Annex E: Consultation Questions

The consultation sets out a number of proposed amendments. Views are invited on the following:

1) Where data relating to a citizen is held it should be accurate.
Do you agree that the approach suggested at paragraphs 9-11 is an effective approach to achieving this?

Yes ☒ No ☐

If No, please describe the approach you feel should be taken.

- How can the issuing of a UCRN and inclusion of a post code in NHS Central Register ensure accuracy? It seems under present proposals that, without a person's knowledge, data can be entered about them which is highly sensitive, irrelevant or incorrect.
- If accuracy of stored data on any individual is the aim, then perhaps protocols for data entry would best involve the individual concerned and their permissions for any entry or any transfer or sharing of data.
- Central to such protocols would also be clear and easily accessible mechanisms for the individual to check and correct as well as limit data stored.
- The proposed digital system will be huge.
- IT experts know that, although organisations want data bases which are big, reliable and secure, we do not have the technology to satisfy all three criteria. So since the government has decided on very very big you will also have either insecure or unreliable or both insecure and unreliable.
- There is no evidence of a back up plan in the event of breach of data, loss or misuse. The government would surely have to supply one for once my data, collected and stored without my knowledge, is lost or stolen or abused how can such a situation be retrieved. I have only one data constellation which is mine and mine alone and which to many external bodies identifies me as me.
- It is the duty of government to protect me. In this proposal it fails so fundamentally so to do that one wonders where it is taking advice and on whose recommendations it is relying when there is disinterested expertise available on up to date secure methods of achieving the government goals of making life simpler for the citizen by provision of appropriate services and collection of taxes.
- It would be possible to achieve the stated aims using authenticating agencies. Data can be requested of the citizen which satisfies the questioning agency with information when required, proportionately, as appropriate and securely and does not leave them and all their information exposed. Such a system would enable the citizen to retain a degree of autonomy giving them knowledge of what information was being held or used by whom and for purposes.

2) We propose to extend the current ability to trace persons a) who go missing whilst in education and b) who should pay for treatment provided by the NHS.
Do you agree with these proposal set out in paragraphs 12-13?

Yes ☐ No ☒

If No please explain why not?

a) Who are these persons who presently go missing? Why is it necessary for the government to take these particular measures to find them? Parents are legally obliged to ensure their children attend school. How does giving everyone a UCRN and having everyone's personal details and highly
sensitive information stored and linked help in cases where parents do not see that their children go
to school? b) How does having every Scottish citizen's personal details and highly sensitive
information stored and linked help in cases where foreigners have left the country without paying an
NHS bill? I don't understand the proposition. Neither makes sense and I find this and the grouping
together of two very different situations rather disquieting. The particular scenarios the government
has in mind would have to be spelled out clearly as well as how and why exactly this system, above
any other less nationally intrusive method, is the only solution.

3) In order to allow citizens to make use myaccount for a wider group of services
(beyond health and local government), as set out in paragraphs 14-16, we propose
to provide access to the bodies named in draft Schedule 3 (Annex B).
Are there any additional service providers who you feel should be included?

Certainly not. It is alarming that the already named bodies, with access to everyone's linked and
highly sensitive data, number around 100 and include such as Quality Meat Scotland! How can
whoever put this together imagine that any citizen would think that it is in their interests for Quality
Meat Scotland or most of the 100 so far named bodies to have any access at all to the personal data
accessible through the proposed system.

This question underlines the flawed assumptions of both this consultation process as well as the
whole proposal to extend the National Health Service Central Register.

Assuming firstly that the project is worth considering, it seems very dangerous that
“Sharing of information from the NHSCR will continue to be at the discretion of the
Registrar General.” To whom is the Registrar General accountable? Why would this office
have control over the collection and sharing of comprehensive sensitive data on every
citizen?

It seems breathtakingly undemocratic that such a system has been in development for many
years with such a vision and without the sanction of parliament. It seems also somewhat
incongruous, for when proposals for such a data base were last debated, they were
vigorously opposed by the SNP, as that data base was linked to the ID card which was
subsequently abolished.

Further, both the nature of the data base itself and the issuing of persistent, unique
identifiers are surely contrary to the excellent Identity Management and Privacy Principles.

In issuing a UCRN and linking that to a Citizen Account, the government appears to be
taking the ID card a quantum step further, for the UCRN both identifies the citizen and
allows access to services or entitlements.

Apparently changes in data would cascade through the system. It follows, therefore, that
any error would cascade through the system also. In a system designed for access to
services this could have seriously inconvenient consequences and could be very difficult
indeed for the citizen to rectify.

The document states privacy will be safeguarded. It is not specified exactly how this may be
achieved. The intention to enable linking all personal data from the NHS and other sources
like HMRC, DWP, DVLA and the citizen's local authority is not accompanied by any
information on how confidentiality and privacy may be maintained.

Access would be given to over 100 bodies, a number of which have commercial interests. In
the face of the assertion in the document, it defies both IT expertise and common sense to
see how such access could be made properly secure and maintain a person's privacy.

The citizen will have no control on the limits of their personal information recorded and no
control on who can access this personal data nor for what purpose nor over how extensive
the mining of the information may be. Nor will they necessarily know when their data is
mined or about the who, what and why of interrogations.

While the document says access is restricted to necessary information, it does not specify
how or by whom that may be determined. No mechanism is described which would prevent
any person or body, on the approved list, governmental or commercial, proceeding with an
interrogation of personal data nor how the purposes might be restricted.

So there are effectively, presently, no apparent restrictions on what information can be
mined, for what purpose and by whom. There are certainly neither restrictions nor
permissions which have been agreed with the citizens of Scotland nor which have been
debated in parliament and yet the system has been set up for each person's very sensitive
data to be available to linking.

- The picture held will be a picture which is fuller than anyone person could retain of
  themselves or of their own information.
- That makes it very valuable and makes me very insecure. It does not make me feel insecure
  it makes me insecure.
- For without my permission or knowledge, my data can be interrogated and then used by
  organisations, or individuals with access, who have their own agendas which do not include
  my well being, my privacy, my dignity, my autonomy.
- And it is open to and invites criminal activity.
- Mention is made of researchers using the data. Again absolutely no restrictions are
  mentioned. The issue of the use of NHS data in research has been well rehearsed elsewhere
demonstrating that, unless in exceptionally skilled hands, even results published using
anonymised data, in a country of relatively small communities, can easily lead to people
being identified with catastrophic personal consequences.

In this proposal, Government which is responsible for the safety and security of the citizen, seems
prepared to run huge risks with the citizen's privacy, security, identity and access to services.

4) Do you consider that the proposals set out in paragraph 18 are an effective
method to identify Scottish Tax payers?
Yes □ No ☒

If No please describe the approach you feel should be taken.

HMRC already knows where all Scottish tax payers live and work. It would be infinitely less
intrusive for the Scottish government to gain the information from HMRC than to give HMRC
access to every individual's health records.