



THE UNIVERSITY of EDINBURGH
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Social licence in health research

Concept note

What is a 'social licence'?

There are many contexts where plans that could affect the lives of community members or the environment are unwelcome and cause concern. These include [mining](#) or [pipeline projects](#) that could have significant and serious impacts on the environment and community [wellbeing](#).

Such controversial actions might well be legal. But being legal is not enough if they do not have community approval. Without sufficient social support, projects can be challenged, delayed, or might fail entirely. These kinds of projects therefore need to do more than merely follow the law and instead [do 'the right thing'](#) by communities. For example, they could:

- be open with communities about project plans;
- listen to communities and respond to their concerns;
- show how they will not exploit communities (and instead act in their interests);
- be clear about how they could be held accountable if things 'go wrong', and
- in some cases, show how they will 'give back' benefit to the community.

If communities are satisfied with such efforts, the project might attain a 'social licence' to operate. Attaining a social licence does not mean that every member of the community must agree; rather, it means that there are sufficiently strong and good reasons for general community support for a project.

The importance of the social licence in health research

Like mining projects, health research also relies on community approval. This approval might be especially important when ethically contentious health research is proposed. An example of this is health research using patient data when people's consent is not sought. In these types of scenario, if researchers fail to attain a social licence for their proposals, disputes could arise with potential participants and other affected people. This might put their whole research project at risk.

One example that illustrates how the absence of a social licence can jeopardise projects is NHS England's care.data programme, which sought to bring together patient data held across the NHS. The Liminal Spaces project at Edinburgh Law School, together with colleagues at Cambridge and Leicester, have [suggested](#) that this programme failed to attain a social licence, leading to its suspension. Reasons for this failure include:

- It did not explain data sharing benefits;
- There was a lack of tough oversight of the programme;
- [It did not win doctors' support](#); and

- Information on possible uses and disclosure of data (including to private companies) was inadequate.

Considering why a social licence has not been achieved in a particular circumstance (like the care.data scenario) provides researchers with an idea of what not to do. In other words, it shows what [types of engagement are necessary](#) for a social licence to be accomplished.

Dealing with disagreements

When a social licence is being sought, parties might disagree about whether an action should go ahead, and in what form. But whatever the decision is, the most important thing is the process of getting there. If this process is sound, then disagreements may be easier to bear and the social licence maintained. The soundness of this process depends on it having strong community foundations that reflect common social values. There are at least [three elements](#) needed to promote this:

- Clear, two-way communication between the communities and researchers / project leads on the objectives and design of a project;
- Avoiding communities being disempowered through exploitation or the perception of this; and
- Demonstrating concrete ways in which the project is for the good of the community.

Maintaining a social licence

The task of attaining a social licence does not stop at the point when it is first attained. **Maintaining a social licence is an ongoing process, not a one-off exercise.** This means that the leaders of a project must work throughout the project to keep showing the community that they are behaving in a trustworthy and responsible way. If they do not, the social licence may be lost and their projects put in jeopardy. Showing how health research has produced clear [social value](#) at its completion is a crucial final step in this process.

Read more:

- [The social licence for research: why care.data ran into trouble](#)
- [Reconfiguring social value in health research through the lens of liminality](#)

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