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Background

The Health and Social Care Information Centre (HSCIC) is responsible for Hospital Episode Statistics (HES) data and, as a result, other users of HES data are subject to HSCIC's terms and conditions of use.

In 2007, when the first 'cancer HES' admitted care HES extract was obtained on behalf of the English cancer registries by Thames Cancer Registry (TCR) and the English cancer registries' HES system began, TCR circulated a guidance document on the release of HES data by the registries. This guidance advised that registries should contact HSCIC in advance about any publication or data release involving HES data, with the exception of publications or data releases including only cancer registration data items that had been augmented with HES data through the cancer registration process. **Figure 1** shows it in flowchart form.

Objectives

Since the original guidance document was circulated in 2007 the English cancer registries have gained considerable experience with the use of HES data. However, there was still some uncertainty about how these data could be used. NCIN wished to enable the English cancer registries to make more use of HES data in publications, or data releases to third parties, by clarifying the circumstances under which these could occur and by introducing a clear framework for publications and releases.

Results

The resultant information governance framework provides an extended policy and procedure for the English cancer registries to achieve publications, or data releases to third parties, involving HES data. It does meet NCIN's objectives. Particularly, it enables the registries to make such publications and data releases without reference to HSCIC in many more cases.

The new guidance document provides a policy and procedure dependent upon the level of identifiability of the analyses or data involved. **Figure 2** show it in flowchart form. It applies when the use of the publication or data release is non-commercial.

The framework is intended to supplement and update existing NCIN and United Kingdom Association of Cancer Registries' (UKACR) information governance and confidentiality policy and procedure, in particular the NCIN policy 'Access to the National Cancer Data Repository'.

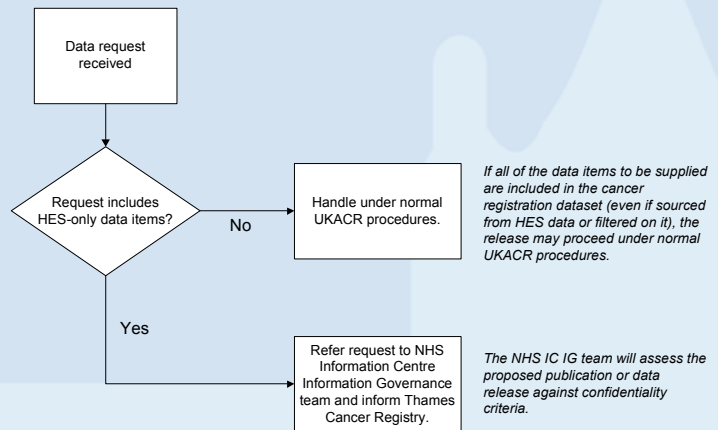
In order to come into effect the new framework needs to be underpinned by agreements between TCR and HSCIC that enable the cancer registries in the English cancer registries' HES system to sub-license HES data from the system to third parties. These agreements have been drawn up and signed subject to their terms being formally cascaded from TCR to the other English registries.

Discussion

The new framework is an example of one for publications and releases by English cancer registries involving cancer registration data linked to a data source for which another organisation is responsible. Other such frameworks have been developed by NCIN for linked cancer registration and Clinical Practice Research Datalink data and linked cancer registration and National Clinical Audit data.

Together these form a first step toward a more general framework within which English cancer registries can manage cancer registration data linked to multiple other sources and use these linked data to improve outcomes for cancer patients.

Figure 1 - Release of HES data by English cancer registries: 2007 version



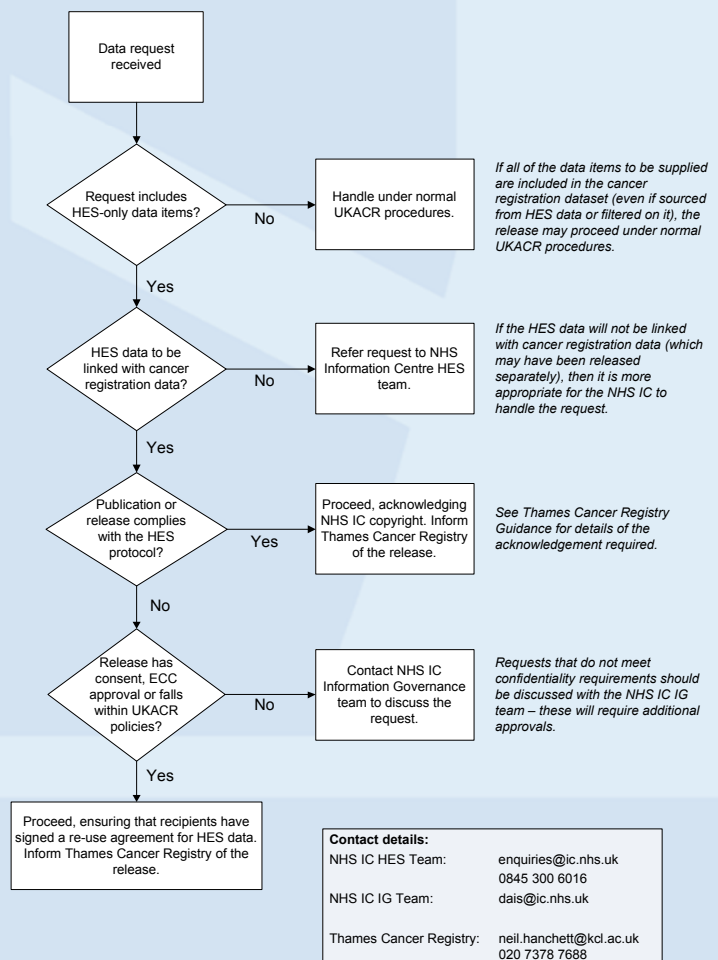
Method

TCR, NCIN and HSCIC held meetings and teleconferences to discuss principles. Documents were drafted, considered and amended by the three parties.

Practical experience with requests for HES data received by the English cancer registries and NCIN played a large part in developing the principles and documents.

Figure 2 - Release of HES data by English cancer registries: new version

To be used in conjunction with the document 'Thames Cancer Registry guidance to the English cancer registries on the release of HES data May 2012'.



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