

Independent Group Advising on Release of Data (IGARD)

Patient data – balancing access and protection
use MY data Workshop

7 May 2019

Why IGARD?

NHS Digital's response to the Partridge Review

“IGARD aims to improve transparency, accountability, quality and consistency through robust, independent scrutiny of NHS Digital data distributions, as well as providing a voice for stakeholders and the public.”

Who is IGARD?

A mix of lay and specialist INDEPENDENT members including:

Patients

Carers

Research participants

Academics specialising in health data research

Medical Professionals

Data protection specialists

Privacy, confidentiality and ethical specialists

“Sharing information can be as important as protecting confidentiality – unnecessary obstacles should not be allowed to prevent information sharing where it is in the interests of patients, service users and the wider public.”

IGARD Terms of Reference
<https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data>

Challenges – how to balance:

- legal duty to respect privacy (NB public confidence) vs.
- potential benefits for patients

Questions: is there a sound legal basis?

Are the benefits to health and social care clearly explained?

Weekly minutes

6

Independent Group Advising on the Release of Data (IGARD)

Minutes of meeting held 28 March 2019

Members: Sarah Baalham, Joanne Bailey, Maria Clark, Kirsty Irvine (Chair), Priscilla McGuire, Eve Sariyannidou.

In attendance: Dave Cronin, Louise Dunn, James Humphries-Hart, Karen Myers.

Apologies: Anomika Bedi, Nicola Fear.

Observers: Dan Goodwin, Geoffrey Schrecker, Maurice Smith (Items 2.1-2.9 and 2.11)

1	<p>Declaration of interests:</p> <p>There were no declarations of interest.</p> <p>Review of previous minutes and actions:</p> <p>The minutes of the 21st March 2019 IGARD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record the meeting.</p> <p>Out of committee recommendations:</p> <p>An out of committee report was received (see Appendix B).</p>
2	<p>Data applications</p>
2.1	<p><u>Cardiff University: MR1314: FRAGMATIC: A randomised phase III clinical trial investigating the effect of FRAGMin® Added to standard Therapy In patients with lung Cancer (Presenter: Dave Cronin) NIC-291941-Z2Q1C</u></p> <p>Application: This was an extension and amendment application for identifiable Medical Research Information Service (MRIS) for a study assessing the effect of adding dalteparin (FRAGMIN) for 24 weeks to standard treatment (trial arm) compared to standard treatment alone (control arm). The primary outcome measure of the trial was overall survival. Future objectives include completion of ongoing health economic analysis and further analysis of the data set to further investigate and publish other secondary outcome measures.</p> <p>Discussion: IGARD noted in section 1(b) (Data Controller(s)) that the Data Protect Act (DPA) expiry date had expired for Cardiff University and asked that this was updated with the new date.</p> <p>IGARD noted the reference to Article 9(2)(j) within section 1 (Abstract) and asked that this was updated to reference that the 'research is in the public interest'.</p> <p>IGARD suggested information provided in section 5(b) (Processing Activities) on derived data that started "NHS Digital has reviewed the specification and description of the data..." which also included the information on fields and access controls was replicated within section 6 (Special Conditions).</p> <p>IGARD noted the sentence in section 5(b) "Velindre NHS Trust may will not store or process the data." and asked that this was updated to remove the word 'may'.</p> <p>IGARD queried the reference in section 3 (Datasets Held / Requested) under the 'Common Law Duty of Confidentiality' to 'Reasonable Expectations' and asked that this was removed as it was not relevant.</p> <p>IGARD noted that historic phrasing was being used in section 4 (Privacy Notice) and it was suggested that new standard wording be used "All data required under this application is personal data under the GDPR. All Data Controllers are expected to provide a privacy notice</p>

How can you see what we are doing?

- Detailed minutes published weekly, usually within one week of an IGARD meeting
- IGARD pages hosted on NHS Digital website
- NHS Digital data release register
- <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/independent-group-advising-on-the-release-of-data>

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