



Department of Health

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Andy Williams
Chief Executive,
Health & Social Care Information Centre
1 Trevelyan Square, Boar Lane
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8 March 2016

Dear Andy,

Direction for 100,000 Genomes Project

I am writing to provide a direction to the Health and Social Care Information Centre to establish and operate an informatics support service for the 100,000 Genomes Project. This service will support the secure management of participant data, linkage (once approved) to HSCIC held data and release of de-identified data to Genomics England's research facility and re-identification of clinical reports for clinicians.

On 1 April 2013, the National Institute of Health and Clinical Excellence (Constitution and Functions) and Health and Social Care Information Centre (Functions) Regulations 2013 came into effect. The regulations make provision for Secretary of State to direct the Health and Social Care Information Centre to exercise functions on his behalf to develop or operate information or communications systems, referred to as "systems delivery functions" under section 274 of the Health and Social Care Act 2012 ("the 2012 Act").

Under section 254 of the 2012 Act, HSCIC are required to:

- host an information system established by Genomics England for approved users to support the collection and storage of consented participant information for Genomics England provided by the NHS Genomics Medicine Centres (GMCs);
- link such data to other data sets held by the HSCIC; and
- return identified clinical reports to GMCs,

and then disseminate that information to authorised recipients at Genomics England, under section 261(2)(b)(ii) of the 2012 Act in support of the 100,000 Genomes Project.

Please accept this letter as a direction given under subsection (1) of section 254 of the 2012 Act to the Health and Social Care Information Centre to exercise the functions in relation to the informatics support service for the 100K Genome project, details of which are set out in the attached schedule.

The Health and Social Care Information Centre is directed to not further publish the information which it obtains by complying with this direction, in accordance with section 260(2)(d) of the 2012 Act, other than in accordance with the instructions in this direction.

The system should be implemented at dates agreed with Genomics England in 2015-16.

HSCIC may charge Genomics England for the provision of this service.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Siobhan Jones', is positioned above the typed name and contact information.

Siobhan Jones
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Cc: John Willshire, HSCIC Portfolio Director;
Cameron Robson, Department of Health
Alison Smith, Department of Health