



CLINICAL GUIDELINES PROGRAM

NEW YORK STATE DEPARTMENT OF HEALTH AIDS INSTITUTE | HIV · HCV · SUBSTANCE USE · LGBT HEALTH

Clinical Guidelines Program Approach to Shared Decision-Making

Date of current publication: August 8, 2023

Lead authors: Jessica Rodrigues, MS; Jessica M. Atrio, MD, MSc; and Johanna L. Gribble, MA

Writing group: Steven M. Fine, MD, PhD; Rona M. Vail, MD; Samuel T. Merrick, MD; Asa E. Radix, MD, MPH, PhD; Christopher J. Hoffmann, MD, MPH; Charles J. Gonzalez, MD

Committee: [Medical Care Criteria Committee](#)

Date of original publication: August 8, 2023

Contents

Rationale	1
Benefits	1
Approach.....	1
Resources and Suggested Reading.....	3
References	3

Rationale

Throughout its guidelines, the New York State Department of Health (NYSDOH) AIDS Institute (AI) Clinical Guidelines Program recommends “shared decision-making,” an individualized process central to patient-centered care. With shared decision-making, clinicians and patients engage in meaningful dialogue to arrive at an informed, collaborative decision about a patient’s health, care, and treatment planning. The approach to shared decision-making described here applies to recommendations included in all program guidelines. The included elements are drawn from a comprehensive review of multiple sources and similar attempts to define shared decision-making, including the Institute of Medicine’s original description [Institute of Medicine 2001]. For more information, a variety of informative resources and suggested readings are included at the end of the discussion.

Benefits

The benefits to patients that have been associated with a shared decision-making approach include:

- Decreased anxiety [Niburski, et al. 2020; Stalnikowicz and Brezis 2020]
- Increased trust in clinicians [Acree, et al. 2020; Groot, et al. 2020; Stalnikowicz and Brezis 2020]
- Improved engagement in preventive care [McNulty, et al. 2022; Scalia, et al. 2022; Bertakis and Azari 2011]
- Improved treatment adherence, clinical outcomes, and satisfaction with care [Crawford, et al. 2021; Bertakis and Azari 2011; Robinson, et al. 2008]
- Increased knowledge, confidence, empowerment, and self-efficacy [Chen, et al. 2021; Coronado-Vázquez, et al. 2020; Niburski, et al. 2020]

Approach

Collaborative care: Shared decision-making is an approach to healthcare delivery that respects a patient’s autonomy in responding to a clinician’s recommendations and facilitates dynamic, personalized, and collaborative care. Through this process, a clinician engages a patient in an open and respectful dialogue to elicit the patient’s knowledge, experience, healthcare goals, daily routine, lifestyle, support system, cultural and personal identity, and attitudes toward behavior,

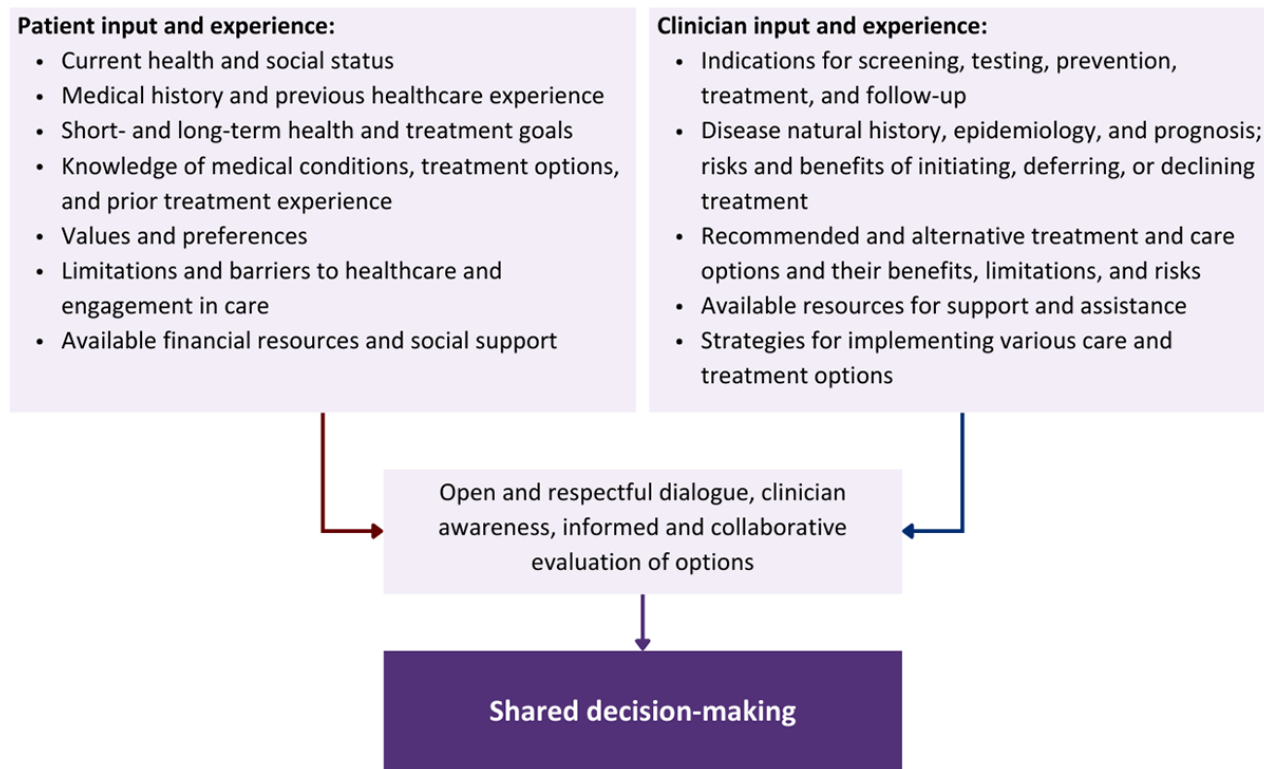
treatment, and risk. With this information and the clinician’s clinical expertise, the patient and clinician can collaborate to identify, evaluate, and choose from among available healthcare options [Coulter and Collins 2011]. This process emphasizes the importance of a patient’s values, preferences, needs, social context, and lived experience in evaluating the known benefits, risks, and limitations of a clinician’s recommendations for screening, prevention, treatment, and follow-up. As a result, shared decision-making also respects a patient’s autonomy, agency, and capacity in defining and managing their healthcare goals. Building a clinician-patient relationship rooted in shared decision-making can help clinicians engage in productive discussions with patients whose decisions may not align with optimal health outcomes. Fostering open and honest dialogue to understand a patient’s motivations while suspending judgment to reduce harm and explore alternatives is particularly vital when a patient chooses to engage in practices that may exacerbate or complicate health conditions [Halperin, et al. 2007].

Options: Implicit in the shared decision-making process is the recognition that the “right” healthcare decisions are those made by informed patients and clinicians working toward patient-centered and defined healthcare goals. When multiple options are available, shared decision-making encourages thoughtful discussion of the potential benefits and potential harms of all options, which may include doing nothing or waiting. This approach also acknowledges that efficacy may not be the most important factor in a patient’s preferences and choices [Sewell, et al. 2021].

Clinician awareness: The collaborative process of shared decision-making is enhanced by a clinician’s ability to demonstrate empathic interest in the patient, avoid stigmatizing language, employ cultural humility, recognize systemic barriers to equitable outcomes, and practice strategies of self-awareness and mitigation against implicit personal biases [Parish, et al. 2019].

Caveats: It is important for clinicians to recognize and be sensitive to the inherent power and influence they maintain throughout their interactions with patients. A clinician’s identity and community affiliations may influence their ability to navigate the shared decision-making process and develop a therapeutic alliance with the patient and may affect the treatment plan [KFF 2023; Greenwood, et al. 2020]. Furthermore, institutional policy and regional legislation, such as requirements for parental consent for gender-affirming care for transgender people or insurance coverage for sexual health care, may infringe upon a patient’s ability to access preventive- or treatment-related care [Sewell, et al. 2021].

Figure 1: Elements of Shared Decision-Making



Health equity: Adapting a shared decision-making approach that supports diverse populations is necessary to achieve more equitable and inclusive health outcomes [Castaneda-Guarderas, et al. 2016]. For instance, clinicians may need to incorporate cultural- and community-specific considerations into discussions with women, gender-diverse individuals, and young people

concerning their sexual behaviors, fertility intentions, and pregnancy or lactation status. Shared decision-making offers an opportunity to build trust among marginalized and disenfranchised communities by validating their symptoms, values, and lived experience. Furthermore, it can allow for improved consistency in patient screening and assessment of prevention options and treatment plans, which can reduce the influence of social constructs and implicit bias [Castaneda-Guarderas, et al. 2016].

Clinician bias has been associated with health disparities and can have profoundly negative effects [FitzGerald and Hurst 2017; Hall, et al. 2015]. It is often challenging for clinicians to recognize and set aside personal biases and to address biases with peers and colleagues. Consciously or unconsciously, negative or stigmatizing assumptions are often made about patient characteristics, such as race, ethnicity, gender, sexual orientation, mental health, and substance use [Avery, et al. 2019; van Boekel, et al. 2013; Livingston, et al. 2012]. With its emphasis on eliciting patient information, a shared decision-making approach encourages clinicians to inquire about patients' lived experiences rather than making assumptions and to recognize the influence of that experience in healthcare decision-making.

Stigma: Stigma may prevent individuals from seeking or receiving treatment and harm reduction services [Tsai, et al. 2019]. Among people with HIV, stigma and medical mistrust remain significant barriers to healthcare utilization, HIV diagnosis, and medication adherence and can affect disease outcomes [Turan, et al. 2017; Chambers, et al. 2015], and stigma among clinicians against people who use substances has been well-documented [Stone, et al. 2021; Tsai, et al. 2019; van Boekel, et al. 2013]. Sexual and reproductive health, including strategies to prevent HIV transmission, acquisition, and progression, may be subject to stigma, bias, social influence, and violence.

→ SHARED DECISION-MAKING IN HIV CARE

- As prevention and treatment modalities in HIV care expand (i.e., vaccines, barriers, injectables, implants, on-demand therapies), it is important for clinicians to ask patients about their goals for prevention and treatment rather than assume that efficacy is the primary factor in patient preference [Sewell, et al. 2021].
- The shared decision-making approach to clinical care enhances patient knowledge and uptake of new technologies and behavioral practices that align with the patient's unique preferences and identity [Sewell, et al. 2021], ensures that the selection of a care plan is mutually agreed upon, and considers the patient's ability to effectively use and adhere to the selected course of prevention or treatment.

Resources and Suggested Reading

In addition to the references cited below, the following resources and suggested reading may be useful to clinicians.

◇ RESOURCES

- [Minnesota Shared Decision-Making Collaborative](#)
- AHRQ: [The SHARE Approach: 5 Essential Steps of Shared Decision-Making](#)
- Medline Plus: [Shared Decision-Making](#)
- NICE: [Shared Decision-Making](#)
- PCORI: [The Significance of Shared Decision-Making](#)

References

- Acree ME, McNulty M, Blocker O, et al. Shared decision-making around anal cancer screening among black bisexual and gay men in the USA. *Cult Health Sex* 2020;22(2):201-16. [PMID: 30931831] <https://pubmed.ncbi.nlm.nih.gov/30931831>
- Avery JD, Taylor KE, Kast KA, et al. Attitudes toward individuals with mental illness and substance use disorders among resident physicians. *Prim Care Companion CNS Disord* 2019;21(1):18m02382. [PMID: 30620451] <https://pubmed.ncbi.nlm.nih.gov/30620451>
- Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med* 2011;24(3):229-39. [PMID: 21551394] <https://pubmed.ncbi.nlm.nih.gov/21551394>
- Castaneda-Guarderas A, Glassberg J, Grudzen CR, et al. Shared decision making with vulnerable populations in the emergency department. *Acad Emerg Med* 2016;23(12):1410-16. [PMID: 27860022] <https://pubmed.ncbi.nlm.nih.gov/27860022>
- Chambers LA, Rueda S, Baker DN, et al. Stigma, HIV and health: a qualitative synthesis. *BMC Public Health* 2015;15:848. [PMID: 26334626] <https://pubmed.ncbi.nlm.nih.gov/26334626>

- Chen CH, Kang YN, Chiu PY, et al. Effectiveness of shared decision-making intervention in patients with lumbar degenerative diseases: a randomized controlled trial. *Patient Educ Couns* 2021;104(10):2498-2504. [PMID: 33741234] <https://pubmed.ncbi.nlm.nih.gov/33741234>
- Coronado-Vázquez V, Canet-Fajas C, Delgado-Marroquín MT, et al. Interventions to facilitate shared decision-making using decision aids with patients in primary health care: a systematic review. *Medicine (Baltimore)* 2020;99(32):e21389. [PMID: 32769870] <https://pubmed.ncbi.nlm.nih.gov/32769870>
- Coulter A, Collins A. Making shared decision-making a reality: no decision about me, without me. 2011. https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf
- Crawford J, Petrie K, Harvey SB. Shared decision-making and the implementation of treatment recommendations for depression. *Patient Educ Couns* 2021;104(8):2119-21. [PMID: 33563500] <https://pubmed.ncbi.nlm.nih.gov/33563500>
- FitzGerald C, Hurst S. Implicit bias in healthcare professionals: a systematic review. *BMC Med Ethics* 2017;18(1):19. [PMID: 28249596] <https://pubmed.ncbi.nlm.nih.gov/28249596>
- Greenwood BN, Hardeman RR, Huang L, et al. Physician-patient racial concordance and disparities in birthing mortality for newborns. *Proc Natl Acad Sci U S A* 2020;117(35):21194-21200. [PMID: 32817561] <https://pubmed.ncbi.nlm.nih.gov/32817561>
- Groot G, Waldron T, Barreno L, et al. Trust and world view in shared decision making with indigenous patients: a realist synthesis. *J Eval Clin Pract* 2020;26(2):503-14. [PMID: 31750600] <https://pubmed.ncbi.nlm.nih.gov/31750600>
- Hall WJ, Chapman MV, Lee KM, et al. Implicit racial/ethnic bias among health care professionals and its influence on health care outcomes: a systematic review. *Am J Public Health* 2015;105(12):e60-76. [PMID: 26469668] <https://pubmed.ncbi.nlm.nih.gov/26469668>
- Halperin B, Melnychuk R, Downie J, et al. When is it permissible to dismiss a family who refuses vaccines? Legal, ethical and public health perspectives. *Paediatr Child Health* 2007;12(10):843-45. [PMID: 19043497] <https://pubmed.ncbi.nlm.nih.gov/19043497>
- Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. 2001. <https://www.ncbi.nlm.nih.gov/books/NBK222274/>
- KFF. Key data on health and health care by race and ethnicity. 2023 Mar 15. <https://www.kff.org/racial-equity-and-health-policy/report/key-data-on-health-and-health-care-by-race-and-ethnicity/> [accessed 2023 May 19]
- Livingston JD, Milne T, Fang ML, et al. The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. *Addiction* 2012;107(1):39-50. [PMID: 21815959] <https://pubmed.ncbi.nlm.nih.gov/21815959>
- McNulty MC, Acree ME, Kerman J, et al. Shared decision making for HIV pre-exposure prophylaxis (PrEP) with black transgender women. *Cult Health Sex* 2022;24(8):1033-46. [PMID: 33983866] <https://pubmed.ncbi.nlm.nih.gov/33983866>
- Niburski K, Guadagno E, Abbasgholizadeh-Rahimi S, et al. Shared decision making in surgery: a meta-analysis of existing literature. *Patient* 2020;13(6):667-81. [PMID: 32880820] <https://pubmed.ncbi.nlm.nih.gov/32880820>
- Parish SJ, Hahn SR, Goldstein SW, et al. The International Society for the Study of Women's Sexual Health process of care for the identification of sexual concerns and problems in women. *Mayo Clin Proc* 2019;94(5):842-56. [PMID: 30954288] <https://pubmed.ncbi.nlm.nih.gov/30954288>
- Robinson JH, Callister LC, Berry JA, et al. Patient-centered care and adherence: definitions and applications to improve outcomes. *J Am Acad Nurse Pract* 2008;20(12):600-607. [PMID: 19120591] <https://pubmed.ncbi.nlm.nih.gov/19120591>
- Scalia P, Durand MA, Elwyn G. Shared decision-making interventions: an overview and a meta-analysis of their impact on vaccine uptake. *J Intern Med* 2022;291(4):408-25. [PMID: 34700363] <https://pubmed.ncbi.nlm.nih.gov/34700363>
- Sewell WC, Solleveld P, Seidman D, et al. Patient-led decision-making for HIV preexposure prophylaxis. *Curr HIV/AIDS Rep* 2021;18(1):48-56. [PMID: 33417201] <https://pubmed.ncbi.nlm.nih.gov/33417201>
- Stalnিকowicz R, Brezis M. Meaningful shared decision-making: complex process demanding cognitive and emotional skills. *J Eval Clin Pract* 2020;26(2):431-38. [PMID: 31989727] <https://pubmed.ncbi.nlm.nih.gov/31989727>
- Stone EM, Kennedy-Hendricks A, Barry CL, et al. The role of stigma in U.S. primary care physicians' treatment of opioid use disorder. *Drug Alcohol Depend* 2021;221:108627. [PMID: 33621805] <https://pubmed.ncbi.nlm.nih.gov/33621805>
- Tsai AC, Kiang MV, Barnett ML, et al. Stigma as a fundamental hindrance to the United States opioid overdose crisis response. *PLoS Med* 2019;16(11):e1002969. [PMID: 31770387] <https://pubmed.ncbi.nlm.nih.gov/31770387>
- Turan B, Budhwani H, Fazeli PL, et al. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. *AIDS Behav* 2017;21(1):283-91. [PMID: 27272742] <https://pubmed.ncbi.nlm.nih.gov/27272742>
- van Boekel LC, Brouwers EP, van Weeghel J, et al. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: systematic review. *Drug Alcohol Depend* 2013;131(1-2):23-35. [PMID: 23490450] <https://pubmed.ncbi.nlm.nih.gov/23490450>