

Applied social care research using routine data: potential and challenges

10 December 2020

Event report



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Introduction

2020 has been a transformational year for many areas of health and care, with widespread changes and increasingly rapid advancements in the way we use health and care data in order to tackle COVID-19. In particular, as a result of the pandemic, there has been an unprecedented level of interest in improving social care and gaining a better understanding of social care delivery, including drivers of infection risk in care homes. Moreover, there has also been recognition that whilst children may be at low direct risk from the pandemic, their collateral risk is high – particularly for those children who were already most vulnerable.

On 10 December 2020, over 150 members of the social care data science community – including academic researchers, care providers and receivers, commissioners, and charities – came together virtually to discuss the current landscape of applied social care research. Attendees shared experiences of significant insights and impacts which have already been realised by research across the spectrum of social care services, as well as the key challenges which must be addressed to maximise impact and emerging opportunities for the future.

The meeting was convened by [Health Data Research UK](#) and the [NIHR Applied Research Collaboration \(ARC\) West](#), a member of the [Better Care South-West Partnership](#). ARC West also provide national leadership around applied health and care informatics across the ARC network.

‘It has become clear that social care is a vital part of health and care research.’ – David Seymour, Health Data Research UK

Key themes

Public and patient involvement and engagement must be at the heart of research

Good quality public and patient involvement and engagement (PPIE) in the design, delivery and communication of applied social care research is not only an ethical necessity, but also improves the quality of the research, leading to high value insights which can be applied to maximise impact. Engagement with care recipients is a fundamental foundation upon which to build trustworthy systems that deliver an excellent service which people feel they can rely on.

To derive the greatest benefit from PPIE requires time and effort to fully inform any participants, gather their feedback and engage them in research delivery. It is essential that researchers tailor communications to make their research accessible, both to PPIE representatives directly engaged in the project, and to the broader community receiving social care.

‘When we say routinely collected data – it’s not necessarily routine for the individual... Every data point is an event that is meaningful for an individual.’ Debbie Keatley, HDR UK Public involvement advisory group member

Research into social care has advanced enormously over the past year

The COVID-19 pandemic has acted as a catalyst to improve the use of data and research in the delivery of social care. Rapid development has occurred in care homes due to the devastating impact of COVID-19 in these settings, with a spotlight being shone on the many opportunities for the use of data and research to improve care. This progress generates a great opportunity to enable changes which benefit both care recipients and providers for the future.

Many projects highlighted during the meeting started as a result of the pandemic, or accelerated significantly over the past 9 months. For example, NHS Digital launched the [Care Management Systems C19 Dataset](#) in July 2020 after an initial pilot in March. This dataset collects information from digitally enabled care homes who are members of [CASPA](#). In its earliest state, the dataset collected data on care home residents and care providers, documenting cases of suspected or confirmed COVID-19, with the data being used to help policymakers understand the spread and severity of the virus in care homes. The project offers great potential for future research by establishing a proof of concept for national data collection using care provider information systems, as well as overcoming many of the key information governance barriers for data sharing in the care sector.

Other projects shared, such as the DACHA (Developing resources and minimum dataset for Care Homes’ Adoption) project led by NIHR East to develop a minimum dataset for care homes. This began before COVID-19 had yet impacted the UK, but their importance quickly grew in the context of the current crisis.

‘For its first 2 months, DACHA was a niche project. We don’t need to persuade anybody now of the need for health and social care data in care homes.’ - Claire Goodman, DACHA project

The [HDR UK Better Care South-West Partnership](#), which launched in May 2020, shared their work to deliver the 'IPACS' project: Improving Patient flow between Acute, Community and Social Care. This work addresses the issue of Delayed Transfers of Care (DTCs), where patients are ready for discharge from acute care in hospital and are not able to be promptly discharged, usually due to capacity in community and social care settings. Amongst other issues, DTCs lead to over 500,000 acute care bed days lost annually, costing £820 million each year. Whilst this work had been in the pipeline before the COVID-19 crisis in the UK, the importance of understanding the flow of patient care has become of even greater importance to the wider health and care community as a result of the recent pressures on health care standards.

Social care data is fragmented, but there is huge potential in further data linkage and improvement in interoperability

Social care data is, in many ways, even more fragmented than health data. Different types of data are collected by social care providers, and there is very little data on those who have self-funded their care. The fragmented nature of data makes interoperability a major challenge for applied social care research. For example, one third of care homes are small private sector businesses, meaning that the data they collect and types of software used vary enormously. Even beyond these examples, many providers are not digitally enabled with no electronic data capture which provides an additional barrier.

Ongoing work is tackling the challenges to link data across areas such as health care, local authority data, care payments, primary and secondary care, emergency care and many more. Researchers at SAIL Databank in Swansea and at Queen's University Belfast shared examples at the meeting of collaboration with systemwide colleagues to link data, including information on areas such as looked after children or family law proceedings. SAIL Databank, for example, recently acquired data on looked after children between 2016-2018 and the Children Receiving Care and Support Census 2010-2018, with the help of [Administrative Data Research Wales](#) (ADR Wales). This data is then linked using Unique Pupil Numbers, facilitating new insights into children's social care delivery.

The NIHR East DACHA project is linking routine social care data with primary and emergency care, local authority, and hospital data to provide a more complete picture of care home residents. The project has garnered a great deal of enthusiasm, with 60% of the care home population now covered through the [Integrated Care Systems](#) (ICs) involved in DACHA. The study aims to create a minimum dataset for care homes over the coming months, through synthesis of existing evidence and data sources with care home generated resident data.

Advances in data linkage and interoperability are helping researchers to build a complete picture of patients' health and care journeys, which will be critical to improve social care delivery in future. Current barriers include: the range of custodians that hold social care data and their varying degrees of digital enablement; inconsistent use of identifiers in data, which hampers linkage; the varying types and quality of data recorded, leading to interoperability challenges; and information governance barriers and concerns around the sensitive nature of this data, raising questions appropriate research access. The last year has not only emphasised that it is crucial we overcome these challenges, but also demonstrated what can be achieved when these challenges are addressed successfully and in a trustworthy manner.

‘The really exciting analyses come when you combine bespoke experimental studies with routinely collected or administrative data.’ - Julian Forder, NIHR ARC Kent, Surrey and Sussex

Reducing data collection burden for care providers is crucial

A key challenge to routine data collection raised by several speakers is that social care staff are already stretched, and that the existing IT infrastructure is more limited than comparable systems in the healthcare sector. Persuading both social care management and carers themselves to participate in wider studies can be very challenging given the pressures they already face. Data collection, therefore, needs to be simple, quick and integrated into existing care delivery as much as possible.

This challenge also presents an opportunity for the social care sector to learn the lessons from healthcare, and develop a data collection strategy which minimises additional burden, whilst also proving integral to care provision, by being used directly by care providers to inform their services.

NHS Digital and everyLIFE Technologies shared details of their collaboration on the NHS Digital Care Management Systems C19 Dataset. The system was used by care home providers who were already recording details of care digitally rather than on paper, and processes were embedded as part of the provider’s daily tasks, streamlining integration into existing care routines. However, even getting care homes to opt-in to be part of this study when they were already stretched was still a challenge, and the variation in consent from care homes did lead to gaps in coverage, therefore requiring weighting of the aggregate data.

A study from UCL using [administrative data to investigate the burden of COVID-19](#) on care homes also addressed this challenge. Whole care home testing was not rolled out until after the first peak of the pandemic, so the study also examined suspected cases and mortality rates as reported by the care homes they worked with. The study was able to provide unique insights through close collaboration and use of routine data collected by the care homes involved, and the study emphasised the importance of engaging care providers throughout the design and delivery of research to ensure its success.

Initially this dataset included 30,000 care givers and just over 30,000 care receivers – a small fraction of the 400,000-plus care home residents across the UK in total, but a large enough asset to enable research. Given the short time frame in which this programme was implemented, the pooled data from the care providers that opted in was impressive in its scale and, at least in the UK, unprecedented. Initial quality checks indicate that the data capture processes are accurate and reliable, correlating well with other datasets. The dataset has been continually updated since its formal launch in July and covers social care delivered both privately and by local authorities. The biggest benefit from the care providers’ perspective, however, was that it did not increase the burden of work for the staff at an already difficult time.

The use of children's social care data to drive better care must also be improved

Care home data and research has, for good reason, been in the spotlight this year, however it is essential that we do not neglect research into social care for children and young adults, and must ensure that lessons across both areas are shared and applied.

Research using routinely collected data in children's social care is in many senses in its infancy. In England research has mainly focused on the national datasets derived from statutory returns on looked after children and children in need. This research has mainly been descriptive. Some local authorities, such as Bristol City Council, have linked data from multiple sources to construct indices of vulnerability to guide targeting of resource and intervention for children and families at greatest risk.

In Wales, the SAIL databank has also made headway in this area. Whilst SAIL originally only held health data, it has now been extended to include administrative data and is therefore able to provide linked datasets in some research areas, for instance those that are subject to family law proceedings and data from [CAFCASS Cymru](#). The data held by SAIL includes children known to social services but not deemed in need of social care intervention, as well as those in the care service, generating greater potential for studies into the impact of different social services pathways. Unfortunately, the databank currently has limited information on children in certain demographics, such as those under 4-5 years old.

Administrative Data Research (ADR) Northern Ireland and Queen's University Belfast are also studying the impact of different forms of social service interactions on children, specifically the impact of care proceedings on the mental health of children known to social services.

Similar challenges exist for children's social care research as with other areas of social care: data collected is inconsistent, of varying quality, held in many different places, and requires linkage. All these considerations contribute to the challenge of moving from the descriptive to the aetiological and a better understanding of how to effectively improve outcomes.

It is also not always possible to build a full picture of a child's health and care experiences because certain data does not exist or is inconsistently completed. For example, in the ADR Northern Ireland and Queen's University Belfast study, a key challenge faced by the team is the lack of data on non-pharmacological interventions in mental health crises for children known to social services. The mental health impact of social care interventions is crucial to understanding the effectiveness of children's social care delivery, and a priority for the research team in the future.

'Really, what we need is more empirical evidence to support what these studies say, but the message hasn't come through to policy relating to children in care yet.' - Aideen Maguire, Queen's University Belfast

Summary

The past year has been transformational for many areas of social care research. Use of routine data in applied social care research may be in its infancy when compared to applied health care research, however, progress is accelerating rapidly – as demonstrated by the many projects presented at this event.

It is very promising that significant advances have been made over the past 12 months, and that the importance of research into care homes in particular has been highlighted. One benefit to the challenges of 2020 is, perhaps, that it has stimulated many unprecedented changes to the social care research landscape and demonstrated how much can be achieved in a short space of time.

Many of the obstacles faced by social care research mirror those in health care, but are currently more exaggerated: fragmentation of data, inconsistency and interoperability, information governance, and the changes in working practices needed to collect this routine data effectively in the first place. There is opportunity for the social care sector to use some of the lessons learnt from the health sector in addressing these challenges, whilst also adapting to the unique challenges it faces.

Moreover, as in health, it is also vital that we continue to involve patients and public in designing, delivering and communicating research – not simply as a tick box exercise, but to help us shape research to which delivers the greatest possible impact and benefit to care providers, care receivers, commissioners, policy makers and the public.