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## Implementing Transparency Standards: The ECHILD Project in Action

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### Background

The Education and Child Health Insights from Linked Data (ECHILD) research database joins health, education and social care information for approximately 20 million children in England, to understand the interrelationships between health and education.

In 2023, UCL acquired sublicensing agreements and ECHILD was approved as a Research Database for wider research benefiting children and young people's healthcare and education. UCL, funded by ADR UK, are able to provide ECHILD data to accredited researchers via the ONS SRS secure environment.

To do this, we need to ensure transparency in our data application processes.

### Objectives

Our Objectives were:

**1- Create a new ECHILD website including information for:**

- a) Researchers: to include guidance on how to apply for data, an open access application form, documentation and guidance.
- b) Public: an animation to show what ECHILD is about, and how linked data are used for research

**2- Conduct lay consultations on website content:** engaging with the lay ECHILD advisory Group to give feedback on the newly created documentation for the website.

**3- Organise transparency events, such as:**

ECHILD Seminar Series  
ECHILD User Group Day  
ECHILD Training Course

### Outputs

We enhanced transparency in our operations by implementing the following:

- 1- Creation of an Animation Video: The ECHILD team commissioned an animation video "What is ECHILD" to explain the purpose and objectives of the project in an engaging and accessible format (<https://youtu.be/X6y7XGhQHNI>).

2- Creation of Illustrations: In addition to the animation video, we engaged with an artist to create illustrations aimed at explaining the project's objectives in a lay-friendly manner. These illustrations can be seen in the "For the Public Section" of the ECHILD website (<https://www.echild.ac.uk/what-is-echild>).

3- Development of the new ECHILD Website [www.echild.ac.uk](http://www.echild.ac.uk).

5- Consultation with Lay Members: The ECHILD team has engaged with lay members to gather feedback and insights on the above initiatives, ensuring that the materials developed are understandable and meet the needs of the intended audience.

6- ECHILD events:

The inaugural ECHILD User Group event took place on 27th March 2024 to engage researchers, stakeholders, and the public, fostering a community of users and beneficiaries; it is expected to be held annually. The Quarterly ECHILD Seminar Series started on 15th April 2024. A 2-day ECHILD course took place on 25-26th March 2024 and will be run again in the Autumn 2024.

### Results

The ECHILD project has significantly improved transparency by employing various methods. These include an animation video and illustrations to convey project objectives, the development of a user-friendly website, and the provision of accessible application forms and guidance. Summaries of approved studies and active consultation with lay members further contribute to transparency. The inaugural ECHILD User Group event in March 2024 fostered collaboration and transparency within the project community. These efforts collectively enhance transparency and engagement across all aspects of the ECHILD project.

### Conclusions

In conclusion, the ECHILD project has demonstrated a firm commitment to implementing transparency standards in its daily operations for data access. Despite notable progress, challenges persist due to limited financial support and personnel capacity. Achieving and maintaining high standards demand substantial investments of both resources and exper-

tise. As the journey towards transparency continues, addressing these challenges will be crucial to ensure the sustained success and impact of the ECHILD project.

**Lessons Learnt:** HDRUK funding and teamwork were vital in pursuing transparency in ECHILD. Lay community engagement gave key insights and highlighted the importance of inclusivity and accessibility.

