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Contextualising data work in Healthcare: A preliminary analysis of the Care.data project

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Abstract. Drawing on a sociology of medical work perspective, this paper offers a framework and empirical example for understanding how the processes of data work in healthcare can be significantly affected by their structural conditions—with unforeseen consequences. During 2012 the UK government and National Health Service (NHS) initiated the care.data project. The purpose of the project was to establish a database containing data linking patients' interactions with the NHS (e.g. referrals, clinical data, prescriptions, treatments) across all care settings. The analysis of this information would enable clinical commissioning groups researchers and others, to increase both the clinical effectiveness of the NHS and its economic efficiency. In 2016, after multiple delays and mounting criticism, the care.data project was officially abandoned. Based on the framework and empirical example, the conditional path that led to the controversy and abandonment of the care.data project is reconstructed. In a conclusion, it is suggested that, in order to be productive, processes of data work in healthcare should be placed in the context of their structural conditions and anticipated consequences—a role that can be undertaken by CSCW.

The care.data project

The CARE.DATA project was a UK National Health Service (NHS) project that ran from 2012 to 2016. Its proximate beginnings can be traced to the decision taken by the NHS Commissioning Board to implement a system for extending the scope of the NHS's patient data collection. The system would combine existing secondary Hospital Episode Statistics (HES) with new person-level primary care data to form Care Episode Statistics (CES). In this way data on individual patients' interactions with the NHS would be linked across treatment pathways, thereby enabling clinical commissioning groups researchers and others to increase clinical effectiveness, to make economic efficiencies, and to widen patient choice.

The CARE.DATA project's more distant beginnings can be traced to the provisions of the Health and Social Care Act 2012 (HSCA). Among its provisions, the HSCA established the Health and Social Care Information Centre (HSCIC). The function of this centre would be to act as a central resource for information on the NHS, with legal powers to implement information systems, and to require and request the provision of information from health, social care bodies and others. The technical aspect of the project's work was to be performed by the General Practitioner Extraction Service (GPES). This would extend its existing collection of aggregate data to incorporate the uploading, by GPs, of individual patients' referrals, clinical data, prescriptions, treatments and other personal confidential data (PCD). Linking of the data in the care.data system would be performed automatically, and without human intervention, via the use of a computer algorithm that would match the GP data with information from other care providers. Once a new medical record had been created, any PCD used in the matching process would be de-identified and replaced with a code.

A number of groups were directly relevant to the work of the CARE.DATA project. These bodies included: the Care.data Programme Board who were responsible for commissioning, managing, and evaluating the different sub-projects involved in implementing the programme including the selection of testbed 'pathfinder' GP surgeries; a Care.data Advisory group charged with communications and public awareness; a GPES Independent Advisory Group (IAG) providing oversight of the routine work of the GPES, along with approvals of non-routine customer extraction requests. Other bodies indirectly relevant to, but highly signifcant for the course of the project, included the National Data Guardian (UK Gov, 2013, 2016), and the establishment of an Independent Information Governance Oversight Panel (IIGOP). In July 2016 the CARE.DATA project was officially abandoned in a communication by the Under-Secretary of Health to the UK Parliament (Freeman, 2016).

Conditional/consequential matrix

Why was the CARE.DATA abandoned? What conditions were operating at the time? How did these conditions manifest themselves in the interactions and processes of the project? With what consequences? The purpose of the conditional/consequential matrix (Corbin and Strauss, 2008; see also Foster, 2016) is to understand how everyday 'micro-level' interactions and processes related to the phenomenon of interest are affected by 'macro-level' structures, and vice-versa. In doing so, the roots of social change and social order can be accounted for. In order to understand the various conditions in play, e.g. legal organisational sub-organisational and group, and how these affected the processes and interactions of the CARE.DATA project, a brief outline of the main tenets of the matrix are outlined. Taken as a whole the matrix consists of a series of concentric circles. At the core of the diagram sits the phenomenon of interest, which in this case is data work. Arrows pointing towards data work indicate the antecedent conditions or structures that shape action and interaction around data work. Arrows pointing away from the phenomenon indicate the consequences emerging from actions and interactions around data work. Beginning at the outside of the matrix, there are international, national, community, organizational and institutional level conditions; then sub-institutional, group levels. Before finally arriving at the interactional and data work levels. Use of the conditional/consequential matrix then gives rise to a coding paradigm that explores why an event happened, what the conditions were, how these conditions manifested themselves in interactions, and what the consequences were. This framework and coding paradigm are used to inform a preliminary analysis of the CARE.DATA project, via a re-construction of the conditional path that shaped its interactions and consequences.

The care.data project in context

Any re-construction of the CARE.DATA project's conditional path, and of the different levels through which it passed, would need to take account of at least the following conditions. At a national level: a) The legal prospectus on which the project was based was at best confusing and at worst conflicting. On the one hand the UK Data Protection Act 1998 establishes i) the principle of fair processing, in this case the processing of PCD by the NHS if it is in the interests of the individual patient; and ii) the patient's legal right to prevent processing likely to cause damage or distress. On the other hand the HSCA 2014 establishes a constitutional right that enables the NHS to process information fairly in the public interest, while also enabling patients to object to that processing. While the interpretation of term public interest is open to question, only an informal and not a formal procedure for this objection was apparent during the lifetime of the project (b) An assumption the general public would view information sharing as an altruistic act; without taking into account the reasoning of individual members of the public about the consequences of processing their PCD. At a community level, the legal and ethical situation was perceived by a significant number of GPs to be unclear; while communications and public awareness were not sufficient to allay the general public's concerns over security and onward processign to third-parties. At an organizational level, the government's economic objective to reduce bureaucracy fed into a history of information sharing vs. patient confidentiality in the NHS; tipping the scales in favour of information sharing. At the sub-organizational level, the division of the NHS into secondary and primary care brought the legal accountabilities of GPs into sharp relief, generating uncertainty around the uploading of their patients PCD. At a group level the social worlds of government, NHS institutions, the medical professions, GPs, and the general public—and how they might be traversed—was not sufficiently taken into account. These structural conditions manifested themselves at the interactional level in the form of a series of significant project delays; and interactions, aimed at articulating CARE.DATA's different sub-projects and at establishing the rights of those involved. In other words, the project gave rise to a conflictual social arena, the lack of a resolution to which led to its abandonment. Had greater attention been paid to this social context this abandonment may have been averted. Indeed a review of the course of the CARE.DATA project demonstrates a structural bias towards legal and institutional conditions that promoted its value, without fully taking into account the range of anticipated and emergent interactions that would be required to mitigate its risks. In summary, the CARE.DATA project illustrates how data work in healthcare will require attention not only to the data aspects of 'data work', but also to the work required to locate data work within the sociological context of its antecedent conditions and anticipated consequences. The role of CSCW will be to support the interaction between the two.

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