



- **FACT SHEET No. 6**

将患者的声音纳入疼痛教育和研究

疼痛是一种多维现象,因人、因病而异并随着病因和病情的变化而变化。患者及其家属可以将他们的疼痛经验分享给教育工作者、学生和研究人员,有助于他们更加准确地了解疼痛如何影响他们的生活。评估他人的疼痛并不容易,在共情护理中通过了解患者的情况或者倾听患者的描述可以促进对他人疼痛的评估^[2,7]。作为疼痛教育和研究的合作者,患者及其家属对其疼痛护理中涉及到的临床和研究的决策具有一定的影响。

疼痛教育中的患者声音

- 为学生提供了了解患者情况或者倾听患者描述的机会,让生物医学学习方法变革为更加人性化、以病人为中心的医疗保健方法^[6]。如此有助于我们了解医疗保健的过程和治疗效果的潜在障碍^[5]。
- 通过个人或临床经验的反思性写作练习可以帮助学生探索疾病的主观体验,使他们产生更大的同理心和自我意识
- 通过课程开发、课程审查,使患者有机会将其主观想法纳入医师教育中,为疼痛教育做出贡献。
- 将疼痛患者作为疼痛教育的“利益相关者”,他们可以参与课程设计、课程实施过程。(例如:患者可以作为委员会成员和/或课堂以及临床研讨的参与者)^[8]。

研究合作者/参与者中患者的声音

疼痛是一种非常个体化和主观的体验。定性研究作为一种研究方法,通常包含对个人情况的了解或个人疼痛体验的描述。 以下是将患者的声音作为研究团队合作者、研究参与者纳入研究的方法。

- 患者和公众参与研究（有时被称为“患者参与”）通常被定义为使用或通过这些人进行研究，而不是针对或关于他们而进行的研究^[6]。

- 患者可以成为研究的合作者，带头收集患者的声音^[5]，并确定研究重点^[6]。

- 患者和公众都参与研究的一系列过程，包括通知、咨询、参与、合作和授权^[4]。

- 患者参与以患者为导向的研究是一项在控制管理、确定优先重点、实施研究以及知识转化中有意义且积极的协作。

- 患者参与研究的指导原则包括包容、支持、相互尊重以及共同建设（从研究开始就作为合作者）^[4]。

- 许多资助机构要求患者参与所有水平的基金发展。

- 让患者作为研究合作者参与研究的好处包括增加研究招募率，提高筹资成功率，改进研究方案，以及提高对患者相关结果的选择^[3]。

- 患者参与研究作为一种新兴的科学评估是一个迅速发展的领域对患者、研究人员和医疗保健具有潜在益处。

- 定性研究为捕捉患者的发言提供了机会，通常包括对个人情况的了解或患者个人情况的自我描述。

- 定性数据可以通过访谈、观察和文件进行收集。

- 通过访谈询问人们的经历，可以获得丰富的信息，也能对感兴趣的话题有更多的了解。

- 开放式问题比封闭式问题可以提供更多的细节，如“告诉我有关”或“如何……”。

- 讲故事在许多文化中根深蒂固，这种定性研究的形式被称为“叙事研究”。

- 当调查的焦点是“生活体验”时，它被称为现象学；例如“患有纤维肌痛的疼痛是什么样的？”

- 小组座谈会是指 6-10 人和一位主持人一起探讨一个特定的问题或主题。这是收集不同观点的有用方法。

- 定性研究方法往往是以患者为中心研究开展的重要切入点。

资料来源

Patient and Community Engagement Research: <https://pacerinnovates.ca/engage/>

<http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/>: This organization helps identify research questions important to patients and addresses the mismatch between clinician-driven research and gaps in evidence that is important to patients.

<http://www.invo.org.uk>: This organization is part of, and funded by, the National Institute for Health Research to support active public involvement in public health and social research.

<http://www.iap2.org>: This organization provides a guiding framework for conceptualizing the spectrum of the public's role in a public participation process.

<http://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub.aspx>: This organization has created a resource hub compiling international open-source tools for patient engagement initiatives to improve health and health care.

<https://www.pcori.org>: This organization funds research to help patients choose health-care options that best meet their needs. It provides a number of resources to guide patient engagement in research.

https://painconsortium.nih.gov/nih_pain_programs/coepes.html: [Patient interviews may be found here.](#)

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