[COUNCIL PAPER 011221-2]

Cochrane Values Statement:

A proposal for a co-creation protocol

Cochrane

Cochrane
Consumer Network

About this document

This document outlines a process for co-creating a Cochrane's Values Statement. The intention of this process is that anyone in the world can have an opportunity to be involved in giving feedback and helping shape Cochrane's values.

This document and the process described within it align with existing documentation, including Cochrane's 'Strategy for Change: 2021-2023',[1] Cochrane's principles,[2] Cochrane's policies,[3] and the 'Consumer involvement in Cochrane – the Statement of Principles'.[4]

Contents

Version

This document is Version 0.2 of the "Cochrane Values Statement: A proposal for a co-creation protocol", created by members of the Cochrane Consumer Executive, for feedback from the Cochrane Council. This version was created on 20th November 2021. The time of the Cochrane Consumer Executive members who contributed was volunteered.

Authors and contributions

The authors and respective contributions are described below.

Author	Tasks
Jack Nunn	Researching methods, summarising proposed co-creation process, creating documentation
Helen Bulbeck	Editing, reviewing
Maureen Smith	Editing, reviewing
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Ndi Euphrasia Ebai-Atuh	Contributed to discussions which informed this document
Ana Beatriz Pizarro Nule	Contributed to discussions which informed this document
Richard Morely	Contributed to discussions which informed this document

Thank you also to Judith Brodie for her comments on Version 0.1

Reporting

The process for creating the Cochrane Values Statement is being reported using 'Standardised Data on Initiatives' (STARDIT). A prospective STARDIT report version of this document can be found in the references.[5]

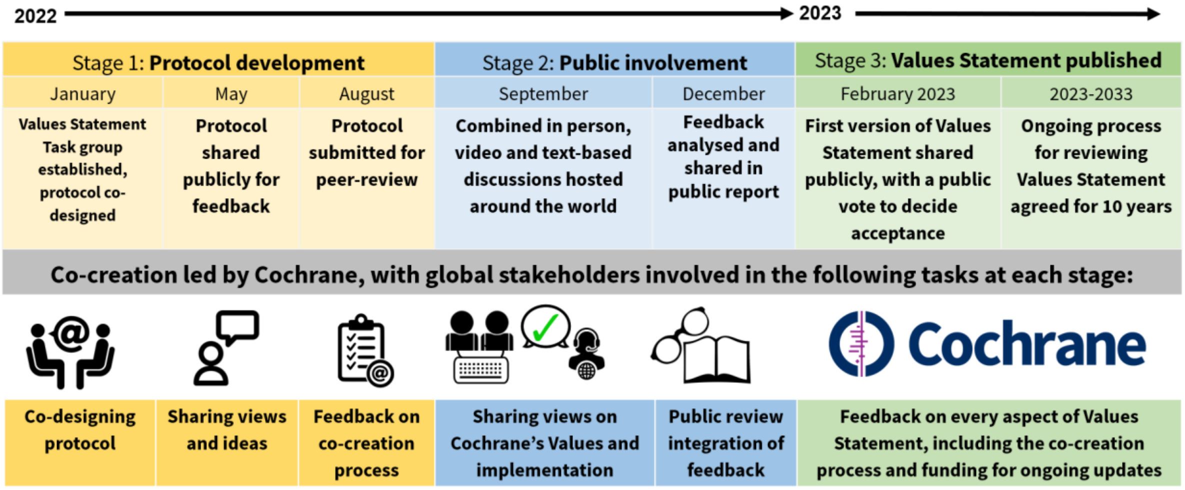
Executive Summary

Purpose

Cochrane is a global not-for-profit organisation, founded on shared values. It is important that these values are transparent and can evolve, with everyone in the global Cochrane community, and the wider public, given a chance to shape these values.

The Values Statement is a way for Cochrane to state publicly what values guide our work. It is also a statement about how our organisation will operate, including how those working for, with or funding Cochrane's activities will be accountable for working within the values codified within the statement.

Proposed stages of Values Statement co-creation



2022 → 2023 →

Stage 1: **Protocol development**			Stage 2: **Public involvement**		Stage 3: **Values Statement published**	
January	May	August	September	December	February 2023	2023-2033
Values Statement Task group established, protocol co-designed	**Protocol shared publicly for feedback**	**Protocol submitted for peer-review**	**Combined in person, video and text-based discussions hosted around the world**	**Feedback analysed and shared in public report**	**First version of Values Statement shared publicly, with a public vote to decide acceptance**	**Ongoing process for reviewing Values Statement agreed for 10 years**
Co-creation led by Cochrane, with global stakeholders involved in the following tasks at each stage:						
Co-designing protocol	**Sharing views and ideas**	**Feedback on co-creation process**	**Sharing views on Cochrane's Values and implementation**	**Public review integration of feedback**	**Feedback on every aspect of Values Statement, including the co-creation process and funding for ongoing updates**	

Proposed Governance and funding of Values Statement co-creation

It is proposed that the co-creation process of the Values Statement will be hosted by the Cochrane Consumer Executive. This will include any appropriate additional funding or support from Cochrane for hosting the 'Values Statement Task Group' (including secretariat support).

The co-creation process for the Values Statement will have any budget approved in advance, which will help inform the process. The co-creation process will be drafted by the 'Values Statement Task Group', with a final vote for approving the process being made open to all Cochrane Members, and potentially the wider public (depending on agreed resourcing for platforms).

It is proposed that the Cochrane Council oversees the entire co-creation process, including facilitating arrangements for any additional funding or resourcing that might be required. It is also proposed that the Governing Board, Central Executive team and any other staff feed into the co-creation process transparently (with membership of the Values Statement Task Group open to anyone), during the proposed stages above, with no subsequent powers of adaptation or redaction granted to any of the above once the co-creation process is complete, including the Chief Executive. Pending further discussion and input from internal governance experts, it is proposed that final acceptance of the Values Statement be formally accepted by the Cochrane Council on behalf of all Cochrane members.

Definitions

Term	Definition
Co-creation	The process of creating something in a collaborative way with multiple stakeholders.
Stakeholder	The term 'stakeholder' means anyone who has a 'stake' in health research or service, in particular those with important knowledge, experiences, expertise or views that should be taken into account. It can include: researchers; research funders; health service commissioners and managers; healthcare professionals; policy makers; people affected by the research; people with specific health conditions; people with specific genomics variations; patients and the general public (including 'tax-payers' for publicly funded research); service users and consumers of health technology.
Values	An organisation's values are prospective and prescriptive beliefs; they affect ethical behaviour of a person or organisation and are the basis of their intentional activities.

Detailed summary of proposed co-creation process

Stage	Tasks
1: Protocol development	Cochrane Consumer Executive drafts Terms of Reference for 'Values Statement Task Group'
	Cochrane Consumer Executive shares invitation to join 'Values Statement Task Group'
	'Values Statement Task Group' established (including finalising Terms of Reference)
	Cochrane Consumer Executive hosts online discussion and decision making process for agreeing protocol development methodology*
	Protocol shared publicly for feedback, including using STARDIT[6]
	Feedback collated and analysed by either *(pending budget)*: 1: Cochrane Consumer Executive 2: appropriate Cochrane staff 3: an external researcher/research team
	Protocol submitted for peer-review in open access journal
2: **Public involvement**	Draft Values Statement is created and shared by the 'Values Statement Task Group'
	Interactive discussions are hosted globally in order to explore and further codify the values of Cochrane's members and other stakeholders
	As per the agreed protocol, feedback is gathered, analysed and incorporated into a draft Values Statement
	Public review of the analysis and integration of feedback
	Final feedback on every aspect of Values Statement, including evaluating the co-creation process and agreeing funding for ongoing updates for the next 10 years
3: Values Statement published	First version of Values Statement shared publicly, with a public vote to decide acceptance
	Ongoing process for reviewing Values Statement agreed for 10 years

*The charity Science for All[1] has offered to host the online discussion and decision making process for the 'Values Statement Task Group' pro-bono. *Note*: Resourcing for facilitation and moderation of the 'Values Statement Task Group' will need to be agreed before this proposal is refined and adapted into a plan.

Proposed paradigms for co-creation protocol

This section summarises the paradigms which will be used to guide the co-creation process. Further detail will be provided in any peer-reviewed protocol.

Rights-based paradigms

Human rights

The United Nations describes human rights as ‘inherent to all human beings’[7]. The United Nations (UN) 1948 Universal Declaration Human Rights states ‘all human beings are born free and equal in dignity and rights’. The World Health Organisation’s 1978 ‘Declaration of Alma-Ata’ stated ‘the people have the right and duty to participate individually and collectively in the planning and implementation of their health care’[8], further connecting concepts of democracy and self-government with universal rights in healthcare implementation.

The United Nations has provided much guidance on working with Indigenous peoples around the world [9], and the 'Declaration on the Rights of Indigenous Peoples United Nations' will be a guiding paradigm during this process[10], including the statement “Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them”.

Informed by the United Nations ‘Universal Declaration Human Rights’ statement that all humans should be able to ‘receive and impart information and ideas’[11], this research process was also influenced by the Open Access movement, which can be considered part of this paradigm, in particular for those who cannot afford to access health information behind a paywall[12].

Within the paradigm of human rights are the rights of women and children, codified in the UN’s ‘Convention on the Rights of the Child’ and the UN’s statements on gender equity and equality[13–15]. The principles of self-autonomy and individual choice in health are monitored by the UN, in particular women having the right to decide whether to terminate pregnancies[16].

Consumer rights or human rights?

While the connection between human rights and democracy is significant, it is important to note that human rights and concepts of ‘social democracy’ can also be contrasted with ‘consumer rights’. From one perspective, the social democratic rights-based paradigm relies on collective action to create public health initiatives, codified by the World Health Organisation (WHO), which stated that health promotion is the process of ‘enabling people to increase control over, and to improve their health’ [17].

Parallel to the human-rights based paradigms (but not independent of them) is the ‘consumer rights’ paradigm, where people are involved as ‘consumers’, ‘users’, ‘tax-payers’, ‘payers’ or ‘customers’. This model is grounded in free-market paradigms, based on the axiom that the market model will create services that are needed in response to the needs of the customers[18]. The origins of the word are associated with a transactional merchant relationship where the ‘consumer’ takes goods or services, and to ‘consume’[19]. A recent assessment of the influence of public involvement on health research concluded that a ‘consumerist approach is still predominant and that in reality the public voice has limited impact upon the research design or upon which research gets funded’[20]. In this document, humans with rights will be described as people, not consumers, and people with a ‘stake’ in Cochrane's work will be described as ‘stakeholders’. It is proposed the word ‘consumer’ is not used in this process at all.

Cultural neutrality and environmental rights

Values, assumptions, ways of thinking and knowing are not shared universally. The participatory process proposed for developing this Values Statement will require that it continually attempts to map cultural variations, in an attempt to avoid unconsciously reinforcing particular (often 'dominant')[9] values. Transparent acknowledgement of differing values and perspectives is critically important, in particular when mapping if different stakeholders' values are complementary or opposing. A participatory process requires mapping all of these perspectives and, where possible, involving people in labelling different perspectives and values.

Many problems facing humans are shared by non-human life forms and ecosystems, including rapid climate change, air pollution and sea-level rise. If initiatives are to operate in inclusive, culturally-neutral ways, reconsideration of the language used to describe relationships between humans, non-human life and the environment is essential.[21] Environmental and social sciences are challenging and redefining colonial-era concepts of what can be 'owned' as property or who 'owns' [21,22]. As a result, ecosystems such as rivers and non-human animals, are being assigned 'personhood'[23–25]. Western European legal and economic traditions are frequently incompatible with those of some Indigenous peoples'.[21,26,27]

It is acknowledged that it will be a challenging process to 'de-colonialise' and 'de-anthropocise' language and action[28,29], as this may be perceived as a challenge to some people's cultural attitudes which may not align with the United Nation's universally enshrined principles of democracy, human rights and environmental rights. Similarly, variation in the values which underpin different economies, healthcare systems and environmental management practices will also need to be mapped.

The participatory process used for developing the Values Statement will need to be transparent about how different stakeholders have been involved in shaping it in order to improve ongoing evaluation of the process.

Participatory action research

Participatory action research is an umbrella term which describes several related approaches, including forms of action research which embrace a participatory philosophy and include 'co-design' and 'co-production' of research [30]. These approaches share a process whereby researchers, the public and other relevant stakeholders "work together, sharing power and responsibility from the start to the end of the project",[31] including knowledge generation and translation[31].

At the core of participatory action research is critical reflexivity, a process which asks people involved to reflect on the causes of problems, any solutions and the actions that people can take to improve the current situation [32(p11)]. It is a form of collective self-reflective enquiry undertaken by participants in order to understand their situation from a number of perspectives, including rationality and a sense of justice [33(p153)]. In a health context, participatory action research attempts to reduce health inequalities by supporting people to be involved in data collection, reflection and, ultimately, actions to improve their own health [34]. It is an interactive process, seeking to understand and improve things through change [34]. Participatory action research integrates knowledge translation into the research process, by involving those who can inform future actions as partners in the research. The concept of 'dominant interests' is especially important in the context of participatory action research with Indigenous peoples around the world, and the UN's recognition that their culture can be threatened by 'dominant' cultures[9]. Methods of mapping such 'interests' in a standardised way are proposed by using STARDIT.[6] Guided by this paradigm, where possible, stakeholders will be invited to be involved in every stage of the co-creation of the Cochrane Values Statement.

Share and share alike

References

1. Cochrane. Strategy for Change: 2021-202. https://web.archive.org/web/20210719155527/https://community.cochrane.org/sites/default/files/uploads/inline-files/Strategy for Change 2021 FINAL.pdf. Published 2021. Accessed November 15, 2021.
2. Cochrane. Cochrane principles. https://www.cochrane.org/about-us.
3. Cochrane. Policies . https://community.cochrane.org/organizational-info/resources/policies. Accessed November 15, 2021.
4. Cochrane. The Statement of Principles for Consumer Involvement in Cochrane | Cochrane Consumer Network. https://web.archive.org/web/20210921021436/https://consumers.cochrane.org/news/statement-principles-consumer-involvement-cochrane. Published 2017. Accessed November 15, 2021.
5. Nunn J. *STARDIT Report: Cochrane Values Statement*.; 2021. https://wikispore.wmflabs.org/wiki/Cochrane_Values_Statement.
6. Nunn J, Shafee T, Chang S, et al. Standardised Data on Initiatives – STARDIT: Beta Version. October 2021. doi:10.21203/RS.3.RS-934285/V1
7. United Nations. Human Rights . https://www.un.org/en/sections/issues-depth/human-rights/. Published 2021. Accessed February 24, 2021.
8. World Health Organisation. Declaration of Alma-Ata. http://www.who.int/publications/almaata_declaration_en.pdf?ua=1. Published 1978. Accessed June 25, 2018.
9. United Nations For Indigenous Peoples. Indigenous Peoples at the UN. https://www.un.org/development/desa/indigenouspeoples/about-us.html. Published 2018. Accessed April 16, 2019.
10. United Nations. *United Nations Declaration on the Rights of Indigenous Peoples United Nations*.; 2007. https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf. Accessed February 25, 2021.
11. United Nations. *Universal Declaration of Human Rights*.; 1948. http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf. Accessed February 5, 2018.
12. Kirsop B, Chan L. Transforming access to research literature for developing countries. *Ser Rev*. 2005;31(4):246-255. doi:10.1080/00987913.2005.10764998
13. UN Women. Human rights of women. https://www.unwomen.org/en/news/in-focus/end-violence-against-women/2014/rights. Accessed March 1, 2021.

14. United Nations. Convention on the Rights of the Child. https://www.unicef.org.au/upload/unicef/media/unicef-simplified-convention-child-rights.pdf. Accessed March 1, 2021.

15. UN Women. United Nations Entity for Gender Equality and the Empowerment of Women. https://www.unwomen.org/en. Accessed March 1, 2021.

16. United Nations. *Abortion Policies and Reproductive Health around the World*.; 2014. https://www.un.org/en/development/desa/population/publications/pdf/policy/AbortionPoliciesReproductiveHealth.pdf. Accessed March 1, 2021.

17. The World Health Organisation. The Ottawa Charter for Health Promotion. *WHO*. 2016. http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.html. Accessed November 3, 2016.

18. Burton H, Adams M, Bunton R, et al. Developing stakeholder involvement for introducing public health genomics into public policy. *Public Health Genomics*. 2009;12(1):11-19. doi:https://dx.doi.org/10.1159/000153426

19. Nunn J. “Consumer” should be a taboo word in public services. *Heal Issues*. (114):38. http://search.informit.com.au/documentSummary;dn=507398570747775;res=IELHEA. Accessed April 27, 2016.

20. Green G. Power to the people: To what extent has public involvement in applied health research achieved this? *Res Involv Engagem*. 2016;2(1):28. doi:10.1186/s40900-016-0042-y

21. Bromley DW. The commons, common property, and environmental policy. *Environ Resour Econ*. 1992;2(1):1-17. doi:10.1007/BF00324686

22. Butler JRA, Tawake A, Skewes T, Tawake L, McGrath V. Integrating traditional ecological knowledge and fisheries management in the torres strait, Australia:The catalytic role of turtles and dugong as cultural keystone species. *Ecol Soc*. 2012;17(4). doi:10.5751/ES-05165-170434

23. Rachel Feltman. Orangutan granted rights of personhood in Argentina. *The Washington Post*. https://www.washingtonpost.com/news/speaking-of-science/wp/2014/12/22/orangutan-granted-rights-of-personhood-in-argentina/?noredirect=on&utm_term=.53d1313c54bc. Published 2014. Accessed April 17, 2019.

24. Hutchison A. The Whanganui River as a Legal Person. *Altern Law J*. 2014;39(3):179-182. doi:10.1177/1037969X1403900309

25. O’Donnell E. *Legal Rights for Rivers: Competition, Collaboration and Water Governance*.; 2018. https://www.routledge.com/Legal-Rights-for-Rivers-Competition-Collaboration-and-Water-Governance/ODonnell/p/book/9780367584160. Accessed April 26, 2021.

26. Genome British Columbia. *Genomics Positively Affects Life, Every Day*.; 2019. https://www.genomebc.ca/wp-content/uploads/2019/06/GBC-4228-2018-AR-FINAL_WEB.pdf?utm_source=Master+List&utm_campaign=8c36d44d96-ANNUAL_RPT_CAMPAIGN_2019_07_10&utm_medium=email&utm_term=0_007b42effb-8c36d44d96-96302171&mc_cid=8c36d44d96&mc_eid=40205f8c68. Accessed July 18, 2019.

27. Indigenous Corporate Training. Who owns Traditional Ecological Knowledge? https://www.ictinc.ca/blog/owns-tek. Published 2013. Accessed July 18, 2019.

28. Rubis JM. The orang utan is not an indigenous name: knowing and naming the maias as a decolonizing epistemology. *Cult Stud*. 2020;34(5):811-830.

doi:10.1080/09502386.2020.1780281

29. Rubis JM, Theriault N. Concealing protocols: conservation, Indigenous survivance, and the dilemmas of visibility. *Soc Cult Geogr*. 2020;21(7):962-984. doi:10.1080/14649365.2019.1574882

30. Macaulay AC. Participatory research: What is the history? Has the purpose changed? *Fam Pract*. 2016;351(3):cmw117. doi:10.1093/fampra/cmw117

31. INVOLVE. *Guidance on Co-Producing a Research Project*.; 2018. https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf. Accessed March 14, 2018.

32. International Collaboration for Participatory Health Research (ICPHR). *Position Paper 1: What Is Participatory Health Research? Version: May 2013*.; 2013. http://www.icphr.org/uploads/2/0/3/9/20399575/ichpr_position_paper_1_defintion_-_version_may_2013.pdf. Accessed June 13, 2017.

33. Kemmis S, Nixon R, McTaggart R. *The Action Research Planner: Doing Critical Participatory Action Research.*; 2014. doi:10.1007/978-981-4560-67-2

34. Baum F, Macdougall C, Smith D. Participatory action research. *J Epidemiol Community Heal*. 2006;60(60):854-857. doi:10.1136/jech.2004.028662