



Public Health
England

What data is held about patients?
What are the roles, controls and
process for access to this data?

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Public Health England



Public Health
England

Public Health England exists to protect and improve the nation's health and wellbeing and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.



What data is held about patients?



Communicable disease
surveillance data



Lifestyle and
behaviours



Notifiable diseases /
organisms



Non-cancer screening



Cancer screening



Disease registration



What data is held about patients?

Notifiable diseases under the Health Protection(Notification) Regulations 2010

Acute encephalitis, Acute infectious hepatitis, Acute poliomyelitis, Anthrax, Botulism, Brucellosis, Cholera, Diphtheria, Enteric fever, Food poisoning, Hemolytic uremic syndrome, Infectious bloody diarrhoea, Invasive group A streptococcal disease, Legionnaire's disease, Leprosy, Malaria, Measles, Meningococcal septicaemia, Mumps, Plague, Rabies, Rubella, Severe Acute Respiratory Syndrome (SARS), Scarlet fever, Smallpox, Tetanus, Tuberculosis, Typhus, Viral haemorrhagic fever (VHF), Whooping cough, Yellow fever



What data is held about patients?

Notifiable organisms under the Health Protection(Notification) Regulations 2010

Bacillus anthracis, Bacillus cereus (only if associated with food poisoning), Bordetella pertussis, Borrelia spp, Brucella spp, Burkholderia mallei, Burkholderia pseudomallei, Campylobacter spp, Chikungunya virus, Chlamydophila psittaci, Clostridium botulinum, Clostridium perfringens (only if associated with food poisoning), Clostridium tetani, Corynebacterium diphtheriae, Corynebacterium ulcerans, Coxiella burnetii, Crimean-Congo haemorrhagic fever virus, Cryptosporidium spp, Dengue virus, Ebola virus, Entamoeba histolytica, Francisella tularensis, Giardia lamblia, Guanarito virus, Haemophilus influenzae (invasive), Hanta virus, Hepatitis A, B, C, delta, and E viruses, Influenza virus, Junin virus, Kyasanur Forest disease virus, Lassa virus, Legionella spp, Leptospira interrogans, Listeria monocytogenes, Machupo virus, Marburg virus, Measles virus, Mumps virus, Mycobacterium tuberculosis complex, Neisseria meningitidis, Omsk haemorrhagic fever virus, Plasmodium falciparum, vivax, ovale, malariae, knowlesi, Polio virus (wild or vaccine types), Rabies virus (classical rabies and rabies-related lyssaviruses), Rickettsia spp, Rift Valley fever virus, Rubella virus, Sabia virus, Salmonella spp, SARS coronavirus, Shigella spp, Streptococcus pneumoniae (invasive), Streptococcus pyogenes (invasive), Varicella zoster virus, Variola virus, Verocytotoxigenic Escherichia coli (including E.coli O157), Vibrio cholera, West Nile Virus, Yellow fever virus, Yersinia pestis



What data is held about patients?

Population screening programmes

- NHS abdominal aortic aneurysm (AAA) programme
- NHS bowel cancer screening (BCSP) programme
- NHS breast screening (BSP) programme
- NHS cervical screening (CSP) programme
- NHS diabetic eye screening (DES) programme
- NHS fetal anomaly screening programme (FASP)
- NHS infectious diseases in pregnancy screening (IDPS) programme
- NHS newborn and infant physical examination (NIPE) screening programme
- NHS newborn blood spot (NBS) screening programme
- NHS newborn hearing screening programme (NHSP)
- NHS sickle cell and thalassaemia (SCT) screening programme



What data is held about patients?

Radiation workers and their health: national study

The national registry for radiation workers (NRRW) is a long-term follow-up study of the health of radiation workers in the UK.

National Drug Treatment and Monitoring System

NDTMS holds information about the types of substances people use, the treatment they receive and how long they use the service for. This information is used to:

- look at how effective drug and alcohol treatment services are
- plan and improve services to meet the needs of local people
- produce figures and support research about drug and alcohol use and treatment



What data is held about patients?

Cancer registration

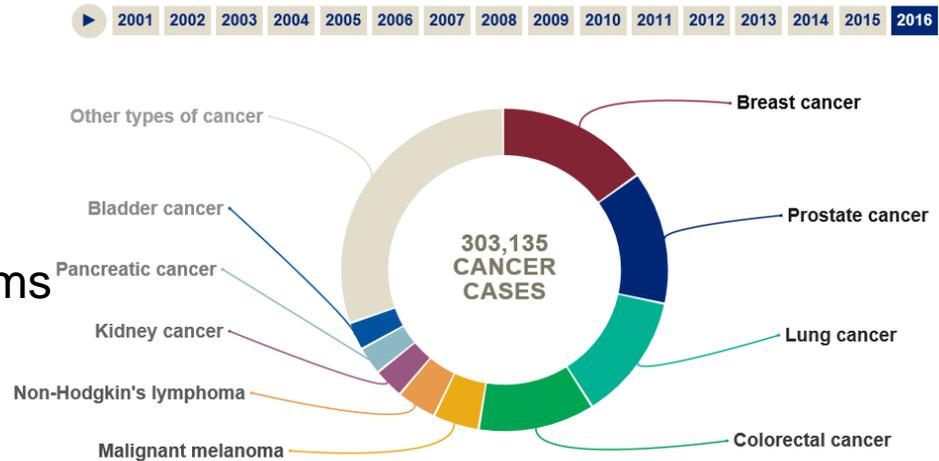
Data collected from:

- 200 MDTs
- 600 local secondary care systems
- 142 chemotherapy centres
- 82 breast screening centres
- 56 radiotherapy centres
- 22 molecular testing labs

Plus over 26 other sources

Cancer incidence

New cases of cancer diagnosed each year





What are the roles, controls and process for access to this data?

If its you, asking for your data.....just ask

If its anyone else.....

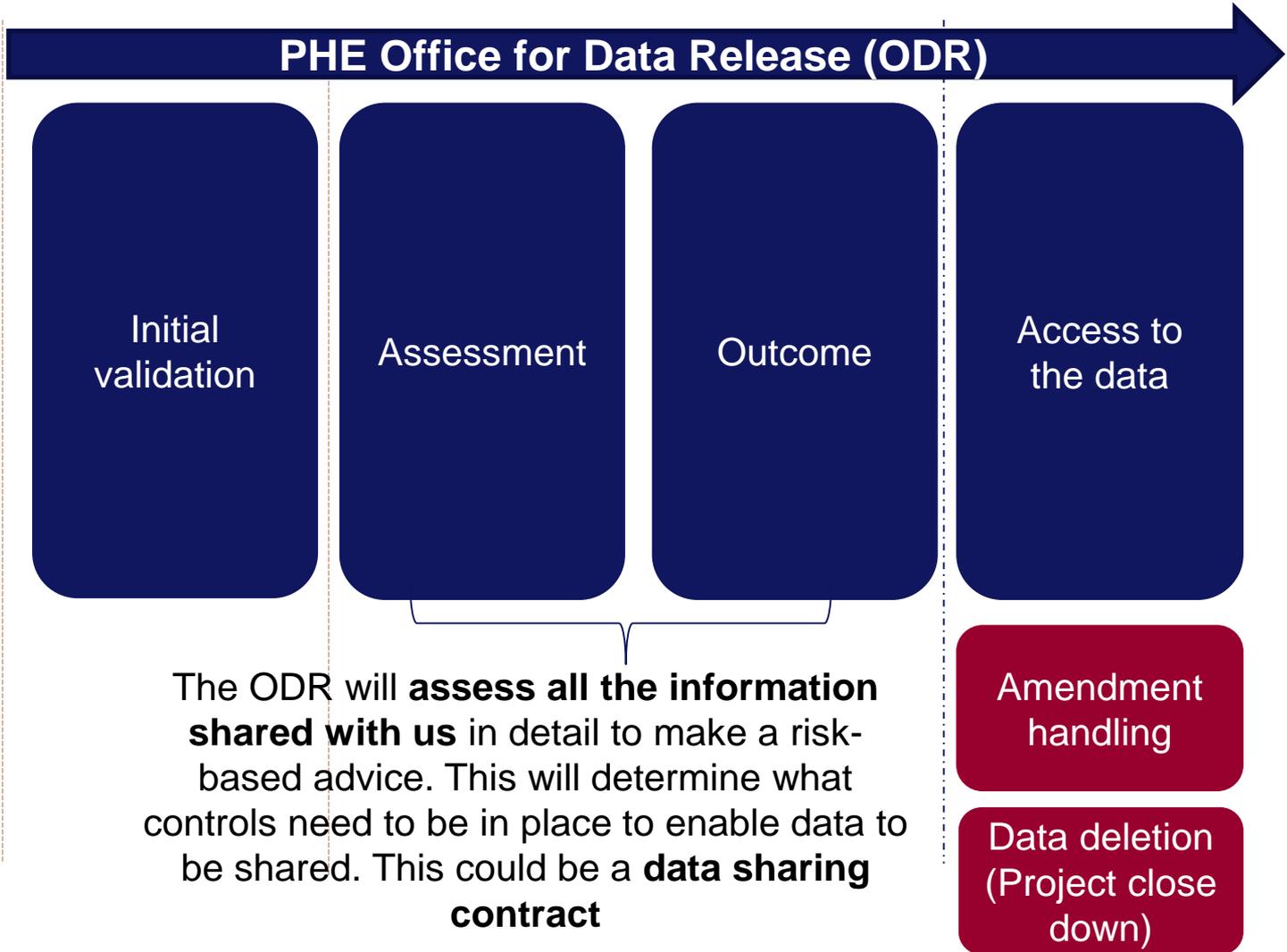


What information do I need to submit a valid application?

- Consistent **minimum requirements** for all requests for PHE data:
 - Completed data request form
 - Clear, specific and unambiguous protocol
 - Data specification
 - Evidence of security and data management
- Depending on (1) the type of request being made, (2) level of identifiability of the data and (3) whether any other organisations are involved, **other evidence**, such as REC approval **may be needed**.



Pre-application
advice





What are the roles, controls and process for access to this data?

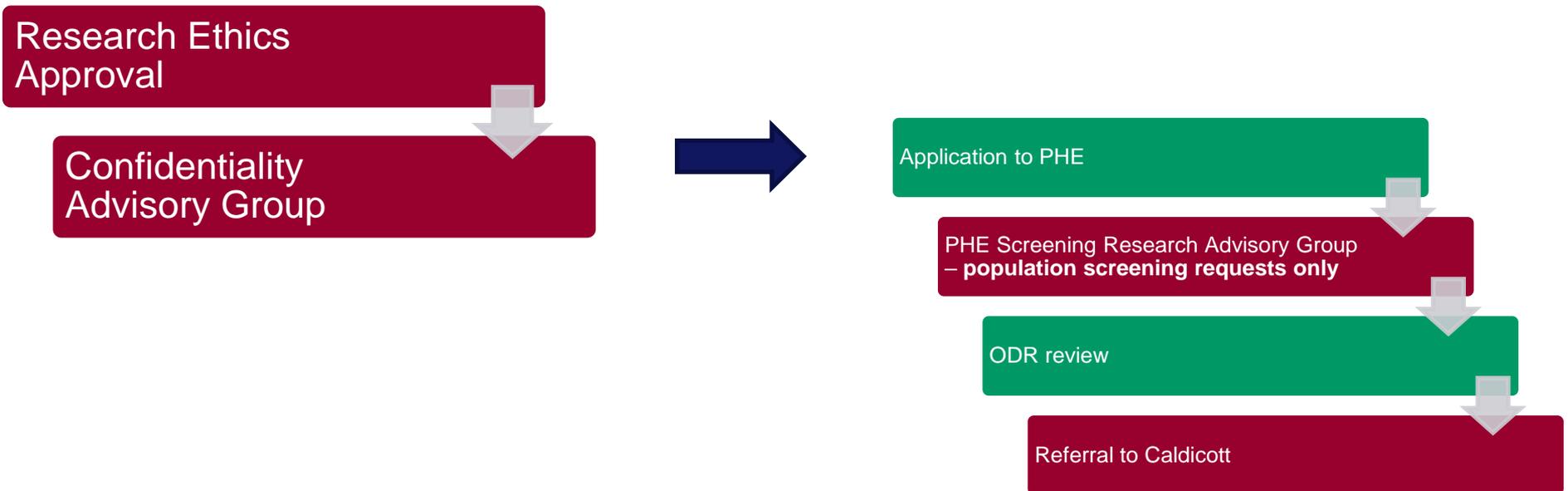
Should we share?



Can we share?



Process for accessing data





Should we

- The Research Ethics - protects the rights, safety, dignity and wellbeing of research participants.....
- Confidentiality Advisory Group - protect and promote the interests of patients and the public.....
- Caldicott Function - responsible for protecting the confidentiality of people's health and care information and making sure it is used properly.....
- PHE Research Advisory Committee - ensure that research, evaluation or audit does not adversely affect the uptake, acceptability and delivery of the programmes and review the scientific merit and feasibility of research, evaluation and audit applications, and their impact on the programmes



Contact and further information

- **Phone:** 020 7654 8030
- **Email:** ODR@phe.gov.uk
- **Monthly newsletter:** email ODR@phe.gov.uk for the link to join