

Rethinking patient data

Improving health & healthcare



Everyone who uses health and care services should be able to trust that their personal confidential data is protected. Unfortunately trust has been eroded and steps need to be taken to demonstrate trustworthiness and ensure that the public can have confidence in the system.”

Dame Fiona Caldicott, MA FRCP FRCPsych, National Data Guardian

Information collected for healthcare reasons is often particularly personal and highly sensitive. But it also offers tremendous value, improving patient outcomes through research, policy, treatment and healthcare planning.

Now – with blanket consents coming to an end, the NHS Framework for Personalised Health and Care 2020 and the introduction of General Data Protection Regulation in May 2018 – questions and concerns about data are at the forefront of the NHS digital transformation.

Healthcare organisations must take this opportunity to:

- Provide a platform where patients can give informed consent for the use of their data to improve health and wellbeing
- Gather high quality, linked data to facilitate better care provision
- Ultimately, share insights that can benefit society

Answering patient concerns

“ Public views show low understanding of data and low knowledge of how healthcare works.”

Ipsos MORI for the WellcomeTrust

With the patient at the heart of healthcare, the same should apply when it comes to the information held about them. Patients want to know the exact purpose for the use of their data. For them individually. For society as a whole. In research conducted for the WellcomeTrust there was scepticism about the use of data, but an understanding of the benefit, as long as intent was proven.

43%

wanted commercial organisations to show a clear intent that research will lead to benefits for wider society

61%

of people would rather see commercial access to health data happen than lose out on the benefits these organisations can bring

Data collection must be transparent, ensuring patients are fully informed and give their consent knowingly. This will strengthen the trust and confidence patients place in the system.

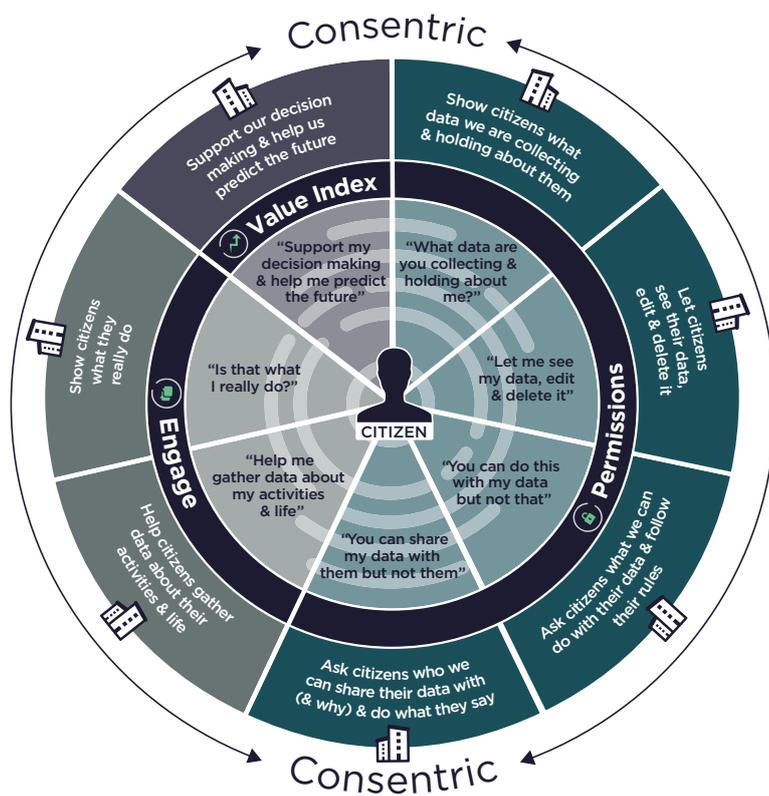
We believe there should be no blanket permission for the use of data. Instead, patients need to be in control of exactly who has access to their data. They can give consent in one area. They can deny use in another. They can be assured that if their data is broadly used that it can be anonymised.

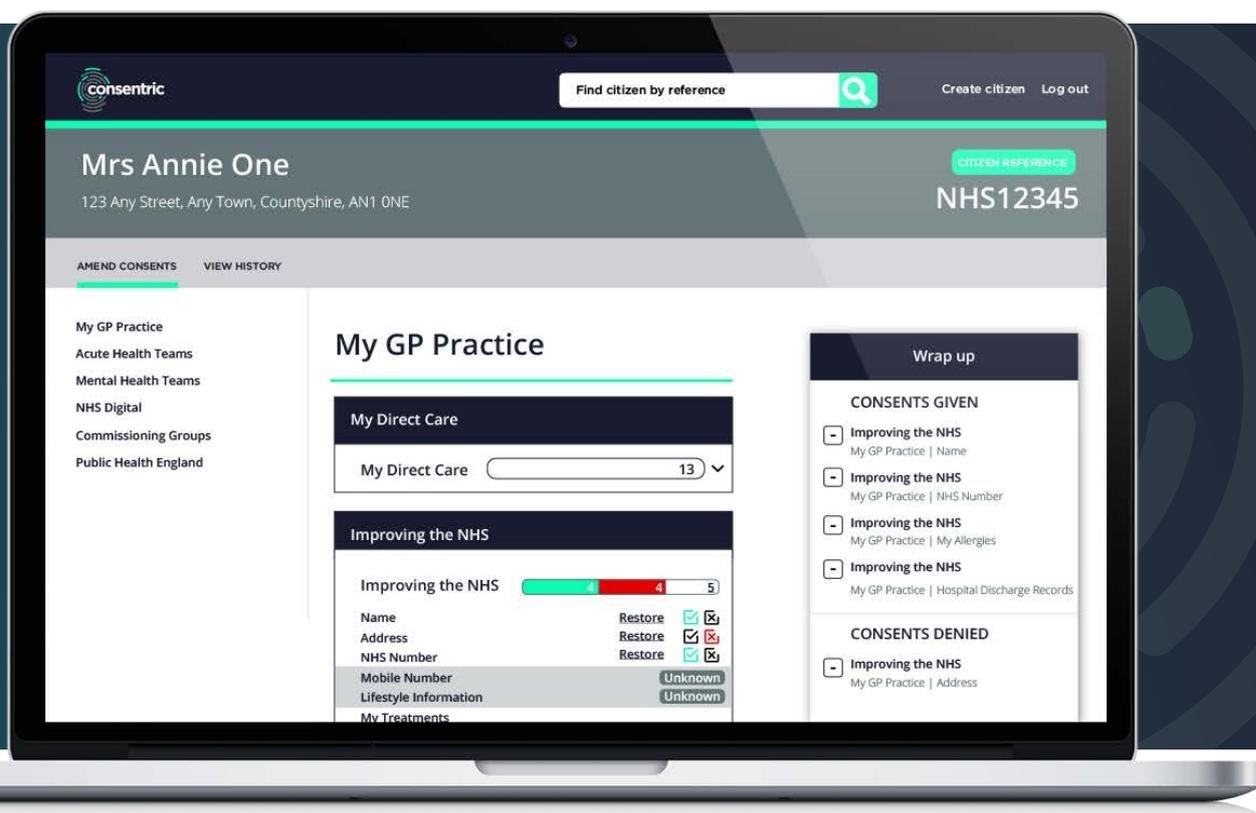
- Patient = See and manage their own data
- Carer = See and manage on patient's behalf with consented proxy
- GP/Direct Care = See and manage personal data (e.g. prescriptions, test results, treatments)
- Secondary Care Teams = See with consent
- Commissioning Groups = See anonymised aggregated data with consent
- NHS Digital = See patient data with consent

Patient data

Our Consentric Platform is patient-centric.

- **Consentric Permissions** puts patients in control of their own data
- **Consentric Engage** allows patients to monitor their own health
- **Consentric Value Index** aggregates data to improve decision making at patient and organisational level





About MyLife Digital

MyLife Digital helps organisations realise the meaning, value and power of their data.

- Meaning.** An individual gives consent for the use of their data.
An organisation gains insights. Both parties improve decision-making.
- Value.** Redefining the relationship between individuals and organisations.
Where there is mutual value exchange.
- Power.** Data is powerful. It gives the opportunity to gain insights.
To see patterns. Insights that deliver change.

Using the Consentric Platform, with consent at the heart of the system, data can be collected, collated and shared to provide informed insights.

Informed insight from informed consent

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www.consentric.io

T: +44 (0)1225 636 280

E: contact@consentric.io

MyLife Digital Ltd, Reg Office: Citizen House, Crescent Office Park, Clarks Way, Rush Hill, Bath, BA2 2AF

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mylife
digital

