'Open Life Data Framework' invites participation in consultation for data project to help UK develop pandemic resilience and live healthier for longer

London, 1st September 2021. The All-Parliamentary Group for Longevity (APPGL) is inviting contributions as part of a wider consultation to the *Open Life Data Framework*, reported recently in the Lancet[1], which will propose the data infrastructure and governance mechanisms to harness datasets in both public and private sectors across the life course to develop personal, population and pandemic resilience solutions. The consultation can be accessed here.

The Open Life Data Framework is a recommendation from the APPGL's report, The Health of the Nation Strategy published in February 2020, setting out key recommendations to meet the government goal of five more years of healthy life expectancy by 2035 while reducing health inequalities ('HLE+5').

The framework will help researchers, policymakers and entrepreneurs work out what 'health-relevant data' (like mobility, consumer, financial, environmental) and health data (like medical records) can be shared and connected to provide the most insight into helping individuals keep healthy while enhancing overall health resilience at a population health level. It will explore how the exposome of complex exposures from multiple determinants of health (such as diet, housing, air quality, physical activity, and social interactions) can advance healthy longevity research and practice.

The principles and methodology of Open Banking will be applied to make health and non-health data useful at scale, taking learnings from the finance model.

This insight will guide the development of ethical, trusted solutions across the private, public, not-for-profit and academic sectors to meet the HLE+5 goal, develop use cases for innovators and entrepreneurs, and inform the value of UK health data assets to feed into UK economic strategy and its global ambition to lead in science and AI.

Use cases that could be enabled by Open Life are being sought as part of the consultation but three have been selected initially to identify the key barriers to wider data sharing and better understand the data value chain, potential benefits and harms, and areas for further investigation:
- Digital Red Book for Life- Focus on weight management
- Healthy Ageing Data Exchange- combines data including epigenetic and shopping data to identify the behaviours that advance healthy longevity and drive healthier consumer choices
- Civic Data Cooperatives- a national grid of health action-research to mobilise trustworthy data uses into actions that benefit the local public's health, social fabric and economy

The group, comprising 45 experts, is chaired by Lord James O'Shaughnessy, former Undersecretary of Health and visiting professor at Imperial College, and directed by Gavin Starks, CEO of Dgen, and co-architect of the Open Banking standard and Tina Woods, Director, APPG for Longevity.
The Health Foundation[2], an independent charity committed to bringing about better health and health care for people in the UK, is funding the work.

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[1] Green D, O'Shaughnessy J, Starks G, Sloggett R, Buchan I,Woods T. Open Life Data to support healthy longevity for all. Lancet. 2021: http;/doi.org/10.1016/S2666-7568(21)000081-7.

Notes for Editors

<u>Background</u>
The All-Party Parliamentary Group for Longevity (APPGL) was set up to address the scientific, technological and socio-economic issues relating to our ageing demographic and promote living healthier and longer lives. The APPGL is chaired by Rt Hon Damian Green MP and Lord Filkin CBE is Strategic Advisory Board Chair.

The Open Life Data Framework emerged as a recommendation from the APPGL's report, The Health of the Nation Strategy published in February 2020, setting out key recommendations to meet the government goal of five more years of healthy life expectancy by 2035 ('HLE + 5') and at the same time to close the large social gap in healthy life expectancy.

The Covid-19 pandemic has revealed how inadequately prepared Britain was for a virus that is most severe for the least healthy in our society[3]. The APPGL calls for more concerted action to address 'our unhealthy nation' and the Framework is referenced in the follow-up report, *Levelling up Health*, in April 2021 with the support of Rt Hon Matt Hancock MP (former) Secretary of State for Health and Care, Professor Chris Whitty, CMO, and Henry Dimbleby, National Food Strategy.

The overall goals of the Framework are:

- explore how better use of data and data-enabled technologies could make a positive contribution to the health, wellbeing and life chances of all people equitably
- propose ethical, trusted solutions for innovating, scaling-up and leveraging these technologies across the private, public, not-for-profit and academic sectors
- ensure that digital health infrastructure and innovation support is fairly distributed and resilient, reducing inequalities in co-creation, access and outcomes
- build public trust in the use of data for individual and collective health and social care purposes.

Balancing the roles, rights, needs and objectives of people, society, business and government are part of the systems design of the framework. The framework is due to be published in October 2021.

<u>Use Cases</u>

eRedbook for Life. The "eRedbook" has been successfully used to put children's data into their parents' hands to enable parents to digitally monitor the wellbeing of children aged 0-5 including their weight. This use case proposes to extend eRedbook benefits to the entire life of those individuals developing new tools based around life data to support weight management in adults. Sitekit would combine prototype work done to provide clinician-led weight management tools that enable the digital interaction of the clinician with the patient with new work to integrate life data obtained from 3rd party sources outside healthcare. Eric Kihlstrom and Cathey Horsfall from Sitekit are project leads. Further information is available by contacting eric.kihlstrom@gmail.com or michael.catania@sitekit.co.uk

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[3] Green D, Filkin G, Woods, T. Our unhealthy nation, Lancet, 2022. https://doi.org/10.1016/S2666-7568(20)30062-3

The Healthy Ageing Data Exchange: The initial use case of this project combines epigenetic and shopping data to identify the behaviours that advance healthy longevity and drive healthier consumer choices while measuring impact and value. It will integrate aggregated datasets shared between retailers and health analytics providers to demonstrate how shopping choices can impact health in the long term and how health analytics can reinforce better preventive health behaviours. Svitlana Surodina and Dr Richard Siow from Ageing Research at King's College London with partners Legal & General, Muhdo, Skein Group, and Spoon Guru are on the project team. Further information is available by contacting Svitlana Surodina on svitlana.surodina@kcl.ac.uk.

Civic Data Cooperatives (CDC)- The CDC envisages a national grid of health action-research in civic critical masses covering NHS and Local Authority Integrated Care System (ICS) or similar footprints covering around 3 million people per system. Each regional/ICS node of the action-research grid has sufficient trustworthy data governance and processing capability to generate intelligence that improves local services and to generate insights or innovations of likely value to the wider grid. Professor Iain Buchan and Dr Gary Leeming from Liverpool University are project leads.Further information is available by contacting Professor Iain Buchan on buchan@liverpool.ac.uk or DR Gary Leeming on Gary.Leeming@liverpool.ac.uk.

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