MRC/CSO Social and Public Health Sciences Unit Consultation Response

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| **Title of consultation** |
| Data Strategy for health and social care |
| **Name of the consulting body** |
| Scottish Government |
| **Link to consultation** |
| <https://consult.gov.scot/digital-health/data-strategy-for-health-and-social-care/> |
| **Our consultation response** |
| **7.1. Questions Part C**  **12. When considering the ethics of accessing health and social care data for commercial, development and research purposes:**  **12A. How do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?**  From the perspective of population health research, health and social care data is most useful when it can be linked with data from other policy areas, such as education, social security, employment, justice, transport and so on. This kind of linkage allows the effects on health and social care needs of changes in those other areas of policy to be identified. At present, such linkages are usually instigated by researchers. Often this means negotiating with multiple data providers, which can be a lengthy, costly and uncertain process. The Scottish Government should take the lead in negotiating access and supporting the curation and sharing of strategically important cross-sectoral linked datasets. We make some detailed recommendations about how this should be done in our response to Q13.  **12B. How can industry and innovators maintain the trust and confidence of the people of Scotland when using their health and social care data for research purposes?**  Transparency is key. Members of the public should be made aware when they use services that their data may be used for research purposes, subject to stringent safeguards, and that such uses are essential for driving improvements in the safety and effectiveness of services. All research using health and social care data, whether by public or private organisations, should be conducted using the open science standards that are becoming increasing commonplace in academia. That means publication or registration of study protocols prior to the analysis being carried out and dissemination of results in open access journals or on other open platforms.  **12C. What do you believe would be unacceptable usage of Scotland’s health and social** |

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| **care data by industry, innovators, and researchers?**  Research (see, e.g., <https://doi.org/10.1186/s12910-016-0153-x>; [https://doi.org/10.1136/bmjopen-](https://doi.org/10.1136/bmjopen-2021-057579) [2021-057579](https://doi.org/10.1136/bmjopen-2021-057579)) suggests that when they are asked, most people support the use of health data for the public good but dislike the idea of data being sold to commercial organisations to be used for profit.  **12D. How should industry, innovators and researchers be transparent about their purposes in accessing, and the benefits of using, health and social care data?**  We suggested in our response to Q12B that the use of open science standards could support transparency in the use of data. These standards should be mandated by data controllers and built into data sharing agreements. The Scottish Government could go further and maintain a publicly accessible register of all research using data from health, social care and other public services so that members of the public can readily see how their data is being used.   1. **We want to create an infrastructure that supports access to data for research and innovation in a safe, secure, and transparent way:**   **13A. How should the Scottish Government seek to store and share health and social care data for research in order that it can best facilitate easier access that is still safe and secure?**  We have recently completed a study of how the potential for wider use of cross-sectoral linked data could be unlocked (see <https://fundingawards.nihr.ac.uk/award/NIHR133585>). We conducted a scoping review of published literature, examined three case studies of health and social care research projects that used data linkage, and spoke to 20 people working in public health policy and practice, information governance or data infrastructure roles. Among the 21 recommendations to emerge from the study, we would emphasise the following (full list and further detail available on request):   * + Key datasets from multiple sectors should be available via a central repository acting as a 'one-stop shop' for sharing and linkage, with differing levels of governance according to sensitivity.   + There should be a focus on the creation, curation, and rapid re-use of linked datasets that can be used many times for multiple different purposes.   + To support ease of discoverability across different sectors, there should be a published list or register of key datasets (including details of what information they contain, standards for collection and curation, and how they can be accessed).   + There should be a national public sector skills initiative to build capacity in professional roles related to the use of health and social care data for research (e.g., data curation, analysis, governance, and public engagement).   + To realise the benefits of cross-sectoral sharing and linkage there should be senior leadership and commitment from across all organisations (e.g., central government, local |

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| authorities, health and social care service).   * Expectations and incentives for policymakers to collaborate with researchers should be developed, as part of a learning culture that seeks to make best use of data for population health gain.   **13B. What do you believe are the key data needs and gaps that are faced by industry, innovators, and researchers when it comes to Scotland’s health and social care data?**  A glaring absence in the data available for population health research in Scotland is linked data on income, receipt of social security benefits/tax credits and health. In several important ways, the welfare system in Scotland now diverges from the rest of the UK, but without such data it is difficult if not impossible to evaluate health impacts of the policies now being implemented in Scotland, such as the ‘Scottish Choices’ in Universal Credit, the new Scottish child payment, and the innovative approaches to employment support implemented under Fair Start Scotland and No One Left Behind.  **14. Used appropriately and well, technologies such as Artificial Intelligence can help to improve decision making, empower health workers and delivery higher quality health and social care services to citizens, improving how you receive health and social care services:**  **14A. What are your views on the benefits of using AI to improve the delivery of health and social care services?**  **14B. What safeguards do you think need to be applied when using AI?**  AI-based health technologies should be subject to the same standards of evidence as other innovations in treatment or the delivery of services. Where possible, randomised trials of the  efficacy, effectiveness and safety of the new technologies by comparison with ‘treatment as usual’ should be conducted prior to implementation in routine care, and wider implementation should be carried out in the context of well-designed cohort studies adequately powered to detect adverse outcomes. The use of linked data should enable such studies to be carried out at scale in a highly efficient way (see e.g., [https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-04459-z) [04459-z](https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-04459-z)) |
| **When was the response submitted?** |
| 12th August 2022 |
| **Find out more about our research in this area** |
| [https://www.gla.ac.uk/schools/healthwellbeing/research/mrccsosocialandpublichealthsciencesunit](https://www.gla.ac.uk/schools/healthwellbeing/research/mrccsosocialandpublichealthsciencesunit/programmes/inequalities/)  [/programmes/inequalities/](https://www.gla.ac.uk/schools/healthwellbeing/research/mrccsosocialandpublichealthsciencesunit/programmes/inequalities/) |
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