



All-Party Parliamentary
Group for Longevity

The Health of the Nation

A Strategy for Healthier
Longer Lives

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Harnessing the Potential of Data to Deliver a Longevity Dividend

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Key Issues

To deliver on HLE+5, we need to reach a fit for purpose agreement between individuals, civil society, businesses and the state about whether and how data can should be leveraged to benefit the health of the nation. This will involve addressing the following questions:

What is 'health' data?

What data cannot tell us something useful about the current and potential health and wellbeing of diverse individuals and populations? What data could drive the development of new and improved treatments and technologies in the service of HLE+5? What data is, then, in scope and out of scope?

How should we prioritise interventions?

Where should priorities lie in investment linked to:

- i) 'data that saves lives' and 'data that cares' (i.e., data about sickness / managing multiple morbidities) as distinct from
- ii) data with the potential to predict and prevent sickness and multiple morbidities when combined with public health legislation and techniques to influence the behaviour of individuals; and
- iii) data with the potential to decelerate or arrest ageing altogether.

Which datasets should be deemed a priority? Who controls priority data and datasets? Do we need new legislation or policies to access and liberate priority data and help deliver a longevity dividend?

To what extent do we need investment to clean or curate priority datasets already in existence versus investment in new, quality data at source?

How should we approach the challenges posed by data bias as well as strike a balance between the need to solicit both 'clean' and 'noisy' data in order to ensure that new data-driven technologies do not function to exacerbate inequalities? Can health data be leveraged to proactively address health inequalities?

How should health data be treated?

Is the treatment of health data about individuals as a special category or as 'sensitive' under GDPR already too narrow or out-dated from the point of view of safeguarding privacy and relying upon 'informed consent'? To what extent is it feasible or desirable to emphasise individual trust versus collective accountability and redress in leveraging data to deliver a longevity dividend?

How might we future-proof any digital contract to underpin access to and usage of data to deliver a longevity dividend? How should we approach leveraging data from the point of view of intergenerational fairness? What might a moonshot look like where harnessing the potential of data from everyone today could be undertaken in the service of delivering a longevity dividend tomorrow and for generations to come?

Do we need an explicit digital contract between individuals, civil society, businesses and the state to enshrine in law when and how data can be leveraged to bring about HLE+5?

Does it make sense to promote a national or networked solution to data-driven innovation in the service of HLE+5 – or a mixed economy of trusted vehicles to leverage individual and corporate buy-in (e.g., data trusts, data co-operatives, data communities, data collaboratives)? Are they mutually exclusive?

Potential Solutions

- Acknowledge that all data is pertinent to healthy longevity insofar as it reflects its wider social determinants;
- Take action and invest to facilitate a data-driven ecosystem that is designed to augment our 20th century 'sick' model of health and care provision - with an emphasis on data to predict and prevent ill-health;
- Promote healthy longevity as a mission or 'moon-shot' to galvanise collective buy-in to and action on the part of individuals, civil society, business and government;
- Afford citizens a say and a stake in access to and usage of data about them to realise collective stewardship of data as an asset in the service of delivering HLE+5.