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Conference Abstract

Widening the lens on risk by connecting data, systems and citizens

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Abstract

The need for integrated pathways and shared data across organisations is not in doubt if services are to reduce risk to health and wellbeing, maintain independence and contain escalating health and social care costs. However, there are three challenges in achieving this. The first is how to connect the data that matters across different systems. The second is how to make this useful to front line carers and system planners while staying within the strict boundaries of data protection and confidentiality. The third is securing citizen consent to do this. Where the chancellor has just announced freedoms to manage our own pensions – the NHS still struggles with allowing us to manage and share our personal health data. Care.data has stalled for at least 6 months while NHSE sorts out how to secure citizen consent.

With our partners, Northamptonshire County, we have cracked the first challenge and can share data safely and connect data accurately across health and social care to build a single view of individuals' health, social, welfare and social environment. We are now mining this unique dataset to assess its potential to support service planning and care management. We are also exploring solutions to the third challenge – how to secure citizen consent to share their data. These three areas are outlined further below

Challenge 1 - We have built an Information Governance framework that exceeds ICO requirements. This was achieved using the Xantura IG Bridge – a unique and patented approach that allows data from multiple sources to be shared, matched and pseudnoymised – while retaining its integrity to be reconstituted by the data owner if required. Borough and further health data will now be added.

Challenge 2 - Early analysis on just social care and community health data – no health diagnosis or acute provider data included yet – has provided new insights about the drivers of dependency and service use. These are now being explored to understand the potential for risk stratification, predictive modelling and service design and management.

Challenge 3 - Despite ICO approval, cultural and behavioural barriers are limiting the pace at which health data is being shared. One solution would be a direct local approach to its citizens to seek approval to share data through a simple web-based/mobile option enabling citizens to opt-out. Kaiser Permanente and Swedish experiences suggest opt-out could be low. If successful we

will have repositioned the relationship between the state and the citizen as a partnership – willing to share and contribute data to improve services, shape future services for themselves and future generations.

The County has started with building the new data asset and IG framework for the Frail Elderly group. The next step is to extend this and start to build risk models around priority agendas such as long term residential care and acute dependency. Combined with direct citizen consent "data" will be positioned, valued and managed as a priceless County asset.

Keywords

data-platform; multi-agency; web-based; prediction; consent

PowerPoint presentation:

https://www.conftool.pro/digital-health-care-2014/index.php?page=adminPapersDetails&path=adminPapers&form_id=150
