Health and Social Care Alliance Scotland

Response: Consultation on proposed amendments to the National Health Service Central Register (Scotland) Regulations 2006

25 February 2015

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. It brings together nearly 900 members, including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals.

The ALLIANCE’s vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

Comments

The ALLIANCE welcomes the opportunity to respond to the consultation, given that the responsible and effective collection, management and use of data are important aspects of the delivery of public services in Scotland. Within this context however, we strongly believe that people themselves should have ownership of data held about them, at all points of their journey through accessing health and social care support and services.

We note the proposals outlined in the consultation document to enable certain data contained on the National Health Service Central Register (NHSCR) to be shared with named bodies and for the NHSCR to hold additional postcode data, with the aim of:

- Improving the quality of personal data held within the NHSCR
- Assisting the tracing of certain persons
- Enabling secure and easy access to online services
- Enabling the identification of Scottish tax payers

Whilst these objectives are legitimate in themselves, it is possible that the proposed means by which these are achieved (in sharing an individual’s unique citizen
reference number (UCRN) with public bodies) may have unintended consequences which may have an adverse impact on an individual’s privacy.

For example, the infrastructure created as a result of the proposal could support the linkage of data across almost every Scottish public body, enabling “the bulk processing of vast amounts of personal data across agencies . . . . data mining, profiling or other techniques that would require the whole population’s personal information to be examined more or less simultaneously.” ¹

It is proposed that access to certain aspects of the data held on the NHSCR is expanded to around 100 public organisations across Scotland, which vary significantly in their activity. These include the Care Inspectorate, Scottish Water, Quality Meat Scotland and Caledonian Maritime Assets Ltd. There is a danger that this proposal to expand the sharing of data within the NHSCR to cover such a broad, and for many people who use support and services unfamiliar, audience could compromise the their relationship with the NHS and lead to a greater fear of disclosure of information. This may be a particular concern for people who experience stigma or discrimination, such as people who have mental health conditions.

As a result of the potentially significant expansions in the NHSCR’s use which the proposals represent, we believe that further consideration of the risks or unintended consequences of such a move, and appropriate associated safeguards, is required.

For More Information

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About the ALLIANCE

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.

¹ Open Rights Group, Draft Response to Consultation on proposed amendments to the National Health Service Central Register (Scotland) Regulations 2006

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- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.

- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.