

Predictive modelling for social care: Next steps workshop

Event report

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In recent years, many NHS organisations have begun using predictive tools to identify which individuals in their population are at risk of a future unplanned hospital admission (Nuffield Trust 2011a). These tools use historic patterns in the population's data to make predictions at the individual level. Recently, Nuffield Trust researchers demonstrated that analogous models can be developed to identify those individuals who are most at risk of starting intensive social care (Bardsley and others 2011). These new models, which are thought to be the first of their type in the world, could help councils and primary care trusts to take earlier action to help people remain independent and stay in their own homes (Nuffield Trust 2011b).

Emergency hospital admission and admission to a care home are analogous, in that both events are typically unwelcome to the person concerned, costly to society, recorded in routine electronic data and sometimes preventable (Lewis 2007). Following the publication of its feasibility study of models that predict future use of social care, The Nuffield Trust was contacted by a number of local authorities that expressed an interest in piloting the new models in practice. This event report summarises the discussion that took place in a 'Social Care Predictions – Next Steps' workshop for these local authorities as well as representatives of the NHS, two universities, and national bodies such as the NHS Information Centre for Health and Social Care, the National Information Governance Board and the Audit Commission.

Predictive models for social care

Predictive risk models for managing health systems were first developed in the United States in the 1990s, and were followed by the construction of the PARR (Patients at Risk of Readmission) and Combined Models in England. More recently, a Nuffield Trust study has shown that it is possible to use the same techniques to predict the start of intensive social care using both health and social care data (Nuffield Trust 2011b).

Background: Nuffield Trust feasibility study

The Nuffield Trust study was funded by the Care Services Efficiency Delivery (CSED) programme at the Department of Health, and analysed data from five sites across England. It used hospital activity information, data from GP systems, community nursing (e.g. community matrons and district nursing) activity and a range of social care data to try to predict, at a person level, the start of intensive social care for people aged 75+ in the next year. Overall, the results showed overall a modest predictive power. One reason for the limited accuracy of the predictions is that social care events are much rarer than unplanned hospital admissions. Another significant limitation was the lack of consistent coding of social care data – particularly social care needs, as opposed to social care activity.

The feasibility study raised a number of information governance issues relating to the use of de-identified ('pseudonymous') linked health and social care data. These information governance issues would rise to the fore if predictive models for social care moved from research into practical use. In particular, there would be issues to resolve about implied consent, about how clients would be notified and by whom, and more generally about how information sharing between health and social care providers should be managed.

Developments in local sites


Each of the local authorities, PCTs and others working with local sites gave a brief presentation about their work or interest in the field of predictive risk modelling for social care.

TCR (Nottingham) Ltd

This software provider has produced a tool that implements the Combined Model and is being used by a number of PCTs. The company is very interested in being able to expand the tool to incorporate social care information. Subject to information governance requirements being met, this type of tool could be used to share social care data with GPs, and certain health information with social care staff.

NHS Kirklees

In Kirklees, the PCT has implemented the Combined Model in 71 out of 72 GP practices via an incentive scheme. The output of the model can be calibrated relative to each individual GP practice population, or each GP consortium or the entire PCT. NHS Kirklees have also developed a 'risk tracker' that monitors the Combined Model score for individual patients over time. For example, the risk tracker provides information to the long-term conditions team of



their community services provider arm. The team includes staff such as community matrons, and specialist cardiology and respiratory nurses.

NHS Kirklees is interested in a possible future project that would aim to link their existing health predictive modelling work with their Care Phone assistive technology scheme. The PCT have identified a cohort of 29 patients from whom they are seeking consent to share their Combined Model risk scores and certain other health data with the Care Phone hub, so that this information is available to staff if an alarm is triggered.

Oxfordshire County Council


In Oxfordshire, the local council and PCT had attempted to build a predictive model for forecasting admission to a residential home or nursing home. Oxfordshire currently spends about £50m per year on residential and nursing home places for older people, and have about 500 new admissions to care homes each year.

A case record review, which was conducted by the Institute of Public Care in 2009, identified a number of conditions that were frequently associated with admission to residential care. These included dementia, stroke, incontinence and depression. Based on this work, the council and PCT pooled together pseudonymous social care data and hospital data for their population spanning a two-year period, which they used to try to identify variables that were predictive of admission to residential or nursing home care in the third year. They tested various models and the results showed that the predictive model was significantly better than chance, but less accurate than the predictions made by models such as PARR and the Combined Model for health care. They also noted that 25 per cent of new admissions were for people who had no contact with social services prior to admission to residential or nursing home care.

Oxfordshire identified three major problems with their attempts to build a predictive model for social care. Firstly, they were trying to predict a rare event, which makes modelling more difficult. Secondly, several factors that are known to be predictive, including incontinence, bereavement and social isolation, were poorly recorded in either health or social care. And finally, a key limitation was that social care data were predominantly activity-based rather than relating to social care needs. Oxfordshire County Council is now moving to a model based on personal budgets and self-directed support. They hope that this will lead to a much richer pool of data on social care needs but they recognise that it will take time for this to develop.

Sheffield City Council

Sheffield Council is at the early stages of this work, but is keen to explore it further. Using care register information, they have developed a predictive model to identify patients with a learning disability who are living with an older carer who is at risk of admission to residential care. The council use the predictions to target 'upstream' interventions to plan for moving on from living with the older carer and thereby reduce the costs arising from emergency admission to residential care by the person with a learning disability.



The council have also begun to do some work with GP practices on predictive risk modelling. They are using this in a project called In Sight In Mind, which targets people who have been identified as being at risk. Such people are offered signposts services, and are given support to build community capacity and to help people develop new social networks. One insight that has come out of this project is that many local GPs were unaware of which of their patients were receiving assistance from social services.

Sheffield City Council can see wider significant benefits from being able to link health and social care data pseudonymously. For example it could be useful in strategic planning, and in analysing the health and social care provision, including continuing healthcare, and a ‘whole lifespan’ analysis of children, young people and adults with a learning disability. In order to support such analyses in the future, the council is currently putting together a business case to promote the routine recording of NHS number for all social care clients. The council also strongly supports the idea that personal budgets will offer better data on expenditure, which should lead to more accurate data for modelling social care needs.

Essex County Council

In Essex Council, there are two ongoing projects using predictive risk modelling: one is looking at admission of adults to residential care or the start of intensive home care; and the other is using a similar approach to try to predict at age 14 those vulnerable children who are at risk of becoming NEET (not in education, employment or training) by age 18.

Their predictive modelling for adult social care uses social care data and demographic data, as well as household factors from the Mosaic™ database. Health data are not currently incorporated. Initial results showed a very high false positive rate of around 90 per cent. However, the analysts found that by altering the dependent variable to include high-cost home care they could improve this to around 70 per cent, which they hope can be improved further with the inclusion of pseudonymous health care data.

Their work on NEETs incorporated data from the police and criminal justice systems, school census data as well as social care information, which they were able to link successfully at the individual level. They noted that currently the model lacks some very important information, such as parental criminal history, and whether or not they have a sibling who is a teenage parent. They have begun to think about how this type of predictive modelling could be used in practice, and have arranged a meeting to discuss data security and sharing with the local Caldicott Guardians and the senior information risk officers (SIROs) from various organisations in Essex.

Lincolnshire Council

In Lincolnshire, the council is in the very early stages of looking at how predictive modelling techniques might be applied to social care. One GP cluster is currently using the PARR tool, and NHS Lincolnshire is hoping to introduce the Combined Model in the county in the near future. They are involved in a new initiative called Place-based Data Sharing, which aims to improve data sharing and reduce duplication.

Wiltshire

In Wiltshire, the council has built a new social care information system partly to address the fact that the existing social care information system was poor at collecting the types of codified information that might be useful in predicting admission to a residential home or nursing home. However, social care practitioners were generally reluctant to record these sorts of data as they do not see the immediate value.

Croydon Council

The final presentation of this part of the workshop was given by Croydon Council, which was one of the sites that provided data for the Nuffield Trust feasibility study. Although the predictive power of this model was limited, the council still felt it had the potential to be very useful. The council is particularly keen to identify people who are not currently in contact with social services. So they applauded the aim of this sort of work, which tries to identify people early and start rehabilitation and recovery, and thereby avoid admission to residential or nursing home care.

Other points raised by Croydon included:

- Local occupational therapists work as part of health services although they are often employed by the council. As a result, they have access to both health and social care information.
- Using routine data to allocate budgets can help improve the quality of what is recorded.
- GPs are a key audience to engage about this work but they can sometimes be sceptical about predictive modelling, as they may feel they know their patients better than any computer model.
- NHS Croydon has been using the Combined Model to identify patients for admission to a virtual ward (Lewis 2010); however, from Croydon Council's perspective this does not appear to have increased demands on social care or costs – if anything the reverse may be true.

Perspectives from universities

University of Westminster

Professor Thierry Chausalet, from the Department of Business Information Systems, explained that his research group has been working on a range of projects relating to predicting hospital length of stay and costs of long-term care. He runs a number of short courses teaching these techniques, and is in the process of developing some new courses. He is also interested in ‘pathway mining’, a technique that follows patients on their journey through the health and social care systems.

New York University

Professor John Billings, from the Robert F. Wagner Graduate School of Public Service, made two suggestions for improving the accuracy of predictive models for social care. First, he argued that either social workers or GPs should be incentivised to record routinely whether or not a person has a close family member living nearby. Survey data has shown that this piece of information is a strong indicator of social support but it is not currently routinely recorded either in health or GP data.

His second suggestion was based on the point that predictive models generally use two years’ worth of data (year $t-1$ and year $t-2$) to predict an outcome in the third year (year t). The greatest amount of influence is exerted by activity in year $t-1$, but this tends to drown out information from year $t-2$. So it might be interesting to ignore year $t-1$, and use instead information from years $t-2$ and $t-3$, to see what effect that had on the accuracy of the modelling.

In the United States the social care system is very different to the UK, with care for low-income families funded by Medicaid. To date, little work has been done to model social care in the US, yet with the enormous costs of long-term care facing Medicaid it is likely that such work will take place at some point.


Perspectives from national bodies

Audit Commission

The Commission is currently conducting a Value for Money review of adult social care and is planning to produce three short reports over the coming months, one of which is focussed on the interface between health and social care. The reports will focus on how to make best use of good-quality local data, and highlight gaps, for example in the capture of information about incontinence.

Information Centre for Health and Social Care

The Information Centre for Health and Social Care (IC) has been compiling a list of concepts and models about social care informatics in order to support current policy initiatives. This has led to the development of the concept of the ‘Adult Care Support Record’. Documents relating



to this framework will be published in the near future on the websites of the IC and the National Adult Social Care Intelligence Service (NASIS). It is important to note that the framework is not focussed solely on social care, but is intended to cover broader information about wider community support. It is envisaged that it will include all people who may need care support, including people who are self-funding their care, and people who have yet to receive support from social services.

Other ongoing work includes:

- A project to develop an ‘information architecture’ for self-directed care; this will be published in the near future.
- Further development of the NASIS website, which the IC is keen to promote as a portal for disseminating information.
- Review of social care data collections, where the aim is to create a core dataset for adult social care. This may consist of three datasets: a person-level dataset, a dataset focussed on investment in prevention and support, and a dataset on the local market. The aim is to use this to move towards a data dictionary for adult social care and to move from aggregated annual returns to person-based returns. This would enable health and social care data to be brought together in a managed way.


Department of Health

The Department of Health is very interested in the sorts of predictive models that the Nuffield Trust developed for the feasibility study funded by CSED, and had acknowledged the issues encountered in linking together health and social care data. A White Paper on data transparency is due to be published soon, and it is possible that some of these issues might be addressed through that White Paper.

National Information Governance Board

The use of pseudonymously linked data for predictive modelling is a secondary use of data that does not require identifiable data. However, any processing or use of identifiable data must be lawful – which means that either consent has to have been given, or that there is a legal statute covering its use. Anyone sharing identifiable data between health and social care without consent would be open to a case under a breach of confidence or a breach of data protection.

In practice, the use of predictive risk modelling that shares health and social care data would require consent from individuals for the use of their data. This consent may be explicit or implied. The pilot sites for the Common Assessment Framework (CAF) are a good example of a consent-based model for data sharing between health and social care, and generally people have been found to be very supportive of data sharing when it is done in this manner.



The National Information Governance Board (NIGB) is currently drafting new guidance on the use of data for predictive modelling and risk stratification data.

There is an ongoing programme to implement use of the NHS number in both health and social care data, although it is not mandated in social care data at present. More recently, an agreement has been reached to allow local authorities to access the 'N3' NHS network and to run applications on the network via the Government Connect Secure Extranet (GCSX).

Discussion

The discussion centred mainly on information governance issues, although there was also some discussion of additional predictor variables and the ways in which social care data are coded.


Information governance

The discussion began considering how the results of predictive modelling techniques could be used in practice. A question was raised about whether or not it was appropriate to carry out predictive modelling using pseudonymous data, and then re-identifying patients and approaching those people with a high risk score. It was suggested in response that a much safer method would be to seek to gain consent to information-sharing from people in advance, so that people can choose to opt out. The point was also made that health care and social care organisations are often very bad at informing people what data is held about them, for how long and how it is used. It was argued that data sharing would become easier if health and social care were to be more up-front about the range of possible secondary uses of their data.

A question was asked about what health data may be useful to social care and *vice versa*. It was pointed out that any information-sharing should be subject to the Caldicott principles, and would be decided on a 'need to know' basis, which would differ from one individual professional to another.

It was asked whether the risk prediction tools could be put online so that people could run these tools themselves, or as a tool that social workers or other professionals could use when they meet clients. One drawback might be 'selection bias', whereby those people who were most likely to benefit might be the least likely to use the tool. In contrast, population-based models such as those developed by the Nuffield Trust can be at scale.

A question was asked about whether GPs should be allowed to see hospital data as used in the Combined Model. In response it was said that the reasonable expectation was that GPs would be expected to have access to those data, in order to provide ongoing treatment. There might be about accessing data about mental health issues, genitourinary clinic attendances and fertility treatment. It was argued that it was all about handling data in ways that people would expect. However, it was also noted that treating certain conditions (mental health, sexually transmitted infections etc.) differently runs the danger of perpetuating social stigma.



It was asked whether expectations in care trust areas, such as Torbay, would be different to those in areas served by primary care trusts. It was stated that the legal frameworks are slightly different, but that individuals should still be consulted about what information could be shared between health and social care, since GP and social care records may often contain detailed personal or financial information that people may not want to be shared. It was noted that people are generally happy for information to be shared with people involved in their care; the important thing is to explain how their information might be used or shared, so that they can understand and be clear about what happens to their information.

A question was asked about whether there was guidance on how to try and obtain people's consent or inform them about how information is shared? The response was that it is a combination that involves telling people about the types of services that are available and how they are managed.

Additional variables

It was suggested that data on incontinence could be obtained by linking with equipment suppliers and pharmacy data. One council noted that when they approached GPs to talk about redesigning incontinence services, they were told that it was not a problem, despite there being significant evidence to the contrary. It was also noted that incontinence services were dispersed with no overall ownership.

Social care coding

One aspect of the ongoing work by the IC in developing a core dataset for adult social care would be in the profiling and categorisation of cases. This will present an opportunity for interested users to suggest markers (such as incontinence) that should be captured and made identifiable in the data. In response, it was noted that diagnostic information is not always what is required, but rather information about function and need. For example, capturing information about factors such as bereavement and social isolation is often vital. The World Health Organisation (WHO) international classification of functioning might be a good place to start, but it will also be important to record data on functioning and diagnosis.

Conclusions

This is clearly a fast-moving field, in which there are many exciting developments expected at both the local and national levels.

Local developments

In 2012, the Nuffield Trust plans to hold another Four Nations Predictive Modelling Summit. This conference will be an opportunity for us to showcase how predictive models are being used across the UK, and we very much hope to include a number of social care case studies.

Information governance developments

As this workshop has demonstrated, several PCTs and councils across England are working to introduce predictive models into the field of social care. Clearly it will be important to ensure that these ambitious plans are fully compliant with the relevant information governance requirements. In 2006, the Patient Information Advisory Group (PIAG) of the Department of Health produced detailed guidance on this important topic (PIAG 2008). This guidance has proved invaluable over the last few years. However, the PIAG guidance is now becoming due for an update to reflect more recent developments in the field of predictive modelling in general, and predictive modelling for social care in particular. It is therefore very timely that PIAG's successor, the National Information Governance Board (NIGB) is planning to publish updated guidance.

Nuffield Trust projects on predictive risk and social care

In the coming months, the Nuffield Trust and our partner universities will be publishing our findings on the following related projects:

- Whole System Demonstrator (WSD) randomised controlled trial of the impact of telehealth and tele-care devices on the use of health care and social care services.
- How can private long-term care insurance supplement state systems? A research project funded by the AXA research fund.
- Use of social care services at the end of life.

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59 New Cavendish Street
London W1G 7LP
Telephone: 020 7631 8450
Facsimile: 020 7631 8451
Email: info@nuffieldtrust.org.uk

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