

Public Interest Model

General Practice Extraction Service Independent Advisory Group

This public interest model was produced independently by the General Practice Extraction Service Independent Advisory Group (GPES IAG). It was not commissioned or produced by the Health and Social Care Information Centre (HSCIC).

The GPES IAG requested that this public interest model be published alongside the minutes of the group's 13 February 2014 meeting.

More information about the GPES IAG can be found on the HSCIC website at <http://www.hscic.gov.uk/gpesiag>.

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Background

The General Practice Extraction Service (GPES) Independent Advisory Group (IAG) is asked to make a recommendation in respect of each extraction request that GPES receives. These recommendations can either be (1) to proceed as is, (2) to proceed subject to further approvals, (3) to proceed subject to changes, or (4) for further consideration or to make significant changes.

In coming to its recommendation, IAG must:

- Confirm that the request is consistent with the GPES Information Governance Principles document and specifically whether the IAG agrees with the Health and Social Care Information Centre (HSCIC) classification of each customer requirement.
- Weigh the risks and benefits in order to assess whether the extraction is, in the view of the IAG, appropriate and in the public interest.¹

As these requirements make clear, IAG's role is to provide a governance assessment, rather than a legal opinion. The primary responsibility for ensuring that the extraction request is compliant with the regulatory frameworks that are applicable falls to GPES and the customer.² HSCIC provides IAG with an account of the legal basis for each extraction request in its Information Governance Assessment. IAG scrutinises this legal classification in the course of its deliberations on whether the extraction is consistent with the GPES Information Governance Principles.

The purpose of this document is to clarify the way in which IAG interprets the second of these requirements, which is hereafter referred to as the “public interest requirement”. Given that the idea of public interest is used in a number of different ways in English law and by administrative bodies, this clarification may be particularly useful for GPES customers.³

Public and private interests

IAG distinguishes between public interests, and private interests. Public interests are

1 GPES IAG terms of reference version 1.2, available at <http://www.hscic.gov.uk/media/9856/GPES-IAG-Terms-of-Reference/pdf/gpes-iag-terms-reference-v1-2.pdf>

2 In addition to the law, these regulatory frameworks include guidance documents such those produced by the Information Commissioner's Office.

3 A recent project at Belfast University argued that public interest is used in at least five different ways in English courts, even leaving on one side its variety of usages in wider public policy contexts. <http://www.publicinterest.info/what-public-interest/how-term-arises-court>.

those that can reasonably be judged to be beneficial to members of the public as such, whereas private interests are those that are beneficial only to specific actors or interest groups, and sometimes at the expense of other actors or interest groups. In weighing the benefits of an extraction, GPES IAG will consider public interests, but not private interests. The fact that an extraction would be beneficial to GPES's customer (the institution requesting the extraction), or to GPES will not be taken to be sufficient by itself to establish a public interest in the extraction. IAG distinguishes between a number of public interests (plural), and **the** public interest (singular). The public interest in a given case will be an all things considered judgement made on the basis of the different public interests that bear on a particular extraction request.

Public interests related to health data that IAG will take into account include, but are not confined to:

- meeting healthcare needs
- maintaining the confidentiality of the doctor-patient relationship
- allowing patients to control access to identifiable health data relating to them
- improving patient choice of healthcare
- reducing health inequalities
- improving population health
- preventing and monitoring outbreaks of infectious disease
- identifying those at risk of diseases where an effective treatment plan is available.
- promoting healthcare research and cooperation between healthcare providers and centres of expertise/excellence.
- maintaining a health system that is run efficiently and effectively, with appropriate clarity and transparency on entitlements for patients to services within the home system, or for those patients who wish to access cross-border healthcare.
- helping to advance the agenda on rare disease through information and knowledge sharing, cooperation on specialised healthcare and improving diagnosis and treatment for patients.

Public interests may conflict in given circumstances – in particular, the public interests in patient privacy and confidentiality may conflict with certain kinds of uses of data that could promote public health. In such cases of conflict, IAG will scrutinise the rationale provided for the extraction particularly carefully. Due regard in such instances will also be given to the GPES Information Governance Assessor's recommendation on the customer requests for the extraction.

Assessing risk

In considering the risks and benefits of any particular data extraction, IAG takes the view that there are no extractions of data that are entirely risk free. Any extraction, even of anonymised or aggregated data will provide support for inferences about the probability of other information about patients. (The most that can be achieved by anonymisation or aggregation is to ensure that the risk of revealing private information about individuals is not substantially increased by the database extraction and any subsequent publication.) In addition, the possibility of accidental or deliberate unauthorised release of data cannot be entirely discounted.

IAG approaches each request by examining whether the benefits of extraction are of a kind and a size that, despite the foreseeable risks, it is in the public interest to recommend extraction. Only those benefits that would result in the promotion of public interests will be considered relevant. IAG considers two aspects when assessing privacy risks: first, the protection of privacy and of personal data of the subjects involved in the extraction; and second, the wider privacy impact of the proposed extraction and its subsequent use.

The privacy risks of data extraction to individuals will be judged to be more or less serious on the basis of a number of parameters, including (i) the likelihood of an unwanted event such as re-identification occurring, (ii) the number of people exposed to the risk, (iii) how harmful it would be to a representative individual if the unwanted event were to eventuate, (iv) whether those exposed to the risk have consented to it or have at least had the opportunity to object to it.⁴ In judging the seriousness of privacy risks to individuals, IAG is supported by GPES's Information Governance assessment.

The wider privacy impact of an extraction becomes more important as the number of patients increases, and the data extracted becomes richer. If a relevant Privacy Impact Assessment has been commissioned, IAG would expect this to be available to the GPES Information Governance Assessor, and to IAG at the time it considers the extraction request. If a request would entail large scale extraction of identifying or potentially identifying information and no Privacy Impact Assessment has been commissioned, IAG may recommend that a Privacy Impact Assessment is undertaken before considering the extraction request.

IAG will not judge an extraction to be in the public interest if the privacy risks entailed by it are more serious than would be reasonably practicable for the stated purposes of that extraction.⁵ In assessing whether the risk imposed is excessive, IAG first examines

4 See the analysis in Jonathan Wolff, "Five Types of Risky Situation", *Law Technology and Innovation* (2) 151-163 available from <http://discovery.ucl.ac.uk/1359912/1/1359912.pdf>

5 See Health Research Authority Confidentiality Advisory Group, "Principles of Advice: Exploring the concepts of 'Public Interest' and 'Reasonably Practicable'", available at

whether the level of individual identifiability, the richness of the data requested, the frequency of extraction, and the duration of the extraction period are necessary for the stated purposes of the extraction. Where data are requested that are not clearly related to the stated purposes of extraction, this may be judged excessive. If some of the data codes that the customer wishes to extract are not necessary for the primary stated purpose (e.g. allowing payments to be made for an Enhanced Service), but are related to a secondary purpose (e.g. collecting data that may later be used for research purposes), this should be explained and justified. Just as for primary uses of data, secondary uses will be considered in terms of the proportionality of their risks and benefits, and the wider public interest.

Even where certain risks of an extraction are unavoidable, IAG will not necessarily judge that this particular extraction would be in the public interest. In cases where risks inherent in a particular extraction request cannot be practicably avoided, IAG may take the view that the benefits of the extraction are not of a type or a magnitude that would justify imposition of these risks on patients. When weighing the seriousness of the risks of a particular extraction, IAG also considers the measures that have been or will be taken to mitigate these risks, and the measures that will be put in place to inform patients about the nature and purpose of the extraction, and how to dissent from it.

Where a customer extraction request aims to establish or further develop a platform such as a biobank or data warehouse, the purposes for which the data will be used may not fully specifiable in advance. In such cases, the customer should provide an account of the governance arrangements that will be put in place to regulate the onward use of the data, and how these arrangements will ensure that the extracted data will be used in the public interest.

Preparing the Public Benefits Plan

Each data extraction request must include a Public Benefits Plan, which explains how the public interest would be promoted by the extraction of the data. The benefits detailed in the Public Benefits Plan should aim to be specific, measurable, attainable, relevant and time-bound. IAG tends to be much more impressed by claims of specific measurable benefits to be achieved within a specified timescale, than with vague and broad statements about potential benefits. This also allows for an evidence based approach to be developed in relation to interventions and the use of public money.

Where the extraction request could conflict with other public interests (such as patients' entitlements to control access to their health data, or duties to reduce health inequalities), the public benefit plan should make the case why the public interest in extraction

<http://www.hra.nhs.uk/EasySiteWeb/GatewayLink.aspx?aId=150290>

outweighs the competing public interests in this case. Where public interests are in conflict, IAG will take a particular interest in whether, and if so how, measures that would mitigate the extent of the conflict have been explored.

IAG is also keen to ensure that the maximum benefits for patients are accrued from data extractions that do occur. As the Caldicott 2 report explained it, “good sharing of information, when sharing is appropriate, is as important as maintaining confidentiality. All organisations providing health or social care services must succeed in both respects if they are not to fail the people that they exist to serve.”⁶

The Public Benefits Plan should usually cover the following:

1. Ensuring requested extraction meets the healthcare needs of patients and wider publics

- Which healthcare need or needs does the proposed extraction address?
- What is the evidence base for these needs? (E.g. systematic reviews; WHO recommendations, surveys, public perceptions)
- How does the customer intend to address these needs?
- How would the proposed extraction output contribute to meeting these needs?
- How will the contribution of the data extraction to meeting these healthcare needs be measured?

2. Ensuring that the benefits of the proposed extraction are proportional to its risks for *all* affected groups

- How will the level of public acceptance of the extraction be assessed?
- Which segments of society will benefit from better healthcare as a result of the proposed extraction?
- Could the proposed extraction have a negative impact on any groups of patients or on wider publics? If so, what measures, if any will be put in place to mitigate these impacts?
- Could the proposed extraction impact disproportionately upon specific groups or unduly discriminate against them?
- Could the proposed extraction exacerbate inequalities in either access to healthcare, or in health outcomes?

6 Information: To share or not to share? The Information Governance Review (2013), p.8. Available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf

- How will society as a whole benefit from the extraction?
- How broadly will the extracted data be shared?
- Could the extracted data, or an aggregated subset of it, be published without undue risk to privacy?
- Where the extracted data, or an aggregated subset of it, could be published without undue risk, will the data be published? If not, why not?