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Roger Halliday  
Chief Statistician  
Scottish Government  
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**General Practitioners**

19 June 2012

Dear Mr Halliday

### **A Scotland-wide Data Linkage Framework for Statistics and Research**

Thank you for seeking the views of BMA Scotland on *A Scotland-wide data linkage framework for statistics and research – Consultation paper on the aims and guiding principles*.

BMA Scotland is generally supportive of the approach outlined in the consultation – that data which is not patient identifiable is shared for the purposes of research. However, BMA Scotland is always cautious in welcoming new proposals regarding data sharing as there is always a risk, despite the proposed policy and intended processes, that patient confidentiality is eroded.

We agree with the proposals regarding a clear anonymisation process and expect a robust process to ensure that individuals would not be identified by any shared data. We are of the strong view that where there is any risk that a patient could be identified, their data is not shared for any purpose in the absence of explicit consent. This is especially important for individuals with rare conditions where the risk of identification is considerably greater.

It is clear that general practitioners, as data controllers of their patients' information, must be informed and asked permission to use practice-based data for any purpose proposed by this consultation. We are very supportive of the proposal that principles similar to the GP Extraction Service (GPES) are applied to any proposed extraction from GP systems.

We would support the development of the National Privacy Advisory Service and expect that it would have significant public/lay involvement. We believe that the extraction of data (even anonymised data from GP systems) would require a set of principles as described above. We also believe that a similar oversight committee should be formed to advise on extraction from GP systems.

We have a number of questions regarding the following from the consent section of the consultation:

*23. Where obtaining explicit consent is not possible/practicable, and in all uses of data which are beyond those specified when consent was obtained then (a) removal of direct identifiers should occur as soon as is reasonably practicable and/or (b) **authorisation from an appropriate oversight body should be obtained which can confirm that the public interest in data linkage is met and appropriate safeguards are in place.***

**Chief Executive/Secretary:** Tony Bourne

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**STANDING UP  
FOR DOCTORS**

Could you please:

- clarify the legislative basis that allows for the creation of an oversight body with powers to disclose patient information in the absence of consent?
- describe under which circumstances the oversight body might support the disclosure of patient information in the absence of consent for public interest?
- clarify an individual's right to appeal following a decision of an oversight body?
- describe the proposed composition of the oversight body?

Also, could you clarify if the data linkage centre intends to hold data or if it will simply links data held elsewhere?

We would be happy to expand on any of our comments provided above and look forward to receiving a response to our questions regarding the oversight body.

Yours sincerely



Carrie Young  
**Head of Primary Care**  
**BMA Scotland**