Listening and building trust: starting as I mean to go on

Welcome to my first blog post as National Data Guardian for Health and Social Care. I am incredibly excited to be taking up this role. During my tenure, I intend to do my utmost to listen to the public and to advise and guide those making important decisions about data use, so that information is used for public benefit in line with people's expectations. Prior to my appointment, the Health and Social Care Committee asked me to share with them my background, motivations and priorities for this role. I submitted a statement, which is available to read in full online.

I am honoured to be following in the footsteps of the late Dame Fiona Caldicott, who did so much during her time as England's first National Data Guardian. She served as a fierce champion for patients, carers, and social care service users in matters related to their data. We have much to thank her for, and her impact on health and social care information governance leaves a legacy we all continue to benefit from.

I take seriously the role that the National Data Guardian should play in supporting and influencing the safe, confidential and effective use of citizens' health and care data. In doing so, I'm keen to support data use to both improve the treatment and care of individuals now, and to advance innovation in illness prevention, treatment, and service planning for shared public benefit in future. We need only look to the last year we've all lived through to see evidence on a global scale of how essential the effective use of data has been to the world's response to the pandemic. Data has provided invaluable insights into questions such as where and how the disease is spreading, who is most vulnerable, how we can best protect ourselves and our loved ones, and what treatments are and are not effective. Using these insights to inform critical decision making has undoubtedly saved lives.

Whilst supporting such innovative data use, I will remain mindful of my responsibility as National Data Guardian to act as an independent 'critical friend' to health and care organisations, ensuring that I always call to attention the inherent risks of data sharing and use, including unintended consequences and 'mission creep', alongside its benefits. Public trust in institutions can be fragile for many reasons and is easily lost, and the effective use of accurate, complete data ultimately rests on the health of the two-way relationship between the individuals whom the data is about, and those collecting and using it. I'll seek to provide advice that maintains a balance between the extremes of individual clinicians and organisations being either too paralysed by risk aversion to use data, or acting as if positive thinking and the integrity of well-meaning individuals alone are enough to make systems worthy of public trust.

My motivation to be National Data Guardian is both professional and personal. As a clinician, I've seen first-hand the growing benefits that data-driven technology is delivering: for example, through individuals having access to digital tools and resources to strengthen their self-management, clinicians having access to AI tools for clinician decision support, and teams seeing real-time aggregated data on incidents to improve the safety of their service. I’m also aware of the need to address more fundamental issues, such as the integrity of our digital infrastructure, system governance and clinician confidence to support timely information sharing between (and sometimes within) organisations. My personal family experience has also brought home the importance of getting these basics right. I’m currently very aware of the frustration, anxiety and sometimes distress that can ensue when critical healthcare information isn’t readily available to the clinicians who need it, when they need it. In my view, ‘cutting-edge’ digital innovation and the arguably less glamorous basics go hand in hand (indeed the success of the former relies on the latter); it’s vital therefore that continuous attention is paid to the balance of investment between each.

As the pandemic abates, and as a society we explore what should (and what perhaps can’t) return to ‘how things used to be’, it is essential that decision makers hear the public’s views about how data and data-driven technology should be used in future. We must understand if attitudes have shifted, and what people expect and want, as we emerge from this (as with any) crisis. Under Dame Fiona, the Office of the National Data Guardian co-commissioned a series of citizens’ juries with the University of Manchester and NHSX to explore these questions; they started last month, and I am looking forward to participating as an observer. I’ve no doubt that listening to a diverse range of citizens’ views on this topic will provide valuable insights to inform discussions about matters such as the use of health and care data for COVID certification – discussions to which I intend to contribute.

Dame Fiona worked with an unwavering commitment for many years to safeguard public trust and advocate for the responsible, transparent use of health and care data. I intend to honour her legacy by building upon the enduring foundations she laid. We share a belief that there should be ‘no surprises’ for the public when it comes to their data: a belief that will guide me as I build upon the long-standing NDG priorities. Because without trust, and the dialogue and transparency that builds trust, we will not earn the public’s support for initiatives that seek to improve health and care using data. I am therefore starting my tenure as I mean to go on, with an active listening exercise. Over the coming months I am greatly looking forward to meeting many of the groups and organisations for whom data matters: to listen, pose questions, and reach a rich understanding of the data landscape, and how organisations within it can build and maintain trust now, from a diverse range of perspectives.

Alongside my NDG duties, I will continue to work as a psychiatrist within adult mental health care. Maintaining a clinical position is important to me, as from previous experience, I’ve learnt that (for me at least), the longer I spend away from the frontline, the easier systemic problems seem to fix (‘If people would just…’). So I intend to stay actively rooted in the complex clinical reality of providing (and receiving) healthcare and support to the population I will also serve in my national role.

As I listen, act and reflect over my first year as National Data Guardian, I intend to share my thoughts and findings in a series of blogs. I’m sure there will be a lot to talk about in 2021, and I look forward to having those conversations.