

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

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Background

The Medical Research Council National Survey of Health and Development (NSHD) is the oldest and longest-running of the British birth cohort studies. It has been following a group of 5362 men and women, since their birth in March 1946.



The NSHD study members at their 78th birthday event

The NSHD has over 25,000 variables covering 26 data collection waves, spanning 78 years. In 2018 we launched the Skylark Wiki - <https://skylark.ucl.ac.uk/NSHD/>, as a central metadata repository and the first port of call for any data sharing queries.

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 carried out 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).

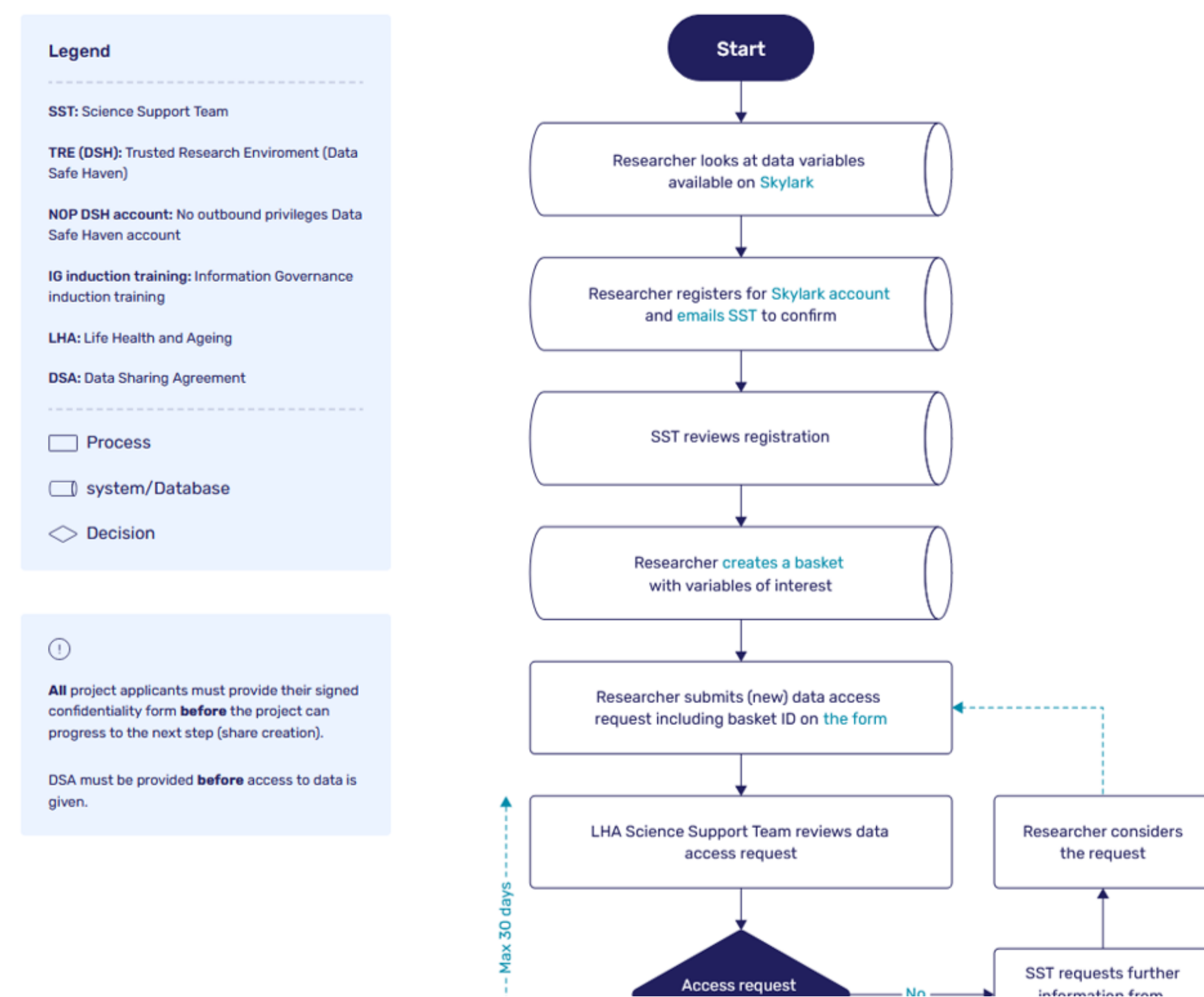
Outputs

Standard 1: Open access application form and guidance

The original Skylark Wiki included an open-access application form. To improve transparency, we created guidance information to explain why the information in the form is being requested.

Standard 2: Transparent application process and criteria

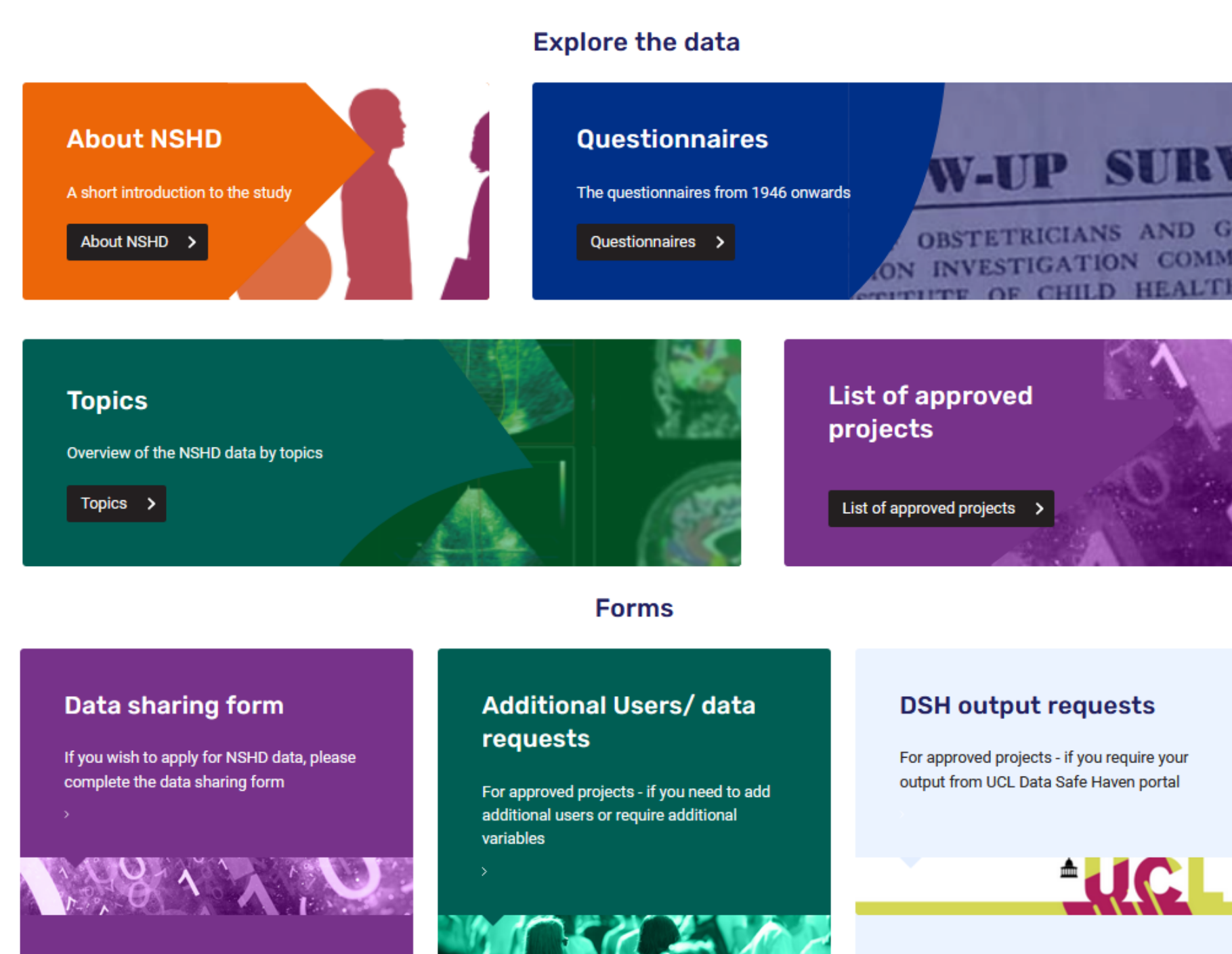
To increase transparency and searchability, we improved the flow diagram of the data sharing process, including links to the relevant web pages. Using any interactive visual tool may be beneficial to a wider pool of users.



Revised flow chart with links to specific pages

Standard 3: Clear website navigation

Feedback from Skylark Users suggested that they could not always find the required information. The navigation has been updated to reflect the User's feedback and we have changed the layout of the front page to include navigation boxes that take users straight to the content.



New navigational boxes to signpost Users to important elements of the website

Standard 4: Consider Target Audience

The NSHD Advisory Panel reinforced the notion of trust 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.

Standard 5: Regular review of website content

The website has been created using WordPress – a more user-friendly contents management system than the Wiki. This requires less technical knowledge therefore, allowing more staff to contribute to regular maintenance.

Standard 6: Transparency of Data Use and Auditing

We reviewed and updated the privacy notice.

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 the benefits of the new website long-term.

Lessons learnt

Ring-fencing time and budgets for activities allows for such key work to be undertaken in a time-efficient manner. Several updates were required, therefore it would be beneficial to set time aside once a year to review the site.

The availability of set guidelines, helps set out targets to be achieved.

In discussing the project with the Advisory Panel it was initially perceived as a reparatory action rather than a proactive approach to improvement: this would suggest that data sharing process and standards should be regular agenda items of advisory panel meetings.

Conclusions

The new Skylark 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.

Acknowledgements

This work was supported by the Health Data Research Alliance and Health Data Research UK (HDRUK2023.0457), an initiative funded by UK Research and Innovation, Department of Health and Social Care (England) and the devolved administrations, and leading medical research charities.