

## Population Health Tool (HealthIntent)

### Fair and Transparent Processing

#### Sources

[Data Protection Act 2018 \(DPA\)](#)

[General Data Protection Regulations \(EU\) 2016/679 \(GDPR\)](#)

[Information Commissioner – Guide to the General Data Protection Regulations \(ICO Guide\)](#)

[ARTICLE 29 DATA PROTECTION WORKING PARTY - Guidelines on Transparency](#)

[ICO Consent Guidance](#)

[Murray v Express Newspapers \[2008\] EWCA Civ 446](#)

[COCO V A N CLARK \(ENGINEERS\) LTD: CHD 1968](#)

#### Definitions / Context

- You must be clear, open and honest with people from the start about how you will use their personal data.
- fairness means that you should only handle personal data in ways that people would reasonably expect and not use it in ways that have unjustified adverse effects on them.
- if anyone is deceived or misled when the personal data is obtained, then this is unlikely to be fair.
- Transparency is, in some cases even more important even when you have no direct relationship with the individual and collect their personal data from another source. In these cases, individuals may have no idea that you are collecting and using their personal data, and this affects their ability to assert their rights over their data. This is sometimes known as 'invisible processing'
- WP29 and ICO guidance stipulate the content of Fair Processing / Transparency materials including all third countries to which the data will be transferred, the relevant legal basis, the source of personal data, the existence of automated decision-making including profiling, the categories of personal data concerned, the different storage periods, contact details for the data protection officer, the actual (named) recipients of the personal data, how to exercise information rights including objection, any further processing,

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- A link to the privacy statement/ notice should be clearly visible on each page of [the] website under a commonly used term (such as “Privacy”, “Privacy Policy” or “Data Protection Notice”)
- Controllers should test the intelligibility of the information and effectiveness of user interfaces/ notices/ policies etc. through user panels.
- A translation in one or more other languages should be provided where the controller targets data subjects speaking those languages
- notices should provide an overview of the types of processing that could have the highest impact on the fundamental rights and freedoms of data subjects in relation to protection of their personal data
- The information to be provided to data subjects pursuant to Articles 13 and 14 may be provided in combination with standardised icons in order to give in an easily visible, intelligible and clearly legible manner a meaningful overview of the intended processing. Where icons are presented electronically they shall be machine-readable
- Language qualifiers such as “may”, “might”, “some”, “often” and “possible” should also be avoided
- WP29 recommends the use of layered privacy statements/ notices, which allow website visitors to navigate to particular aspects of the relevant privacy statement/ notice that are of most interest to them.
- WP29 recommends that layered privacy statements/ notices should be used to link to the various categories of information which must be provided to the data subject, rather than displaying all such information in a single notice on the screen, in order to avoid information fatigue
- It is critical that the method(s) chosen to provide the information is/are appropriate to the particular circumstances, i.e. the manner in which the data controller and data subject interact or the manner in which the data subject’s information is collected
- where processing changes are implemented, notices should ensure the data subject does not “miss” the change and to allow the data subject a reasonable timeframe for them to object
- Expecting the individual to frequently check for changes are considered unfair
- In particular, the right to object to processing must be explicitly brought to the data subject’s attention at the latest at the time of first communication with the data subject and must be presented clearly and separately from any other information.
- Public authorities, employers and other organisations in a position of power over individuals should avoid relying on consent unless they are confident they can demonstrate it is freely given.

## Assessment

Consent is not the selected lawful basis for processing of healthcare data and the legal gateway under data protection law has been determined to be “public task” and “medical purposes”.

There is still a legal requirement to ensure that the patient population are informed about the processing and have the opportunity to ask questions or to object to processing.

Additionally, there is a need to ensure that the common law duty of confidentiality is also satisfied.

Traditionally, the test arising from *Coco v. AN Clarke Engineering Ltd* (*Coco*)<sup>1</sup> applied. This provides that a duty of confidentiality arises where information has a quality of confidence, and a relationship of confidence exists.

Whether or not the obligation arises from a confidential relationship; case law development is such that, disclosure by a person that ‘receives information he knows or ought to know is fairly and reasonably to be regarded as confidential’, may result in a legal wrong.

Therefore, the test for a breach of confidence has developed (in correlation with the application of the Human Rights Act 1998 and Article 8 (1) of ECHR) and now concerns whether individuals have a reasonable expectation of privacy<sup>2</sup> such that sharing information may constitute misuse of private information.

The duty can be overridden where it is deemed that the individual reasonably expects such a disclosure.

It is therefore recommended that a fair processing campaign is put in place to make the patient population of Suffolk aware of the Health Population Tool and to ensure that the “reasonable expectations” of the population align with that of the project.

## Proposed Approach to Ensuring Reasonable Expectations

The proposed approach aims to provide a lawful basis for processing health information through the following activities;

1. The duty of confidence is lawfully set aside by virtue of proportionate and legitimate sharing.

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<sup>1</sup> [1968] EWHC 415 (CH).

<sup>2</sup> *Murray v Express Newspapers* [2008] EWCA Civ 446.

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2. Patients will be fully informed in line with Rec.39, 58, 60; Art.5(1)(a), 12-14 which provides that controllers provide certain minimum information to data subjects, regarding the collection and further processing of their personal data.
3. This information must be provided in a concise, transparent, intelligible and easily accessible form, using clear and plain language. Information provided to children should be in such a clear and plain language that the child can easily understand.
4. Patients will have a clear and ongoing option and opportunity to object to sharing.

In order to process health information using the 'reasonable expectations' approach, it is crucial that the stakeholders launch a communications campaign that is COMPACT;

- Comprehensive
- Ongoing
- Multi layered
- Provides opportunities for queries and objections
- Accessible
- Clear
- Targeted

## Comprehensive

This requires complete mapping of all sharing partners so that information can be provided about;

- Standard flows of data between partners
- The lawful basis for processing the method of transfer
- How long records are retained for
- Technical and organisational methods in place to protect information
- The rights of data subjects

## Ongoing

To ensure that the general consciousness around information sharing in for the project remains adequate, the campaign must be a rolling campaign that includes an active portal for individual to access throughout the year and periodic proactive communications through renewed posters and newsletters.

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There must be a model and resources in place for regular review and amendment with specific initiatives such as the introduction of new data sets.

## Multi-Layered

To ensure the message is received by the patient population, there must be a move away from single point notification such as websites or posters within the practice.

Though must be given to alternative access points for data subjects that are not frequent practice visitors;

Some options to available are;

- Website
- Posters
- Mailshots
- Text
- Radio
- TV
- Apps
- Social Media
- Billboards

The plan may include sourcing communications / marketing resource.

## Provides opportunities for queries and objections

Where the general consciousness is raised, it is likely to result in an increase in queries and requests from the general public. A standard FAQ pack should be developed to provide assurance around sensitive read codes, proportionality and data security to alleviate burden on practices or project leads.

Objections to processing / sharing will be dealt through the usual way, ensuring the individual understands the impact and observing the right to object where possible and lawful.

## Accessible

Another component of ensuring the message is received by the patient population is accessibility. The campaign will include, accessing patient engagement groups and an equality

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impact assessment to ensure that the approaches taken include a variety of communication types such as easy read, braille, large font, videos, emojis and alternative languages.

## Targeted

A population segmentation exercise will allow the stakeholders to consider the communication needs of its patient population. This will ensure that the methods selected are appropriate for the audience. Information will be produced that is directed towards children and young people – commensurate with the ability for this patient group to make decisions about their care and information sharing.

## Collaboration

The plan would best be executed in collaboration with sharing partners to ensure that partners launching similar campaigns do not result in a media bombardment of the patient population.

## Conclusion: Roll Out Plan

Activity	Timeframe	Responsible Party	Dependency
Complete population segmentation	TBC	TBC	TBC
Present to patient engagement groups	TBC	TBC	Engagement of PEG
Develop Patient Portal website	TBC	TBC	TBC
Source Communications / Marketing resource	TBC	TBC	TBC
Develop Communications Plan	TBC	TBC	TBC
Roll out of Communications Plan	TBC	TBC	TBC

## Risk Identification

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Risk / Gap	Action	Status
There is a risk that fair processing materials will not include a consideration of the population segmentation and accessibility needs	Undertake population segmentation and engage with patient groups	Pending
There is a risk that the fair processing materials will not include sufficient information about profiling or the joint controllership	Review materials within IG Working Group	Pending
There is a risk that there will not be an appropriate lead time for comms to ensure common law is satisfied	Do not permit Go Live until sufficient time frame has elapsed	Pending