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The SafeGUARDS: Getting the balance of scientific utility and social acceptability “just right”

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The Science Academies of the Group of Seven (G7) nations' have identified an urgent need for a principles-based governance framework to support the research use of data. In response, the Pan-UK Data Governance Steering Group of the UK Health Data Research Alliance has developed the “GUARDS” principles: a set of high level, enduring and globally relevant principles with public input. The GUARDS require that research using data about people must be: Guided by public and professional stakeholders, Understandable and transparent, Aligned in using common tools, forms, contracts and accreditation standards, Responsible in meeting ethical requirements and delivering equitable outcomes, and must Deliver public good in times of crisis, with recognition of data Stewardship as a distinct profession needed to ensure the appropriate use of data. The GUARDS principles sit alongside

the internationally recognised “Five Safes”, together forming “SafeGUARDS”. Within this, the Five Safes effectively inform decision making needed to balance data utility and confidentiality, and the GUARDS inform decision making about broader principles relating to involvement, transparency, equity and responsible data use. Collectively, we intend the principles to support the “Social Licence” to operate with the pressing need to unlock the potential held in rich, linkable datasets. Each of the GUARDS has associated “aspirations” for organisations to use as examples of how to turn the principle into action. Further international discussion will be needed to develop the SafeGUARDS, driving consistency and harmonisation and facilitating trustworthy and fair research to address global issues.

