Legitimate Interests Assessment Form

The LIA is a light-touch test complete in three parts.

It is not necessary to follow this exact process, but you can use this form to help assess whether legitimate interest can be applied to your processing of personal data.

You should complete and keep a record of this assessment to provide justification for your decision to use legitimate interest as a legal basis before you start processing the data.

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| Description | Cross-Sectional Multi-Centre Study of UK Adults with Congenital Adrenal Hyperplasia (CaHASE). Use of data obtained from NHS Digital. |
| Data Subject(s) | Patients with Congenital Adrenal Hyperplasia |
| Nature of personal data processed | Fact and cause of death and cancer registration data |
| Special category, criminal offence or children's data? | No |
| Process owner | Society for Endocrinology/University of Sheffield |
| Assessment Owner | Society for Endocrinology/University of Sheffield |
| Assessment Start date | October 2019 |
| Decision Date | October 2019 |

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| **1) Purpose**: **identify the legitimate interest(s). Consider:** |
| Why do you want to process the data – what are you trying to achieve? | Most of the current literature on CAH is centred on CAH in childhood. The studies published on adults have generated some conflicting data. Now that an increasing number of patients are surviving into adulthood, further research is needed to collate information on morbidity and mortality in these patients. We wish to see how co-morbidities and different treatment modalities might influence outcomes.  |
| Who benefits from the processing? In what way? | Processing cause of death and cancer registration data this data might uncover information that could help inform the day to day management of these patients. Improving day to day management might help to prolong life and enable earlier detection/better surveillance of certain morbidities/causes of mortality. |
| Are there any wider public benefits to the processing? | Whilst the CAH specific knowledge obtained in this study is likely to be of interest only to individuals with CAH, those involved in the care of these patients, patients families, and the scientific community interested in researching CAH, the wider public benefits from clinical research as a whole. Clinical research is important to the NHS and benefits us all, whether we are fit and healthy or suffering from an illness or condition. Research helps our understanding of the causes, prevention and treatment of disease and to improve the health care we receive. |
| How important are those benefits? | Improving patient care is linked to improving patient outcomes. Benefit can range from improved quality of current life to prolonging life itself. |
| What would the impact be if you couldn’t go ahead? | If we are unable to process the data as requested we would not be able to collect accurate and complete cause of death or cancer information for CAH patients. In turn we would then be unable to investigate how co-morbidities and different treatment modalities might influence outcomes. Day to day management of these patients would remain the same and their healthcare would not be improved. |
| Would your use of the data be unethical or unlawful in any way? | No. In addition the research study and the collection and processing of this data as described has been reviewed and approved by a Research Ethics Committee and the Health Research Authority. |
| **2) Necessity: apply the necessity test. Consider:** |
| Does this processing actually help to further that interest? | Retrieval and processing of the data allows the reporting of number of deaths in the cohort, number of deaths in each cause subgroup, the distribution of age at death, number of cancers reported in the study cohort and frequency of cancer subtypes. Linking this data with other data collected in this study allows us to fulfil the ultimate interest; to see how co-morbidities and different treatment modalities might influence outcomes and to determine how day to day management of CAH patients can be improved. |
| Is it a reasonable way to go about it? | Yes. The data is needed to achieve the aim, though can be sourced from several places. Obtaining data from NHS Digital (as opposed to the hospitals directly) is the best way to ensure accurate and complete data. Obtaining data directly from patients or their families would be an unnecessary burden to them, would likely result in recall bias when questioned on past events and would increase the likelihood of collecting poor quality data. |
| Is there another less intrusive way to achieve the same result? | No. The method proposed is the least intrusive to CAH patients and their carers/clinicians. Only the minimal amount of data required has been requested. |
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| What is the nature of your relationship with the individual? Is it pre-existing and have you used their data previously? | The individual is a research participant and they have consented to take part in the study. Their data has been collected for use in this study only in line with the approvals gained for this study. The data will be destroyed when this study ends. |
| How has the data been obtained? If supplied from a third party what did they tell the individual about reuse? | The data has been provided by NHS Digital (the national information and technology partner to the health and social care system. NHS Digital use digital technology to transform the NHS and social care). The NHS has its own web pages advising individuals on the use/reuse of their data: <https://www.nhs.uk/using-the-nhs/about-the-nhs/sharing-your-health-records/>. Individuals are told that “Research bodies and organisations can request access to their information. Your confidential patient information is looked after in accordance with good practice and the law. Data release registers are published by NHS Digital and Public Health England, showing records of the data they have shared with other organisations.” |
| Do you have the means and processes to keep the information up to date. | NHS Digital keep their information as up to date as possible. We request information at regular intervals and will ensure any publication makes clear the dates the data covers.  |
| Is any of the data particularly sensitive or private? | Data relates to the participants health and is therefore sensitive. |
| Would people expect you to use their data in this way? | Participants have consented to the use of their data to achieve the study aims. They are therefore expecting us to use their data in the ways described. |
| Are you happy to explain it to them? | The study has a participant information explaining the use of data to participants. Use was also explained during the consent process and participants are able to contact a member of the local research team at any time. |
| Are some people likely to object or find it intrusive? | This is unlikely, however, anyone objecting will not participate in the study. |
| What is the possible impact on the individual? | If there was a data breach or privacy violation this could have an impact on the participants as there is processing of sensitive and identifiable information. This would constitute a potential loss of control over the future use of the data breached.* The following potential impacts have been considered but are not considered to be relevant:
* a barrier to individuals accessing services or opportunities;
* any loss of control over the further use of personal data;
* physical harm;
* financial loss, identity theft or fraud; or
* any other significant economic or social disadvantage (such as discrimination, loss of confidentiality or reputational damage).
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| How big an impact might it have on them? | The impact is moderate but unlikely due to risk minimisation. |
| Are you processing children’s data? | No |
| Are any of the individuals vulnerable in any other way? | No. Patients without capacity are not eligible to participate in the study. |
| Can you adopt any safeguards and technical measures to minimise the impact? | There are a number of safeguards adopted to minimise loss of control data. These include adherence to system level security policies, encryption of data during data transfer, password protection of data files, timely and absolute destruction of data no longer needed, appropriate training of staff involved in data handling and processing, third party data security evaluation and GDPR compliance checks. |
| Can you offer an opt-out? | Any member of the public can opt out of their confidential patient information being used for planning and research. In England there is a national data opt out policy. As the data in this assessment refers to data collected for research purposes, individuals must provide their consent for this to be obtained and used as described. Patients are able to withdraw (opt-out) at any point in the study. |

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| **Decision** |
| Outcome Date | 2019 |
| Outcome | Legitimate interest (with additional consent) |
| How was the outcome decided | By consideration of the items in this assessment |