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FAMILY PRIVACY, FAMILY AUTONOMY AND COERCION IN DIGITAL HEALTH

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Digital technology is increasingly being used to support children's health. Expectant mothers may be pressured to use pregnancy trackers, to monitor their health, to prioritise their unborn child's well-being (Neely and Reed, 2023) and 'to conform to the ideal of the "digitised reproductive citizen" (Lupton, 2020, 399). Parents of new-borns are similarly offered, and encouraged to use, an array of digital health tools (Ball and Keegan, 2022; Bonafide Jamison and Foglia, 2017; Langton, 2023). Many older children also wear smart watches monitoring their activity and sleep, with the World Health Organisation highlighting the potential such wearable devices have for tackling a worldwide need to increase physical activity, particularly in adolescents (WHO, 2018).

The monitoring of children's health and wellbeing is not new; Lupton and Williamson (2017, 783) recognise that '[c]hildren have been subjected to close monitoring as part of the government of childhood for centuries in an attempt to promote their health'. What is different is the breadth and depth of such monitoring and the way such information is used. As many researchers recognise, children are increasingly datafied; our society is one where the digital is viewed as 'the norm' (Barassi, 2019). Whilst much academic focus has been upon the role of big tech in this caring dataveillance (Lupton, 2020; Barassi, 2017), the state is also involved in the coerced datification of children (Barassi, 2020; Bessant, 2022).

This paper uses family privacy theory and dataveillance literature as twin lenses through which to explore the state's use of telehealth technologies to support children's healthcare, and the contribution such technologies are making to children's datafication. These issues have received little consideration in the literature.

Family privacy

Family privacy is an important ideology which emerged in the nineteenth century. It still informs legal and political understandings of the family, and influences laws governing

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the family's relationship with state and society (Diduck and Kaganas, 2012; Fineman, 1999; Hayes and Higgins, 2014). Respect for family privacy is commonly understood to entail state non-intervention in ordinary family life (Fineman, 1999; Kim, 2006, Woodhouse, 1999). Some scholars, however, recognise that family privacy may be more widely understood to entail family autonomy, or a right to determine matters relating to the family (Cahn, 1999; Bessant, 2023). Such a perspective is evident in England's Children Act 1989, which introduced the notion of 'parental responsibility', confirming that 'it is parents, rather than the court or the state, who take primary responsibility for their children's upbringing and who are the primary decision makers in matters concerning children's welfare' (Re W, 2012). Family privacy can also be understood to afford parents control over family information, and a right to determine how children's information is used (Berardo, 1999; Bessant 2023). An understanding of parents as protectors of children's privacy underpins the UK and EU General Data Protection Regulations whilst the parental role as protectors of children's rights and interests is recognised in Articles 5 and 18 of the United Nations Convention on the Rights of the Child. The UNCRC itself explicitly affords children rights, including a right to privacy and a right to be heard on matters affecting them (Articles 12 and 16).

Digitalisation in children's healthcare

Whilst an extensive body of literature considers the privacy implications of commercial apps designed to support parental monitoring of children's wellbeing, far less consideration has been given to how state healthcare bodies use technology to support children's care. That state healthcare professionals may encourage or coerce parents to engage with digital technologies is highlighted in Katrin Langton's (2023) work on Australian breastfeeding apps. Langton identifies an expectation that parents will 'perform good responsible parenthood through datafication as a form of health monitoring' and a potential privileging of technology and the data it produces over parent's own knowledge and experience. Such a focus upon data over knowledge contrasts with the basic tenets of family privacy ideology, which understands that parents are uniquely positioned to prepare their children for life, to protect them, educate them, meet their needs, and guarantee their rights (Peterman & Jones, 2003; Moller-Okin, 1989). It could also be argued that this privileging of data over parental knowledge and experience and an expectation that parents agree to use of technologies which impact upon children's privacy conflicts with traditional understandings of parents as the best people to make decisions regarding their children.

To develop understanding of how digital technology, particularly telehealth and remote monitoring technology, is used in paediatric healthcare across England, freedom of information requests were additionally sent to 42 Integrated Care Boards (ICBs) and 38 NHS Trusts between August and October 2024. Further information was gathered from the NHS Transformation Directorate's website. 16 ICBs and 18 trusts confirmed that telehealth is used to support paediatric healthcare in their area and, more specifically that monitoring technologies are being used, many collecting extensive amounts of data about children. Technologies being utilised include virtual wards (where patients may be reviewed using video technology) and apps, wearables and other medical devices which monitor patients' vital signs (UK Authority, 2023). For example, the myMobileapp

is used by some child patients with Anorexia Nervosa to monitor vital signs and to record answers to symptom related questions (Tunstall, 2022), the patientMpower app is being used for remote monitoring some children with cystic fibrosis (NHS England, undated) and diabetes monitoring systems offered by Dexcom, Libre and Glooko are also widely used.

Such technologies afford benefits both to the NHS and to families, enabling patients to monitor physical symptoms and recovery without the need for face-to-face contact, maximising the effective use of NHS staff resources, reducing the risk of hospital-acquired infections, reducing travel costs and minimising disruption to schooling or parental employment. Such, digital monitoring nonetheless has potential to reshape assumptions about good parenting and to exacerbate existing concerns around the coerced datafication of children.

Key issues

The UK General Data Protection Regulation provides a valuable framework for exploring what transparent, lawful and fair use of children's data entails in the context of digitised healthcare. It explicitly obliges data controllers (e.g. trusts) to provide child data subjects or their parents with information about how and why their data is being used. Documentation provided by trusts reveals, however, that children and their parents are often not told by the NHS how such technologies use patient data. As one trust explained, it is for patients or their parents to review the privacy policies that explain how these technologies use patient data.

Important questions are raised about how the NHS could better support parents and children to understand the implications of these technologies for children's privacy. Parents have a key role to play as children's privacy stewards but are not being supported by the state to effectively fulfil this role. Where health professionals encourage child patients' parents to register with health technology providers but do not inform them how children's data will be used, the parent's role as steward of the child's privacy is diminished. One might argue that the state is coercing parents into facilitating children's datafication.

This paper ultimately argues both for greater acknowledgement of the state's role in children's health monitoring and for greater attention to be paid to children's privacy and the agency of child patients and their parents.

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