



## REVIEW OF PRISON HEALTHCARE INFORMATION LEAFLET

**PLEASE READ THIS LEAFLET CAREFULLY. IT EXPLAINS WHO WE ARE, WHAT WE ARE DOING AND HOW WE KEEP DATA CONFIDENTIAL AND PEOPLE ANONYMOUS.**

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is doing some work to try and improve the quality of healthcare provided to prisoners.

### WHAT IS NCEPOD?

NCEPOD is a national organisation that runs confidential enquiries to improve the quality of care for people in the UK. For over 30 years we have run studies, in different areas of healthcare, that have had a real impact on how healthcare is now delivered. NCEPOD looks at areas of care where we think it could be improved by reviewing the care that people have received in the past.

### WHAT IS THE STUDY ON PRISON HEALTHCARE ABOUT?

This study will mainly focus on a review of the healthcare provided to prisoners who died of a 'natural' death e.g. heart attack or 'other non-natural' death e.g. accidental drug overdose. We will look at the care they received before they died to see what could have been done better, and what was done well. We will also ask the prison staff for information on how healthcare is organised and accessed.

As part of the study, we will also collect the views of prisoners, ex-prisoners and their family and friends to hear their first-hand experiences of prison healthcare. This will be done using anonymous online surveys and online focus groups.

### WHAT PERSONAL, CONFIDENTIAL INFORMATION WILL BE COLLECTED?

**FOR THE REVIEW OF THE CARE RECEIVED BY DECEASED PRISONERS:** we will collect healthcare information about prisoners who died between 1<sup>st</sup> January 2018 and 31<sup>st</sup> December 2020. They will be identified via the Prison and Probation Ombudsman and personal information will include NHS and prison number, date of birth, sex and health conditions. We will then:

- Obtain any other healthcare reports that already exist (e.g. the NHS clinical review) plus additional medical records
- Ask a clinician who was involved in the care of the deceased prisoner to complete a questionnaire to give their view on what happened

- Recruit a group of clinicians to look at all the data and tell us what they think went well and where things could have been improved. Before they do this, we will have removed any information that would identify the deceased prisoner or their relatives/friends who may have been named.

**FOR THE DATA COLLECTION ON VIEWS FROM PRISONERS/EX-PRISONERS AND THEIR FAMILY/FRIENDS:** we will run anonymous surveys and focus groups online for anyone who would like to volunteer to share their experiences of prison healthcare with us.

### IS THE CONFIDENTIAL, PERSONAL INFORMATION SECURE?

**Yes**, all the information we receive is secure. All the data sent electronically to us will be secured with a password. Access to the information we collect is limited to the small NCEPOD team. All personal information in the clinical notes we collect will be removed. All data is kept in a secure, alarmed office, either in locked cabinets or on secure computers.

### WHAT WILL HAPPEN TO THE INFORMATION?

**FOR THE REVIEW OF THE CARE RECEIVED BY DECEASED PRISONERS:** no information will be shared that can identify any person, alive or dead, with any other organisations for any reason other than for linking datasets with approved partners. All prisoner data, including clinical notes, will be securely disposed of at the end of the study and names will **never appear** in any project publication. It will be **impossible** for anyone to be recognised from the analysis as we will combine the data with that of lots of other people.

**FOR THE DATA COLLECTION ON VIEWS FROM PRISONERS/EX-PRISONERS AND THEIR FAMILY/FRIENDS:** the anonymous survey will remain anonymous and be deleted once all data has been extracted from it. Any personal data collected during subsequent focus groups will be removed from the dataset at the end of the study and all recordings deleted.

### WHY DOES NCEPOD NOT HAVE TO GET CONSENT TO USE PERSONAL INFORMATION?

**FOR THE REVIEW OF THE CARE RECEIVED BY DECEASED PRISONERS:** we will be collecting personal information only on prisoners who have died, and we have approval from the Secretary of State for Health for the purpose of this confidential enquiry to store and use this information without consent. More information is available [HERE](#)

**FOR THE DATA COLLECTION ON VIEWS FROM PRISONERS/EX-PRISONERS AND THEIR FAMILY/FRIENDS:** we will be using anonymous surveys, or people will have given their consent to be contacted about further involvement in online focus groups.

## HOW TO OPT OUT OF YOUR DATA BEING USED

**FOR THE REVIEW OF THE CARE RECEIVED BY DECEASED PRISONERS:** if they opted-out of having their healthcare data used through the national data opt-out this will be identified by NCEPOD and the data not included. Relatives cannot request that these data are not reviewed.

**FOR THE DATA COLLECTION ON VIEWS FROM PRISONERS/EX-PRISONERS AND THEIR FAMILY/FRIENDS:** If you choose to take part in the focus groups you can [opt-out](#) at any time and your data will be deleted. Participation in the online survey will be anonymous so there would be no way NCEPOD could remove any one person's data. You can access our Privacy Notice [HERE](#)

## Who is commissioning and funding the work?

This study has been commissioned by [the Health Foundation](#).

## What do I do if I think any data has not been handled correctly?

If you have concerns about the way personal data are being handled, please contact Marisa Mason at the address/phone number below or email [mmason@ncepod.org.uk](mailto:mmason@ncepod.org.uk). If you feel it is serious enough, you also have the right to contact the Information Commissioner's Office, the authority in the UK responsible for data protection law. They can be contacted by telephone 0303 123 1113 or via their website <https://ico.org.uk/concerns/>

## Contact details

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