A year in a pandemic - lessons learned

Dawn Monaghan, Head of IG Policy at NHSX
14 May 2021

Context

- The COVID-19 response showed **the benefits and power of data**

- The need for **collaboration**, wider planning and policy decisions

- Providing and maintaining **confidence** on the frontline and with the public

- It also highlighted some of the **continuing barriers** such as:

  - cultural and behavioural issues
  - structural issues
  - misunderstandings, lack of clarity, myth and legend.

IG input to policy and solutions

NHSˣ

Pre pandemic:

- Involvement tended to be post policy and decision making

- Lack of understanding or acceptance of privacy by design concepts

- IG reactive and often not joined up

- Decisions sometimes endlessly deliberated, perceived as excessive and slow

- Focus on guidance and advice for IG professionals and organisational legal obligations

- Reticence to share personal information (concerns about liability).

IG input to policy and solutions

NHS^x

During the pandemic:

- Focus on societal benefit rather than organisational obligations

- Acceptance of the need to be involved at policy and design stages

- IG perceived as integral to the policy process

- Recognition of the need to ensure frontline staff were clear about the use of information

- Opportunities to champion transparency

- Requirement to share information.

Positive outcomes

- The importance of proportionate IG and the need for transparency recognised and accepted

- Clear guidance for frontline about issues that mattered to them

- Public recognition that an individual's information is key to achieving societal benefit

- Increased collaboration across sectors

- Focus on sensible and appropriately sharing information for specific purpose(s)

- New ways of working

- New relationships.

Challenges

- Interfaces with other legislation

- Differences in knowledge and experience of IG staff

- A little bit of knowledge is dangerous (DPIA's)

- The importance of audit trials

- Expectations that the landscape has changed forever.

Going forward

- Building upon the successes

- Ensuring the **benefits and lessons learned** from the COVID-19 response are realised

- Maintain and increase **public trust in the system**

- Foster new relationships across sectoral divides

- Improve access to information whilst maintaining compliance

- Simplifying IG law and guidance

- Focus on the issues that will have the greatest impact.

Health and care response

NHS^x

We will:

- Ensure the rules, guidance and law allow data to be shared for direct care and the effective functioning of the system, and safely used for research;

- Enforce standards and build according to architectural principles that will mean the data can be shared appropriately;

- Make sure the citizen has access to their own data, and increasingly put them in charge of their data;

- Ensure the whole country is covered by Shared Care Records that allow data to be safely shared between care settings;

- Over time, drive the separation of data storage from the applications using that data, so that Electronic Patient Records become a platform for cooperation and innovation with data being accessible to those that need it, not siloed within individual systems.

Health and care data strategy

NHS^x

Who will it benefit

1 Empowering **people** to take control of their own care.

2 Giving health and care **professionals** what they need to give the best possible care.

3 Supporting local and national **decision makers** with data.

4 Improving data for **adult social care**.

5 Giving **researchers** access to what they need to develop new treatments and insights.

6 Helping colleagues develop the **right technical infrastructure**.

7 Helping **developers and innovators** to improve health and care.

Connect with us

NHSˣ

Web: www.nhsx.nhs.uk

Email: feedback@nhsx.nhs.uk

@NHSX

www.linkedin.com/
company/nhsx