

...to publish or be *damned*



decision-making around patient confidentiality in case study research

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Aim

To produce an algorithm that can guide would-be case study practitioner-researchers through the decision-making process about seeking informed consent and how (and whether) to proceed without it.

Background

As a form of qualitative research, case studies offer practitioners the possibility of contributing from their own clinical experience to innovating palliative care practice (Campbell 2013). However, clinical information must be used sensitively and must protect patient confidentiality (McCurdy 2015; UKBHC 2014).

Best practice dictates gaining informed consent. However, where consent is either not possible or would not be appropriate, the anonymization of identifying details is recognized as an alternative way to protect confidentiality. Yet practitioner-researchers remain ethically responsible for protecting confidentiality.

Methods

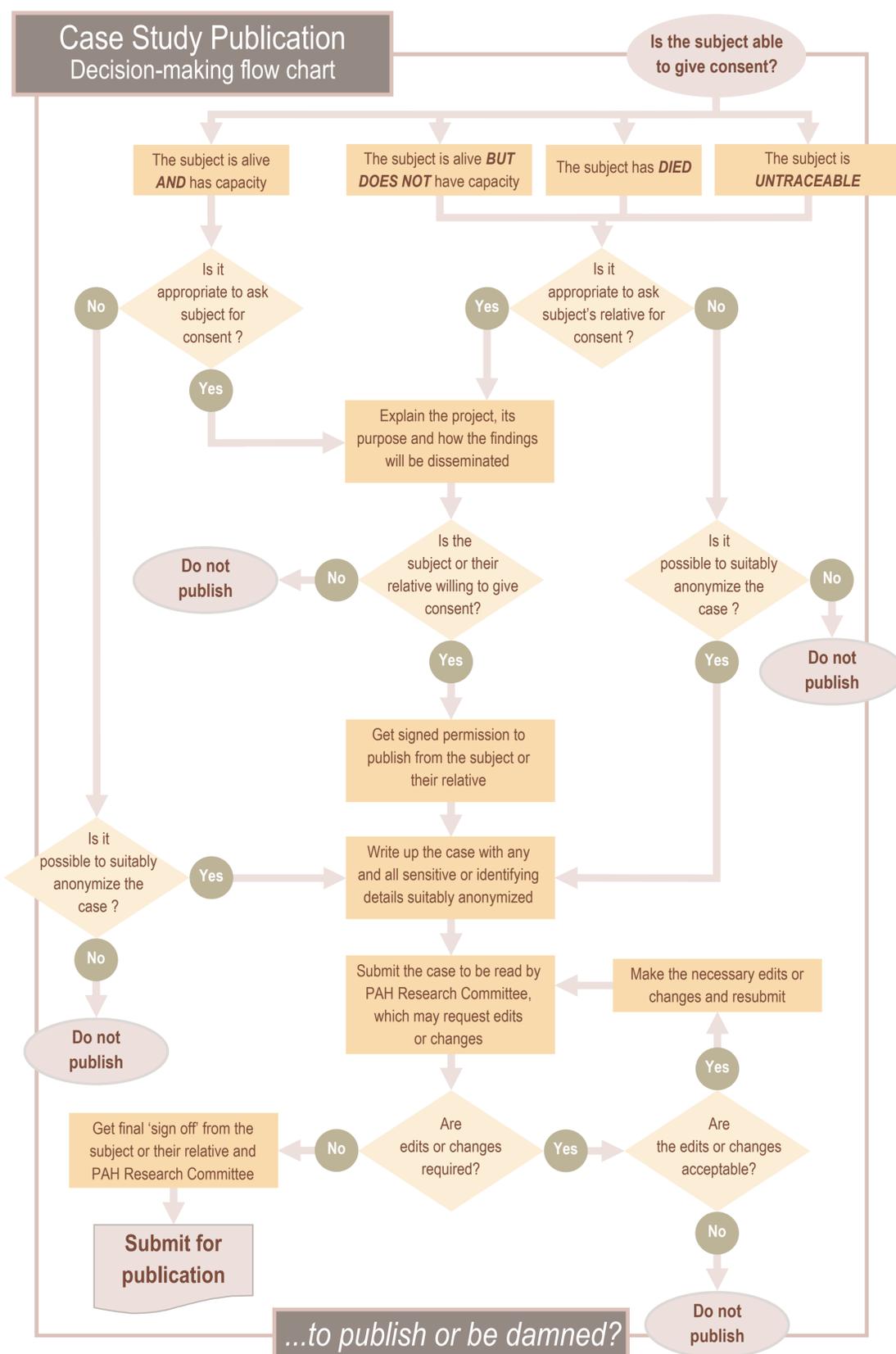
The issue was first discussed by the Hospice Ethics Committee. This identified the range of concerns the algorithm needed to address. These concerns were discussed further by the Hospice Research Committee, which requested a draft algorithm. The draft was presented and refinements were recommended. Once accepted, the algorithm was tested against a request by the Hospice Chaplain to publish a case study.

Results

An algorithm was produced that guides would-be practitioner-researchers through the decision-making process about seeking informed consent towards case study publication. Beginning with the question, 'Is the subject able to give consent?' the flowchart guides practitioner-researchers step-by-step through a series of 'pinch-points' in making their decision, highlighting key questions that need to be considered. These include: whether the subject has capacity; the appropriateness of requesting consent from the subject or their relative; whether the case can be suitably anonymized; and how to respond to organizational peer-review.

Conclusion

The algorithm is an effective tool that can guide practitioner-researchers step-by-step through the process of deciding whether or not they can proceed to publish clinical case material while properly respecting patients' confidentiality.



References:
 Campbell, M.L. (ed.) (2013). *Case Studies in Palliative and End-of-Life Care*. John Wiley & Sons, Inc.
 McCurdy, D.B. (2015). *Ethical issue in case study publication*. In G. Fitchett and S. Nolan, *Spiritual Care in Practice: Case Studies in Healthcare Chaplaincy* (pp.282-298). London: Jessica Kingsley Publishers.
 UKBHC (2014). *Code of Conduct for Healthcare Chaplains*. Cambridge: UK Board of Healthcare Chaplains.