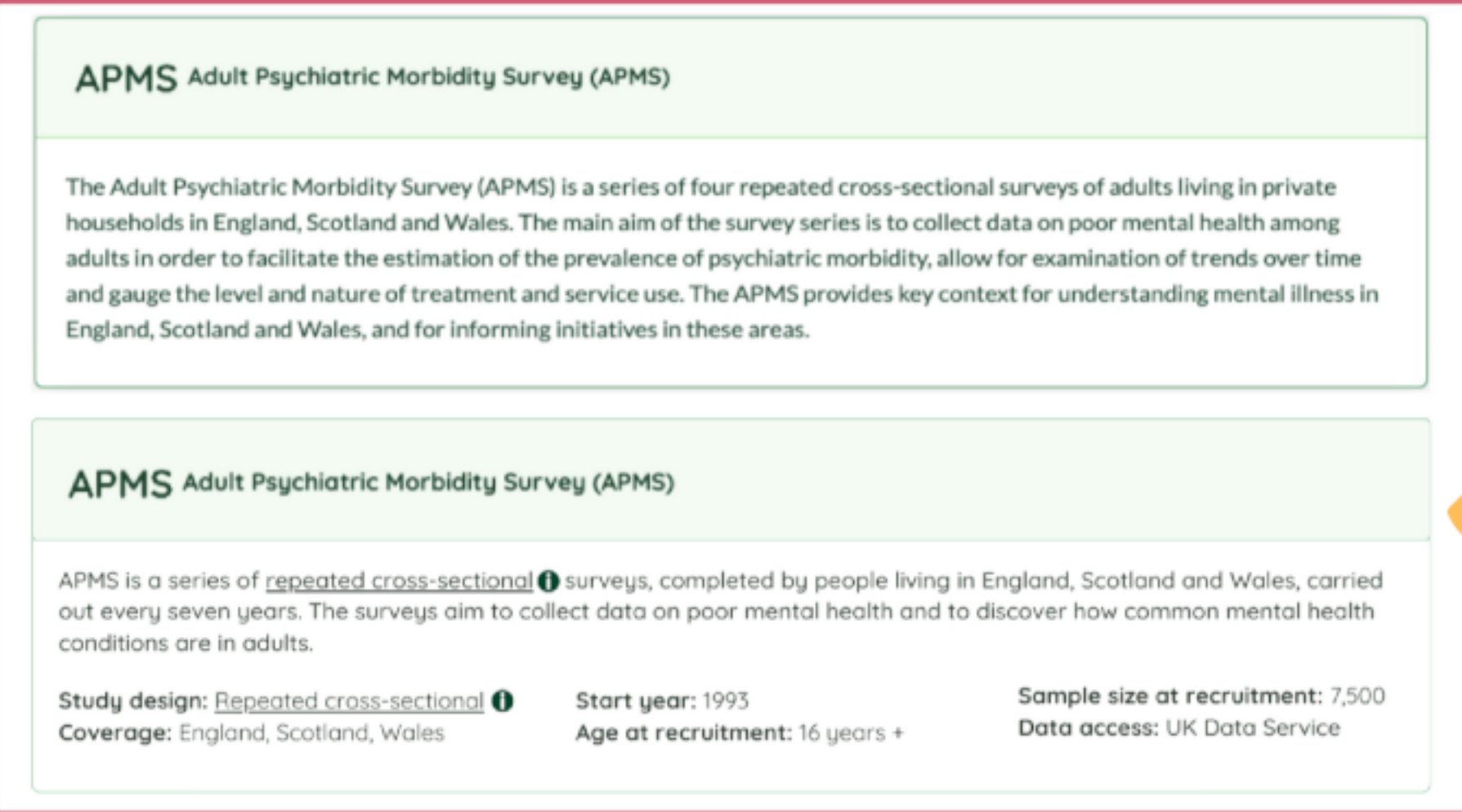
AIM: To create three infographic concepts, we collaborated with a graphic designer and the PPI Lead at the UK Longitudinal Linkage Collaboration (UK LLC) to develop initial draft illustrations. These drafts were subsequently refined for clarity, accessibility, and diversity by members of the DATAMIND SRAG

- IMPACT**
- A transparent, visual explanation of opportunities for becoming part of longitudinal health research
 - Enabling and empowering everyone to understand how they can be involved



SUMMARIES

AIM: To provide transparency and understanding of studies on the Catalogue of Mental Health Measures, early career researchers and the public wrote and reviewed drafts of **58** bite-size summaries in plain language at a facilitated workshop. Terms encountered during the process were also added to the DATAMIND glossary

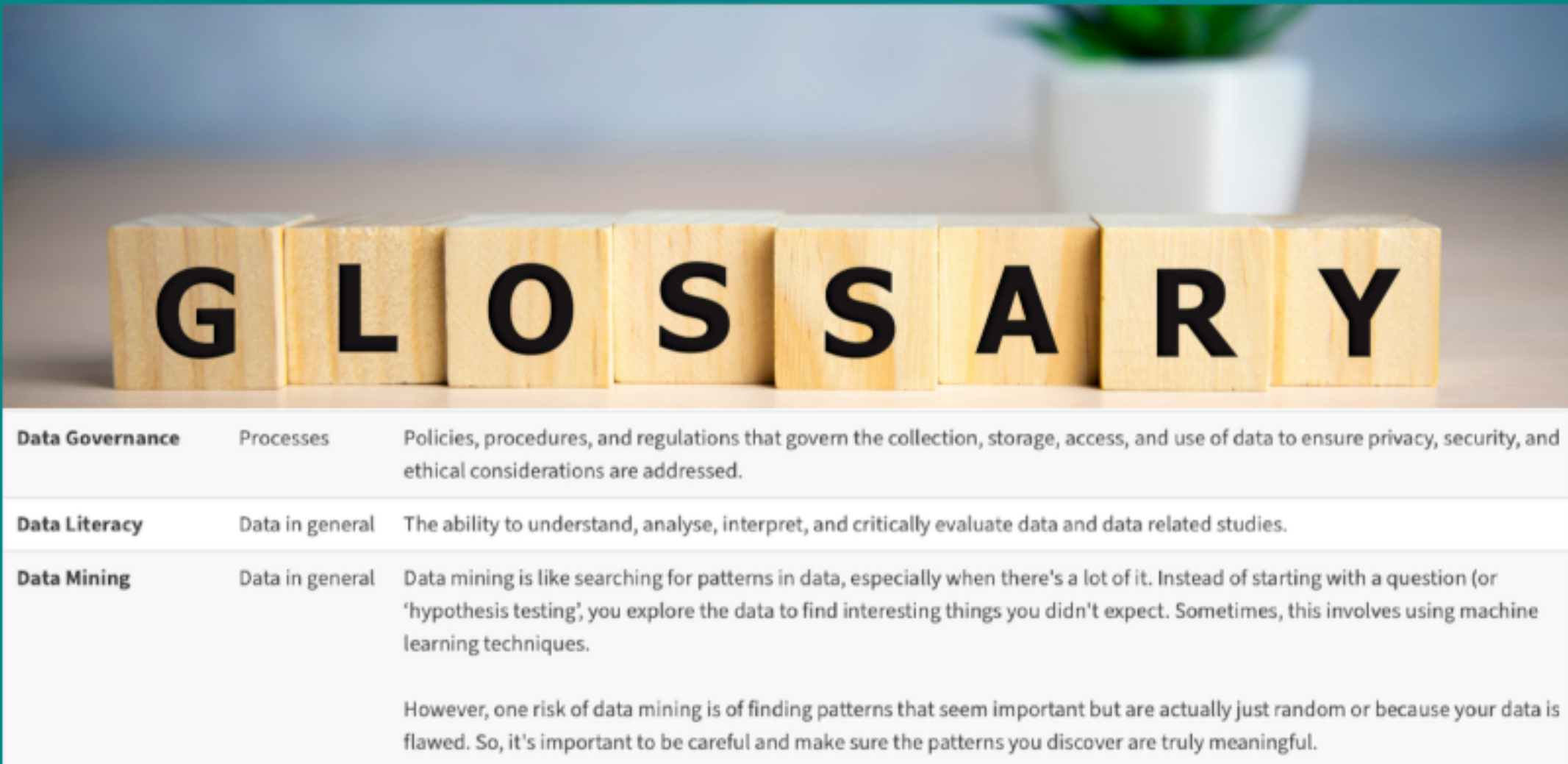


- IMPACT**
- Transparent accessible summaries of UK based studies
 - Allows easy viewing for the public
 - Terms remain searchable for researchers
 - Allows for patient led research
 - Template for future study summaries



GLOSSARY

AIM: To expand the current DATAMIND glossary with terms and phrases pertinent to longitudinal health research, our partnership identified and agreed upon accessible definitions of additional terms. This process ensured relevance and inclusivity



- IMPACT**
- A transparent, accessible, sharable glossary
 - Enables public understanding
 - Empowers data literacy for all



CO-PRODUCTION



IMAGE: Researchers from KCL and SRAG working together through workshop and coffee morning

- KCL Early Career Researchers new to PPI
- Collaboration with UK LLC to ensure transferability of materials
- Every stage of the project was reviewed by the SRAG ensuring public perspective and collaboration



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