# National Audit of Pulmonary Hypertension

## Methodological Change Notice, 13th Annual Report

Published 13 January 2023

Improving lives with data and technology

# Contents

# Introduction

This document describes the change in methodology to the survival analysis conducted for the National Audit of Pulmonary Hypertension (NAPH) 13th Annual Report and any subsequent publications.

# Background

The NAPH sets out to measure the quality of care provided to people referred to pulmonary hypertension (PH) services in Great Britain.

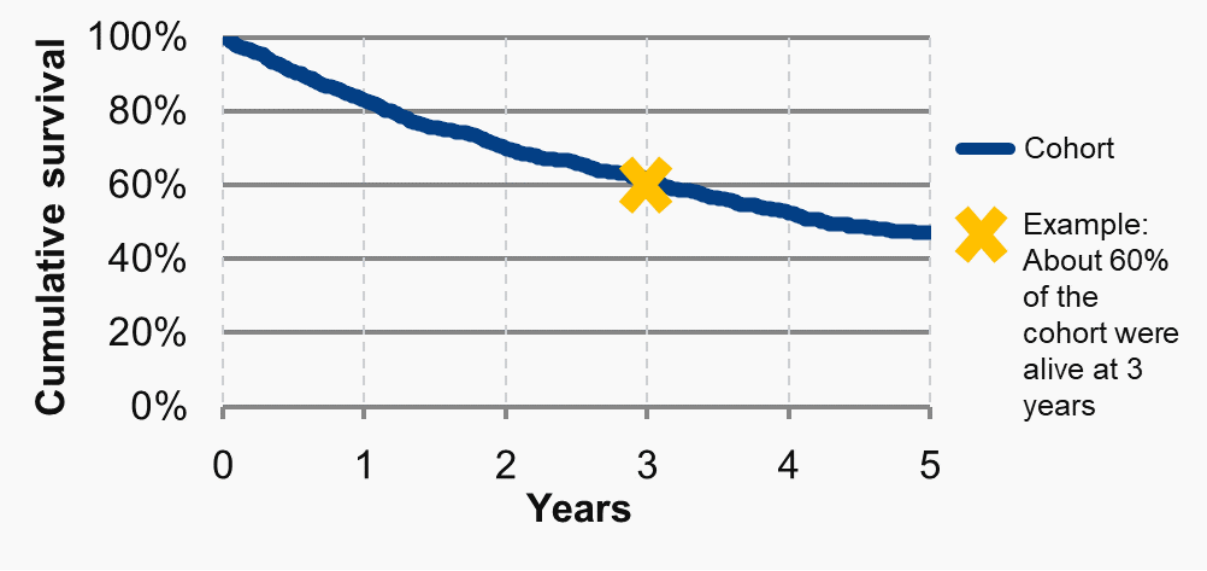
## Survival analysis

The Audit also measures survival for different PH diagnostic groups. PH may be a life shortening condition and one of the aims of treatment is to prolong life as well as to improve its quality. Measurement of survival is used as a clinical outcome and can be used to assess the effect of treatment on many life-threatening diseases.

Survival does not necessarily refer to the time from when a person experienced a certain event to when they died. It can refer to time relating to any outcome such as time to treatment or time to diagnosis. In the NAPH, survival is measured as follows:

- Survival time from the earliest diagnosis date for the person's latest diagnosis to the person's date of death.
- Survival time from the person's latest main diagnosis date to the person's latest discharge date from a PH centre.

In the NAPH annual reports, survival from diagnosis date to date of death is presented using Kaplan Meier curves, broken down by PH diagnostic groups. These are used as a way of graphically displaying an estimate of the proportion of people who will still be in a defined group a number of days after a chosen start date. For example, it provides an estimate of the percentage of patients that will still be alive x years after they received a diagnosis (see below).



However, in the NAPH annual reports, survival from diagnosis date to discharge date is presented differently. This analysis is presented in a reference table as the percentage of patients who were discharged from a PH service within 5 years of diagnosis, broken down by audit period and the following PH diagnostic groups:

- Chronic thromboembolic pulmonary hypertension (CTEPH)
    - Broken down further by:
        - Operated
        - Not operated
- Pulmonary arterial hypertension (PAH)

## Reason for methodological change

Following a review of the methodology (described above), it has been updated to improve the validity of the results. These changes are described within this document.

# Description of changes

## People diagnosed and died/discharged on same day

In previous annual reports, people who were diagnosed and then died or were discharged on the same date were recorded as having survived 0 days after diagnosis. These people are now recorded as having survived 0.5 days after diagnosis to take into account cases where the person was diagnosed with PH but then died or were discharged later that day.

## Censoring

The NAPH survival analysis not only measures the time between a person's diagnosis date and their date of death/discharge. It also takes into account when a person's survival can no longer be traced. In the case of the Audit this refers to when a person is still alive at, or has not been discharged by, the end of the audit year (e.g. for the 2021-22 audit year the end date is 31 March 2022) and it is no longer possible to track their survival beyond this date. This inability to track the time to the event is called censoring.

How censoring is handled in the NAPH survival analysis has changed.

In previous annual reports when a person was still alive on, or had not been discharged by, the last day of the audit year (time period x), they were not included in the survival analysis calculation for that time period. This meant that, despite being alive/not being discharged, they were not considered to have survived the last day of the audit year (time period x) and were excluded from the survival analysis for time period x. This has been changed so that when a person is still alive on, or had not been discharged by, the last day of the audit year (time period x), they are now considered to have survived the day and are included in the survival analysis calculation for time period x.

# Impact

Due to the small number of people affected, for the 13th Annual Report the methodological changes resulted in no change to the overall key findings of the analyses and only minimal change to the underlying results.

For example, the changes did not affect the percentage of patients who were discharged from a PH service within 5 years of diagnosis, broken down by audit period and PH diagnostic groups. This is except for the audit period 2009-2020 for patients with CTEPH (operated) where the percentage decreased from 22% to 21%.

# Further information

For further information on the NAPH 13th Annual Report see: https://digital.nhs.uk/data-and-information/publications/statistical/national-pulmonary-hypertension-audit/13th-annual-report

# Information and technology
## for better health and care

**www.digital.nhs.uk**

**0300 303 5678**

**enquiries@nhsdigital.nhs.uk**

**@nhsdigital**

This publication may be requested
in large print or other formats.

**Published by NHS Digital,**
**part of the Government Statistical Service**