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Response to *A consultation on strengthening the NHS Constitution*

Summary

BPS welcomes the additions to the NHS Constitution regarding patient data that make clear patients' legal rights. Changes to the NHS Constitution represent an important step in supporting patients in making fully-informed decisions and ensuring that research based on patient data becomes routine throughout the NHS. To realise the potential of these changes, it is essential that appropriate support is offered so patients understand how their data is shared and why that data sharing is important.

Safeguarding & using patient data

BPS supports unlocking the power of the NHS patient data as an unparalleled resource for drug discovery. Existing access to patients' anonymized records through the Clinical Practice Research Datalink (CPRD) promotes more precise monitoring of the efficacy, safety and utilisation of medicines after regulatory approval, as well as faster delivery of new medicines and new approaches for using existing medicines.

The Constitution pledges that the NHS will *anonymize the data collected during the course of your treatment and use it to support research and improve care for others*. We welcome this clarification about how data will be handled and consider it an important step in ensuring use of anonymized data is routine within the NHS. However, for patient support for data collection to flourish, we believe patients must also feel confident that their health records are held safely and securely, and that any use of NHS data is demonstrably justified, with appropriate and national governance approval processes. We suggest that plans to raise awareness of the NHS Constitution might provide a welcome opportunity to provide information to patients about the value, routine use and storage of NHS data.

The pledge to *inform you of research studies in which you might be eligible to participate* must be accompanied by support and resources for patients to ensure patients are able to make a fully informed decision about participation in clinical studies. The Constitution emphasises the value of patient involvement with their care; this should extend to patient involvement with research. Patients should understand how they have been identified for a trial (data sharing), why they specifically have been sought out and the value of participation to research. It will be vital that all NHS staff are trained to, and feel confident that they can, talk to these points and answer questions about use of data and about clinical studies.

In order to inform patients about data use in research, the purpose and worth of that use must be clear i.e. health research, of which a crucial aspect is clinical trials. The National Institute for Health Research's (NIHR) Clinical Research Network's recent [Mystery Shopper Report](#) demonstrated a failure to provide information about clinical studies to patients. While the Constitution primarily covers clinician-led study participation we are aware of

the need for a suite of information to be readily available to all patients and would see the Constitution as an important opportunity to raise wider awareness of the:

- relevance of data use to each patient
- value of clinical studies
- value of patient participation
- link between data use and future health benefit.

Furthermore, given public concern that has been expressed historically about government data collection schemes, a key requirement for an informed and empowered patient must be a means for withholding their NHS data. For patients who do not wish to allow any data to be shared, the means of exercising their right to withhold this data must also be clearly presented and accessible to the diverse NHS patient population.

About the NHS Constitution

The NHS Constitution brings together the principles, values, rights and responsibilities that underpin the NHS and is intended to empower patients and staff to know, understand and exercise their rights within the NHS.

About BPS

BPS is the primary UK learned society concerned with research into drugs and the way they work. Our members work in academia, industry, and the health services, and many are medically qualified. The Society covers the whole spectrum of pharmacology, including laboratory, clinical, toxicological and regulatory aspects.

Clinical pharmacology is the medical specialty dedicated to promoting safe and effective use of medicines for patient benefit. Clinical pharmacologists work as consultants in the NHS and many hold prominent positions in UK Universities