National Audit of Care at the End of Life

Information Governance guidance for Trusts/UHBs

Several organisations have been in contact with the NACEL Support Team in relation to the information governance arrangements for NACEL, and particularly the implications of GDPR requirements. For NACEL, **the Trust / UHB is a Data Controller for the purposes of the data collection and then HQIP becomes the Data Controller for the use of the anonymised data that is submitted**. The Trust / UHB is therefore responsible for compliance with GDPR in respect of the data collected for the audit. It should be noted that no personal identifiable information is being passed to the data processer (NHS Benchmarking Network (NHSBN)). All data is anonymised by the Trust / UHB, before being submitted to NHSBN. The NACEL data flow chart is available https://www.nhsbenchmarking.nhs.uk/nacel-resources .

Legal basis for NACEL

Under the regulations, the legal basis for Trusts / UHBs to undertake clinical audit is direct care, dealt with under:

> *Article 6(1)(e) '…for the performance of a task carried out in the public interest or in the exercise of official authority..', using the Article 9 condition for direct care or administrative purpose 9(2)(h)@...medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems…'*

Trusts are reminded that the audit should be identified as processing activity in line with data protection requirements and Trust / UHB fair processing notices should be reviewed to ensure compliance with legislation.

The legal basis for the processing of data by NHSBN is under contract with HQIP, the Data Controller.

Case Note Review data collection

Data is anonymised and collected via an online portal. Data is collected and input by the Trust / UHB staff undertaking the audit who may be clinicians or clinical audit managers. Access to the data collection portal is password protected. All users of the portal have unique log in details.

GDPR legislation applies to a 'natural person' which means living individuals. Therefore, GDPR is not relevant to the case note review element of the audit. However, a common law duty of confidence (which is English law defined by precedent over 200 years) applies to deceased individuals and generally applies to things in their health record that they may not have wanted their family to know about.

GDPR/Data Protection Act 2018 does apply when contacting carers for any survey activities. We suggest that this is done in line with the Friends and Family initiative as discussed below.

Duty of confidentiality

The only organisations that have access to directly identifiable data linked to deceased individuals are the Data Controllers (Trusts and Welsh UHBs) that are participating in the audit. The data transferred to the NHS Benchmarking Network is anonymised, and data included in outputs will be anonymised and further aggregated.

As regards the duty of confidentiality, all data that is collected is obtained directly from deceased individuals clinical record and is factual with elements of that data already accessible via other means – as an example death certificate, coroner court or disclosure as part of the death notification process. There is no disclosure of confidential data to NHSBN since all data received by NHSBN is anonymised.

The risk of re-identification of the individual from the anonymised data has been assessed and judged extremely low (see NACEL Data Protection Impact Assessment).

Legal basis for NACEL Quality Survey

The above basis (direct care) would also function as the legal basis for the Trust / UHB to collect the data needed to contact the carer (name, address etc) for the NACEL Quality Survey.

Trusts should add the NACEL Quality Survey as an activity to their web sites via their Fair Processing Notices. This advice is in line with the following from NHS England Friends and Family Test: Guidance July 2014:

> *Where the [FFT process] requires the use of personal data, providers should ensure that [patients] are informed about uses and disclosure through fair processing notices.*
>
> *If [patients] are to be contacted either by employees of a provider, or a contractor acting on its behalf to complete the [FFT], the provider must take reasonable steps to ensure that this is understood by [patients] beforehand, and that they have the opportunity to decline permission for this to happen. Again, this can be achieved by the provision of fair processing information.*

Trust / UHBs should check with their Information Governance (IG) team whether any additional actions are required. **It is suggested Trusts engage with their IG team and Data Protection Officer at the earliest opportunity to check requirements. NHSBN can provide additional advice and guidance to a Trust IG Team or Data Protection Officer but the final decision about whether to participate resides with the organisation.**

As regards the process for storing information about carers required for the audit, you will again need to contact your local IG team to ensure your local Trust / UHB processes are followed.

Families and others data collection (Quality Survey)

Data is collected from families and others via a web-based survey form. A link to this form is provided to the bereaved person in a letter sent by the Trust / UHB. The link is unique and can only be used once. The person's contact details are not shared with the Network. The data input by the bereaved person is saved in the Network's SQL database and data security applies as above.

The legal basis for the actual data collection from carers (taking the form of an online survey submitted to NHSBN) is explicit consent. Wording is included on the survey form to explain the use of the data to carers.

National data opt-out

The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning. For further information see https://digital.nhs.uk/services/national-data-opt-out-programme