

## Domain 6: Types of data and potential requirements for setting up a screening programme



Preparing to introduce organised screening involves establishing what data are required to monitor and evaluate the programme for quality improvement. This resource explores top-line examples of the types of data that might be needed to support the set-up of an organised screening programme, and existing data management systems that the programme may be required to access within each health system. A range of national and international examples of sources of data have also been provided.

This list is not intended to be exhaustive.

| Purpose  | Examples of data                                      | Example data sources   |
|--|---|--|
| Identifying the target population                | Lung cancer incidence mortality                       | Population survey data<br>Population-based cancer registries <ul style="list-style-type: none"> <li>• <a href="#">Global Cancer Observatory</a><sup>1</sup></li> <li>• <a href="#">European Cancer Information System</a><sup>2</sup></li> </ul>   |
| Identifying the target population                | Socioeconomic data                                    | Population health survey data <ul style="list-style-type: none"> <li>• <a href="#">World Bank Health, Nutrition and Population statistics</a> (range of data)<sup>3</sup></li> <li>• <a href="#">OECD Health Statistics</a> (range of data)<sup>4</sup></li> <li>• <a href="#">European Cancer Inequalities Registry</a><sup>5</sup></li> <li>• <a href="#">Demographic and Health Surveys</a><sup>6</sup></li> </ul> Insurance databases  |
| Identifying the target population<br>Recruitment | Smoking prevalence and smoking history                | Population survey data <ul style="list-style-type: none"> <li>• <a href="#">Global Burden of Disease 2019</a> (GBD Compare)<sup>7</sup></li> <li>• <a href="#">Global Tobacco Control Progress Hub</a><sup>8</sup></li> </ul> Primary care electronic medical records  |
| Identifying the target population<br>Recruitment | Lung cancer comorbidities                             | Disease-specific registries <ul style="list-style-type: none"> <li>• <a href="#">European Medicines Agency</a> inventory of patient registries<sup>9</sup></li> <li>• <a href="#">National Institutes of Health list of registries</a> (US example)<sup>10</sup></li> </ul> International data sets <ul style="list-style-type: none"> <li>• <a href="#">Global Burden of Disease 2019</a> (GBD Compare)<sup>7</sup></li> </ul> Electronic medical records<br>Hospital admissions data <ul style="list-style-type: none"> <li>• <a href="#">NHS Hospital Episode Statistics</a> (UK example)<sup>11</sup></li> </ul> |
| Recruitment                                      | Medical and personal information for each participant | Electronic medical records<br>Electoral roll<br>Insurance databases  |

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| Purpose   | Examples of data  | Example data sources  |
|---|---|---|
| Training, equipment setup and quality assurance | Existing thoracic computed tomography (CT) scans<br>Data to calibrate CT scanner<br>Protocol data   | Hospital Picture and Archiving Communications System (PACS)<br>Other repositories (e.g. sets of scans collected from randomised-controlled trials, manufacturer data sets) <ul style="list-style-type: none"> <li>• <a href="#">The Cancer Imaging Archive</a> (National Cancer Institute)<sup>12</sup></li> <li>• <a href="#">The International Clinical Trials Registry Platform</a> (World Health Organization)<sup>13</sup></li> </ul> Electronic medical records (communicating results to primary care) |
| Monitoring and evaluation                       | Participant outcome data (e.g. cancer detection rate, false positive rates, incidental findings, number of invasive procedures for nodules not found to be cancer, participation rate, adherence rate between screening rounds) | Population-based cancer registry (via linkages with screening programme data) <sup>14</sup><br>Electronic medical records<br>Cancer screening registries (an example of how these might be setup for other cancers is <a href="#">CanScreen5 project</a> ) <sup>14</sup>  |
| Future research (e.g. to improve recruitment)   | Biospecimens (e.g. blood samples)   | National/regional or local biobanks <ul style="list-style-type: none"> <li>• <a href="#">Global Biobank Engine</a><sup>15</sup></li> <li>• <a href="#">Global Biobank Meta-analysis initiative</a><sup>16</sup></li> </ul> Research institution databases   |

## REFERENCES

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