



THE UNIVERSITY of EDINBURGH
Edinburgh Law School



Public interest in health research

Concept note

Public interest in general terms

Actions taken in the public interest can be broadly described as those that [promote objectives valued by society](#).

Public interest is a concept that can be called on to support a course of action in various contexts. These include in [journalism](#) where reporters seek to publish information that the public should know, or in politics where civil servants use the concept to decide [how to respond to freedom of information requests](#).

Public interest in the context of health research

In health research contexts, public interest is often a core part of policies and laws that regulate activities designed to improve health and wellbeing. For example, it is [one of the legal bases](#) that researchers can rely on to process people's health data for research uses as an alternative to another legal basis, such as seeking participants' consent.

It is a powerful claim to state that an action associated with health research is legitimate because it is 'in the public interest'. Its power lies in the fact that the action is being done in the name of society and its citizens.

Challenges for public interest in health research

In the health research context, public interest might be pitted against keeping people's information private – that is, suggesting that only one of these objectives can 'win'. However, this does not accurately reflect how privacy and public interest are actually *linked* rather than in competition with each other. For example, a participant who is assured that their information will remain sufficiently anonymous might be more likely to cooperate with research. This cooperation serves the public interest in supporting the progress of health research. Public interest and privacy interests are therefore not either/or objectives.

Further challenges that might affect the role of public interest in health research need to be addressed seriously. These include:

- **Uncertainty about its definition:** Despite its use in health research, the concept has been [described as notoriously uncertain](#). Because it is not well-defined, it might mean that it could be used to justify illegitimate actions.

- **Disconnection from ‘real people’:** ‘The public interest’ can often be approached as merely a legal test and/or tool. This disconnects the concept from the people it refers to, meaning that it lacks social legitimacy.

The future of public interest in health research

The Liminal Spaces project at Edinburgh Law School has suggested that **public interest is a valuable but neglected concept and requires more scrutiny to allow it to have stronger applications to real-world situations and to ensure its robustness**. Part of this scrutiny requires us to address the above challenges to support researchers and regulators in their actions and decisions and to act as openly as possible. As far as is possible, **the public must also be involved when appeals are made to the public interest to undertake health research**.

Read more:

- [Conference report: Liminal Spaces Symposium at the IAB 2016: What does it mean to regulate in the public interest?](#)
- [Sharing confidential health data for research purposes in the UK: where are ‘publics’ in the public interest?](#)

This project was supported by a Wellcome Trust Senior Investigator Award (Grant No. WT103360MA) entitled ‘Confronting the Liminal Spaces of Health Research Regulation’.