

# Ethics and the co-production of knowledge

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## Article History

Publication date: 15 June 2022

Citation: Page K. Ethics and the co-production of knowledge. *Public Health Res Pract.* 2022;32(2):e3222213. <https://doi.org/10.17061/phrp3222213>

## Key points

- To date, ethical issues that arise during the research co-production process have primarily been dealt with on an ad hoc basis
- This paper describes two frameworks, several key principles and ethical values that could be considered in the co-production of research, and argues that all stakeholders have a responsibility to adhere to a set of ethics, including health equity, intellectual property considerations, and respect for the rights of individuals and groups
- The development of an explicit ethical framework to guide decision-making at all stages of the co-production process is vital to ensure successful and synergistic co-production of research

## Abstract

There is an increasing focus on co-production in public health research. By their very nature, such research endeavours involve a different set of relationships, goals, and values than traditional research. To date, ethical issues that arise during the co-production process are dealt with on an ad hoc and case-by-case basis. There is a need to make the ethical considerations of co-production explicit. This article outlines several ethical values that could be considered in co-production using two different ethical frameworks. It also draws upon practical co-production research that highlights some of the ethical issues that arise. It argues that all stakeholders in the co-production process have a responsibility to ensure that the knowledge they co-produce is as beneficial as possible. In doing so, they must adhere to a set of ethics surrounding the generation of such knowledge, including health equity, intellectual property considerations, and respect for the rights of individuals and groups.

## Background

*“Co-production should be approached as a practice governed by a set of values, rather than an exact science or process.”<sup>1</sup>*

This was a key finding from a recent report by the Co-production Collective at UCL, UK.<sup>1</sup> It highlights the importance of values and ethics in the co-production of knowledge. Co-production has gained increasing traction in the Australian public healthcare landscape, which is in part driven by the growing importance placed on the participation of all stakeholders in healthcare decision making.<sup>2</sup> This increased interest reflects the wider societal trend of shared decision making and autonomy in healthcare.<sup>3</sup> Co-production is a problematic term to define, and there is much debate about its scope and overlap with other terms, like co-creation and participatory research. I use the term here in its broadest sense. It can involve any research endeavours where citizens, policy makers, and researchers work together to jointly contribute to the development, production, and implementation of initiatives to improve health outcomes. A paper in this special edition addresses these definitional issues.<sup>4</sup>

With the increasing emphasis on co-production, several challenges arise. Recent literature calls for a set of shared values and a greater understanding of the costs and challenges of co-production.<sup>5-7</sup> However, important questions

remain about when co-production should be used and the best methods to approach the co-production of research.<sup>8</sup> There is also an absence of empirical research to assist in making these decisions.<sup>5</sup>

In trying to conceptualise these challenges and costs, I contend that all parties engaged in co-production need to consider the ethical aspects of the co-production of research. When knowledge is co-produced between stakeholders with different contributions, agendas, and interests, a different or wider range of ethical codes and norms might need to be considered. To date, the ethical issues that arise during the co-production process have been dealt with on an ad hoc and in situ basis. However, there is a need to make the ethical aspects and considerations of co-production explicit. This should be done both a priori, to help researchers decide whether co-production is the best approach<sup>1</sup>, and during the research process to increase awareness of the ethical issues and develop an approach to dealing with ethical issues prospectively.<sup>2</sup>

In this article, I describe several ethical considerations or values that could be considered in co-production. I first describe these principles and then discuss how they might be important in designing and implementing healthcare research using co-production. This discussion references only some key issues and challenges that have been identified in co-production research.

## Ethical principles and co-production

The principlism approach and framework developed by Beauchamp and Childress has become the dominant method used in both the teaching and evaluation of ethical issues in medicine and arguably in healthcare more generally.<sup>9,10</sup> The four core moral principles of non-maleficence, beneficence, justice and autonomy have been the cornerstone of medical ethics since their development in the late 1970s.<sup>11,12</sup> These principles were initially designed for medical ethics, with the individual at the heart of the interaction. They were subsequently expanded and augmented to be relevant to a public health context, resulting in the seven mid-level principles in the Principlism Framework (Table 1).

A comparative review of these principles and behavioural norms by Byrd and Winkelstein<sup>13</sup> showed that these core principles and norms exist in all eight key health associations and ethical codes covering professions of medicine, nursing, public health and informatics in the US.<sup>13</sup> This suggests that they are commonly agreed and endorsed principles in healthcare. Therefore, it is not by chance that these same principles form the framework for ethical collaborations in the *Australian Consensus Framework for Ethical Collaboration in Healthcare* (ACF).<sup>14</sup> This framework was developed by the Australian Healthcare and Hospitals Association (AHHA), Australia's national peak body for public and

not-for-profit hospitals and healthcare providers. The ACF framework outlines five substantive principles (Table 1) and 10 procedural principles.

As the principles were originally designed to be prima facie (i.e. binding unless they conflict with another principle), ethical challenges can arise when the application of these principles are considered from the perspectives of different stakeholders with differing priorities. Nevertheless, these principles can act as discussion points in the planning stage of co-production and the resolution of conflicts that may arise. They may also help stakeholders understand the differing perspectives of other parties in the co-production process. The ACF is particularly useful in helping guide the process because its procedural principles outline how interactions should ideally be characterised and include honesty, transparency, shared understanding, oversight and reasonableness. These ethical principles are designed to be broad and help guide both clinical practice and research conduct. Moreover, I espouse they will be useful in the design and conduct of co-production.

## Use of the principles in practice

There have now been many successful and unsuccessful attempts at co-production in various health domains.<sup>6,15-19</sup> Case studies have highlighted several issues<sup>5,7,20</sup>, including significant issues related to ethical conduct such as ownership and intellectual property, objectivity and maintenance of the scientific method, power imbalances, and conflicting agendas. There are many more, but I use these to highlight the use of the principles in practice.

There are two broad questions. Firstly, in determining whether co-production should take place at all, perhaps a more utilitarian ethical approach is warranted. This approach involves various parties weighing up the costs and benefits of engaging in co-production. This can be challenging because many of the costs and indeed benefits are very uncertain, particularly if the project is a brand new relationship. To address these questions, each party could consider the ethical principles and ask whether such a collaboration will yield social benefits, while being efficient and equitable. The key question individuals or groups should ask themselves is whether the expected net benefits of this co-production will be greater than the net costs, bearing in mind the uncertainty (these costs and benefits will differ in nature and importance for various individuals and groups). If so, then co-production is a worthwhile way forward. If not, then another approach should be explored.

The second question is how to use these principles during the collaboration process to address the issues outlined above. For considering ownership and intellectual property issues, principles of justice will be paramount. Determining contributions a priori and negotiating a fair, shared understanding of contribution at the outset is critical to avoiding disputes about responsibilities and

**Table 1.** Ethical principles from Beauchamp and Childress (Principlism Framework)<sup>8</sup> and the Australian Consensus Framework (ACF) for Ethical Collaboration in the Healthcare Sector<sup>14</sup>

Framework	Principle/Norm	Description
Principlism	Non-maleficence	Do no harm
Principlism	Beneficence	Do good or produce benefit for individual patients or clients or society
ACF	Benefit and welfare	Acting in ways that advance the health, wellbeing and interests of patients, consumers, communities, populations, healthcare systems and the healthcare sector, and that avoid or minimise harm.
Principlism and ACF	Justice	Health equity – equality of opportunity and fair distribution of outcomes. Fair distribution of access, opportunities, and privileges, and socio-political and economic inequity reduction.
Principlism	Autonomy	Respect for the rights of the individual to decide
ACF	Respect for patients, consumers, communities, students, educators, colleagues, and organisations.	All interactions and activities are respectful of the dignity, worth, rights, beliefs, values, preferences, customs, and cultural heritage of all involved.
Principlism	Health maximisation	Maximise health at a population level (social beneficence)
ACF	Solidarity	A collective commitment to equitably sharing costs and benefits for the good of a group, community, nation, or the global population.
Principlism	Proportionality	Balancing individual freedom against public good
Principlism	Efficiency	A moral duty to use health resources efficiently and avoid waste
ACF	Effectiveness Efficiency, safety, sustainability	Continuous commitment to improving outcomes in healthcare through promotion of responsible innovation, generation and utilisation of evidence, economic cooperation, reduction of waste, and productive utilisation of limited resources.

credit. If circumstances change through the dynamic co-production process, these agreements need to be updated in line with the changes in the stakeholders' contribution.

When considering objectivity concerns and issues surrounding research methods, principles of respect and autonomy are needed. Co-production, by its nature, should respect the views and values of all parties. This means traditional research methods may need to be renegotiated, to realign with the objectives of the research. While acknowledging that a researcher's main goal may be to get the results published, and thus certain parameters need to be maintained in the scientific process, it is also necessary to consider that this is unlikely to be the goal of other stakeholders. Therefore, benefit and welfare considerations must also be borne in mind as health maximisation. Agreements must be reached about how the objectives of each stakeholder can be achieved and where that intersection of differing objectives lies. Making these goals explicit for all

stakeholders at the beginning of the research process can help avoid protracted disputes later.

All social relationships are characterised by power imbalances. Throughout a relationship, power can be thought of as moving along the continuum and at some points, the power can balance when both parties are working towards the same goal. When such imbalances exist, it is incumbent upon the more powerful party to prioritise the principles of beneficence and justice. Therefore, in co-production, working towards a mutually agreeable goal where parties are engaged and have their preferences heard (autonomy) is the key to successfully dealing with power imbalances.

Conflicting agendas require that parties reflect on the principles of respect (autonomy) and solidarity to ensure there is a broader collective goal and that each agenda can be met while maintaining the integrity of the overarching goal of the research. Discussion of these values and priorities from the outset is key to understanding conflicts and resolving them.

An important ethical principle in the Australian public healthcare landscape is health equity, equality of opportunity and fair distribution of outcomes. One population that has experienced significant health inequalities is the Aboriginal and Torres Strait Islander population. There have been attempts to leverage co-production to address such health inequalities in recent years. An example of this is the Coalition for Research to Improve Aboriginal Health (CRIAHA), an Aboriginal-led, multidisciplinary, co-production research model.<sup>21</sup> Key ethical issues raised by CRIAHA include trust, respect, and sharing of power and leadership. Such principles are paramount to ensure health equity in such vulnerable populations. Health equity is also of paramount importance for other vulnerable groups where there is an imbalance of power, including the aged, disability groups and minors.

Ultimately, all co-production research should be assessed and evaluated by considering ethical principles. Specifically, such research should ideally maximise the public good while ensuring that all stakeholders' interests are considered and optimised. Such "common ground" has been nicely conceptualised in the relational model of collaborative inquiry.<sup>22,23</sup>

Each stakeholder will face various and different ethical challenges in the process. For researchers, these can include maintaining objectivity and ensuring the integrity of the research process, while for policy makers, it can be about achieving organisational goals and evidence generation that meets the needs of stakeholders. For consumers, it can be about having their voice heard and being an integral part of the research generation process. Finding a space where the interests of all concerned parties can co-exist will result in optimal co-production outcomes. To get to this space, the preferences and positions of each party need to be made explicit and then negotiated, based on the goals of the research. Ethical principles and norms are integral to trying to achieve this common ground.

## Conclusion

Successful and synergistic co-production requires an ethical framework to guide early and ongoing decision-making. This paper is a first step to outlining what form this framework could take. Further work is needed to ensure a consistent and ethical approach to co-production that is feasible and in the interests of all parties. More work is needed to further elaborate on how these principles can be implemented and adapted to suit the differing issues and contexts of co-production research, and more discussion is needed around funding and infrastructure support.

## Peer review and provenance

Externally peer reviewed, invited.

## Competing interests

None declared.

## Author contributions

KP is the sole author and is responsible for all aspects of the work, including ideas and writing.

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