

International Journal of Population Data Science

Journal Website: www.ijpds.org



Skylark Wiki: Accessing research data of the MRC National Survey of Health and Development

Maria Popham¹, Andrew Wong¹, Phil Curran¹, Alisia Carnemolla¹, and Paulina Januszewicz¹

¹MRC Unit for Lifelong Health and Ageing at UCL

Background & Introduction

The Medical Research Council National Survey of Health and Development (NSHD) is the oldest and longest-running of the British birth cohort studies. In 2018 we launched the Skylark Wiki, a central metadata repository and the first port of call for any data sharing queries. In 2023 we utilised the HDRUK funding initiative to work with our advisory group and research community to improve the transparency of our data access process and make the content more accessible.

Methods

We conducted a focus group session with the NSHD Participant Advisory Panel to understand their views on the data sharing process and whether the information we provided them, sufficiently explained how their data are shared. We also sent out a questionnaire to all Skylark Users to identify areas of improvement. Lastly, we undertook an audit of the website's content and used Google Analytics to see how Users navigated across the site. Combining all this information we identified areas requiring improvements, from the point of view of our stakeholders, and comparing these to the requirements indicated in the HDRUK Transparency Standards we mapped out updates to the Skylark Wiki. The work was carried out by an external agency (Aubergine262 Ltd).

Results

To increase transparency and searchability, we improved the flow diagram of the data sharing process to include links to the relevant web pages. We also created guidance to explain why the information in the data request application form is being asked. As feedback from Skylark Users suggested difficulties in finding the required information, the navigation has been updated. We have also changed the layout of the front page to include navigation boxes that takes users straight to the content. The NSHD Advisory Panel reinforced the notion of trust that study participants place in the study and its approach to data sharing. They confirmed the information provided on data sharing was adequate and appreciated that this information was placed on the main study website

(<https://nshd.mrc.ac.uk/>) for their benefit.

Initial feedback from Users indicates that it is easier to find information on the website. We will keep monitoring access to the website, the number of queries, and data access requests to evaluate long-term benefits.

We have changed the sitemap and added in large link boxes, to make it easier to find the different sections. We hope this will improve the searchability of the site so users can find information they required. We hope this will therefore lead to fewer emails and correspondence between the data sharing team and users. We have also updated the flow diagram of the data sharing process to include links to the web pages which are related to that section. We hope this will help the users find the information they require.

Conclusions

The new Skylark data-sharing website supports easier navigation providing a better User experience. In return, this should lead to fewer queries from Users. The website will be easier to maintain having changed the content management system from a Wiki to WordPress. WordPress requires less technical knowledge, allowing more staff to contribute to regular maintenance.

References

1. Skylark data-sharing website: <https://skylark.ucl.ac.uk/NSHD/>
2. Aubergine: <https://www.aubergine262.com/>

