

## Data saves lives: reshaping health and social care with data (draft) - Royal College of General Practitioners response

August 2021

1. The Royal College of General Practitioners (RCGP) welcomes the opportunity to respond to the Department of Health and Social Care (DHSC) and NHSX's draft data strategy for health and care.
2. The RCGP is the largest membership organisation in the UK solely for GPs. Founded in 1952, it has over 54,000 members who are committed to improving patient care, developing their own skills, and promoting general practice as a discipline. The RCGP is an independent professional body with expertise in patient-centred generalist clinical care.
3. The RCGP welcomes this draft strategy and the attention given to the importance of data within health and care. We are supportive of the overall aims of the strategy and look forward to working with DHSC and NHSX to ensure its success.
4. Below we have outlined some general comments on the draft strategy before responding to items of particular interest and relevance to general practice from the various chapters in turn.

### General comments

5. **Engagement and communication** - The RCGP particularly welcomes the focus within the strategy on engagement and communication with the public and clinicians. Trust in the ways data is used and safeguarded by the NHS is critical to the success of the strategy and associated projects.
6. **Clinical safety and oversight** - We would like to see more detail within the strategy regarding clinical safety, oversight mechanisms, user feedback and regulation. This is fundamental to ensuring that there are no unintended negative impacts on patient safety and outcomes as any new uses of data, new technology or digital transformation programmes are developed within the NHS. Professional input such as is provided by the Joint GP IT Committee of the RCGP and BMA, and the RCGP Health Informatics Group, is critical to providing such oversight.
7. **Upholding standards** - It would be beneficial to consider further how the various standards and guidelines proposed in the strategy will be upheld. This will be key in ensuring compliance and clinical safety as well as consistency across the NHS.
8. **Distinction between use of data for direct care and secondary uses** - In discussions around health data there is often conflation between its use for direct care and secondary uses such as research and planning. In the interests of transparency and

maintaining public trust and consent, it is important that the strategy makes extremely clear the distinction between these different uses.

9. **Existing systems and direct care** - While there is much to welcome in this strategy in terms of ambitions for future developments within NHS data and technology, the RCGP would like to see a greater focus on improving direct care and existing systems. There are many areas of IT within the NHS, such as a lack of joined-up patient data and poor data flows for basic items such as prescriptions and referrals, which require investment and improvement and could offer a better experience for patients and clinicians. We hope that these areas will be prioritised as much as wider big data ambitions and emerging technologies.

## Chapter 1: Bringing people closer to their data

10. **Better access to records** - We are supportive in principle of the suggestion of giving people better access to their own records, and the ability to self-manage their data. However, issues of security, privacy, consent and clinical safety must be considered as record access is expanded. For example, risks arise where patients may be able to immediately see test results which require interpretation or explanation by a clinician. There are also concerns around a minority of patients who may seek to manipulate their own records or access records of others such as in cases of domestic abuse, drug abuse or violent behaviour patterns.
11. **Decentralised personal data stores** - This proposed development offers significant potential in terms of safeguarding data privacy for individuals while providing the patient benefit associated with joined-up data sharing across NHS services. We look forward to further details as these plans are developed and assume that relevant expert advice and healthcare professional input will be sought to ensure challenges such as data quality, security and consistency can be appropriately addressed.

## Chapter 2: Giving professionals the data they need

12. **Reducing data collection burden** - The RCGP welcomes this commitment as an important step to support workload management at a time of significant workload pressures within general practice, as well as to avoid duplication of effort and the risk of errors associated with repeated entry of certain data. Application Programming Interfaces (APIs) are critical to reduce replication by ensuring existing data is prefilled for the user.
13. **Duty to share deidentified data** - This proposal is of particular concern to the RCGP in its current format as there is a lack of clarity over which data this duty would apply to and how it would operate. While the sharing of data that was never identifiable is of less concern, it is widely acknowledged that deidentified data is easily re-identifiable given the rich level of detail contained in health records. As has now been agreed at a national level with respect to the General Practice Data for Planning and

Research programme, pseudonymised data must not be disseminated and should only ever be accessed via secure Trusted Research Environments.

14. **Shared care records** - We are very supportive of the development and roll out of shared care records and better flows of data across the NHS for the purposes of direct care and the provision of a more seamless experience for patients. However, given the highly sensitive nature of the data held by general practice, it is important that consideration is given to what information needs to be available to which clinicians within which parts of the health and care system. This will help to avoid unnecessary risk associated with widespread disclosure. One possibility for consideration would be establishing a section of the GP record which is secured and never shared beyond the practice unless safeguarding issues come into play. This would allow for the recording of particularly sensitive topics or issues which a patient has asked their GP not to share more widely.

### Chapter 3: Supporting local and national decisions makers with data

15. **Secondary legislation to enable the proportionate sharing of data** - This proposal is also of concern given ambiguity over how "proportionate" and "appropriate" data sharing will be defined by the proposed legislation. Given the many existing legal bases for data sharing, it is unclear what the additional legislation would aim to achieve. The RCGP would be unlikely to support legislation which sought to compel data sharing, particularly on a non-consented basis. We welcome however, the commitment to ensure transparency and clarity on appropriate safeguards as part of these proposals. It is critical that any changes are made in a way which maintains trust amongst the public and healthcare professionals.

16. **Collaboration with wider partners** - We are supportive of the sharing of data across the health and care system so long as this is done securely, proportionately and with the support of patients. We also recognise the potential benefits of collaboration with wider partners across the public sector. However, any proposal to share healthcare data outside of the health and care system requires careful consideration and justification. The RCGP was pleased that previous plans to share NHS data with the Home Office for purposes of monitoring immigration did not go ahead and we could not support any similar initiatives in the future.

### Chapter 6: Helping colleagues develop the right technical infrastructure

17. **Data validation** - The proposal for data to be validated at the point of entry is welcome but we would note that this alone is not sufficient to ensure wider data quality. While systems may be able to ensure the correct type or format of data is entered into a certain field, this does not offer a guarantee that the correct codes have been used or that the data entered is a fair representation of a patient's experience.

- 18. Fair returns in data partnerships** - The RCGP is supportive of this principle and recognises the value of NHS data. We believe it is important to avoid situations where NHS data is made available for the development of products which go on to be sold back to the NHS at high prices.
- 19. Openly licenced standards and open-source code** - We welcome this aspiration which will contribute greatly to reducing the costs and challenges of standardisation for all involved in NHS systems, data and IT. The RCGP would also support consideration of extending this to the SNOMED-CT standard which is currently closed and proprietary.
- 20. NHS Account** - The development of an NHS Account offers many potential benefits in creating a high-quality and secure digital mode of interaction with NHS care. However, there is significant danger of amplifying existing digital exclusion and health inequalities. The RCGP would caution against any moves which lead to digital routes being the only front door to accessing general practice or wider NHS services. We discuss the importance of continued telephone and face to face access options which meet patient need and preferences in our recent report *The future role of remote consultations & patient 'triage'*<sup>1</sup>.
- 21. Separating the data layer from applications** - The RCGP recognises and supports the benefits that this proposal could offer in terms of data portability and expanding the range of user interfaces able to access the same data. However, we believe this to be a highly ambitious aspiration which could prove very challenging given the current position of NHS IT, with widely used older applications tightly coupled to underlying database design. There are also several areas which would need to be addressed as part of this process including how to ensure the usability of applications was not damaged, and where and how the separate data layer would be held and safeguarded.

## Chapter 7: Helping developers and innovators to improve health and care

- 22. Innovation friendly regulation** - While the RCGP welcomes efforts to support innovation, it is critical that regulation of healthcare innovation always prioritises clinical safety. We are not convinced that setting an ambition from the outset for regulation to be "innovation friendly" is consistent with this priority.

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<sup>1</sup> <https://www.rcgp.org.uk/policy/general-practice-covid-19-recovery-consultations-patient-triage.aspx>