REPORT OF THE COUNCIL ON MEDICAL SERVICE

Subject: Update on the Use of Formal Shared Decision-Making

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1 At the 2008 Interim Meeting, the House of Delegates established policy directing the American
2 Medical Association (AMA) to educate and communicate to physicians about the importance of
3 shared decision-making (SDM) guidance as a tool to advance patient-centered care (Policy
4 D-373.999). At the 2010 Annual Meeting of the AMA, the House of Delegates adopted as
5 amended the recommendations in Council on Medical Service Report 7-A-10, which define the
6 core elements of a formal SDM process, and support the voluntary use of SDM processes and
7 tools, the use of demonstration projects to increase knowledge about using the SDM process in
8 clinical practice, and efforts to ensure the quality of SDM tools (Policy H-373.997).
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10 Policy H-373.997 also directs the AMA to continue to study the concept of SDM and report back
11 to the House regarding any developments. Since the House considered Council Report 7-A-10,
12 efforts to advance the use of formal SDM processes have been limited, due in part to the lack of
13 funding available to advance the SDM activities highlighted in the Affordable Care Act (ACA).
14 Efforts to learn more about the potential benefits of using formal SDM processes are ongoing, but
15 policymakers and other stakeholders are taking a broader view of ways to encourage greater levels
16 of patient engagement. This informational report reviews the core elements of a formal SDM
17 process, discusses the role of SDM processes in the context of patient-centered care, and highlights
18 activities related to SDM research and implementation.
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20 BACKGROUND AND AMA POLICY
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22 Although most physicians engage patients and their families in making health care decisions, the
23 term "shared decision-making" is often used to describe a formal process that may involve multiple
24 steps designed to give patients the opportunity to systematically evaluate their medical options in
25 accordance with personal preferences and values. Per Policy H-373.997, the AMA recognizes a
26 formal SDM process as having three core elements to help patients become active partners in their
27 health care: (a) clinical information about health conditions, treatment options, and potential
28 outcomes; (b) tools to help patients identify and articulate their values and priorities when choosing
29 medical treatment options; and (c) structured guidance to help patients integrate clinical and values
30 information to make an informed treatment choice. The AMA supports the concept of voluntary
31 use of shared decision-making processes and patient decision aids as a way to strengthen the
32 patient-physician relationship and facilitate informed patient engagement in health care decisions,
33 and supports the development of demonstration and pilot projects to help increase knowledge about
34 integrating shared decision-making tools and processes into clinical practice.
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36 A formal SDM process is generally facilitated through the use of patient decision support aids,
37 which are often developed by patient education groups and licensed for use by health plans,
38 hospitals or physicians. Notably, the National Cancer Institute has developed several patient
39 decision aids related to screening or treatment options for various forms of cancer, including
40 prostate cancer, breast cancer, and colorectal cancer. Decision support aids – and the formal SDM

1   process in general – are intended to supplement, not replace, direct communication between the
2   patient and physician, and provide a mechanism through which patients can understand complex
3   medical information in the context of their own lives and personal values. Policy H-373.997
4   supports efforts to establish and promote quality standards for the development and use of patient
5   decision aids, including standards for physician involvement in development and evaluation
6   processes, clinical accuracy, and conflict of interest disclosures. In addition, Policy H-373.997
7   emphasizes that the use of patient decision aids or formal SDM processes should be voluntary, and
8   should not be included as a condition of health insurance coverage or physician participation in a
9   health plan.
10
11   SHARED DECISION-MAKING AND PATIENT-CENTERED CARE
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13   The ACA, signed into law in March 2010, included language promoting the formal SDM process
14   as a way to facilitate patient-centered care. Section 3506 of the law requires the Secretary of the
15   Department of Health and Human Services to establish a program that develops, tests and
16   disseminates certified patient decision aids. It also authorizes funding for SDM pilots and
17   demonstration projects, and provides for the creation of "shared decision-making resource centers"
18   to provide technical assistance to providers interested in implementing SDM processes. In light of
19   these federal incentives, it was anticipated that there would be a heightened interest in SDM, and
20   Council on Medical Service Report 7-A-10 was developed in order to establish a policy foundation
21   that would allow the AMA to take an active role in shaping the use of formal SDM processes in
22   health care delivery.
23
24   Funding has not been appropriated for the targeted SDM initiatives outlined in the ACA, and to
25   date no specific SDM activities have been implemented under the ACA. A handful of states,
26   including Maine, Minnesota, Oregon, Vermont and Washington, are using multiple approaches to
27   encourage the use of SDM, including passing legislation authorizing funding for pilots and
28   demonstration projects, and creating task forces charged with learning more about best practices
29   for providing and implementing SDM. Minnesota considered legislation that would have required
30   physicians to use SDM for certain conditions, but it was defeated in part because of concerns about
31   mandating SDM before there are sufficient data regarding SDM's effectiveness and the best ways
32   to implement it.
33
34   Given that patient-centered care remains a high priority for policymakers and other stakeholders,
35   there is increased interest in identifying ways to help increase patient engagement and enable
36   patients to make informed choices based on their personal values and priorities. To the extent that
37   policymakers or others are encouraging the use of formal SDM processes, it is recognized as one of
38   several potential mechanisms through which to promote patient-centered care. For example, the
39   Medicare shared savings program final rule requires that accountable care organizations (ACOs)
40   have systems in place to promote and facilitate patient engagement, and to take into account
41   patients' individual needs, preferences, values and priorities. Although the rule does not mandate
42   the use of a specific process or set of protocols to fulfill this requirement, decision support tools
43   and SDM processes are mentioned as options for encouraging patient engagement.
44
45   The Patient-Centered Outcomes Research Institute (PCORI), which focuses on the development
46   and dissemination of comparative clinical effectiveness research (CER), is actively involved in
47   efforts to increase patient engagement and identify ways to ensure that patient preferences are
48   incorporated into medical decisions. PCORI's mission is to generate information that is necessary
49   to support informed decision-making by patients and their physicians. To that end, in addition to
50   funding clinical research, PCORI's research priorities include studying the best ways to
51   communicate and disseminate CER information, and ways to empower people to ask for and use

1 the information. PCORI has allocated funding for 50 two-year pilot projects, some of which will
2 test the effectiveness of alternative approaches to encourage effective patient participation in care
3 decisions, and to incorporate patient-desired outcomes in the health care decision-making process.
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5 ORGANIZATIONS ENGAGED IN SHARED DECISION-MAKING RESEARCH
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7 The Informed Medical Decisions Foundation (IMDF), a resource that was used in the development
8 of Council on Medical Service Report 7-A-10, continues to be a leader in efforts to advance formal
9 SDM through research, policy, clinical models and the development of patient decision aids. Its
10 website, www.informedmedicaldecisions.org, includes comprehensive information about
11 developments in the SDM field, including reports on SDM implementation efforts in individual
12 states, a resource center for physicians, and links and articles related to SDM research. The IMDF
13 also funds clinical demonstration sites and research initiatives to increase the knowledge base
14 associated with the use of formal SDM tools and patient decision aids. The IMDF currently
15 supports 10 demonstration sites, encompassing primary and specialty care, rural and urban sites,
16 and academic medical centers and community practices.
17
18 The Ottawa Health Research Institute (OHRI), another resource referenced in Council Report
19 7-A-10, continues to support a research group dedicated to patient decision aids, and maintains an
20 A – Z inventory of patient decision aids developed by universities, research entities, hospitals, and
21 not-for-profit organizations that focus on developing patient education tools.
22
23 Policy H-373.997 supports efforts to establish and promote quality standards for the development
24 and use of patient decision aids. Council on Medical Service Report 7-A-10 described the ongoing
25 work of the International Patient Decision Aids Standards (IPDAS) Collaboration, which has
26 developed standards for the evaluation of patient decision aids. Although the work of the IPDAS
27 resulted in the development of an evaluation tool intended to measure the quality of patient
28 decision support aids, it does not appear that there have been any significant developments in this
29 area since the Council's last report.
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31 CONCLUSION
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33 Although work in the area of SDM is being advanced by organizations such as IMDF and OHRI,
34 the lack of funding for the core SDM-related provisions in the ACA has resulted in few significant
35 developments with respect to how the vast majority of physicians practice medicine. At this time,
36 it does not appear that increased pressure is being put on physicians to use a specific SDM
37 framework to enhance patient engagement. The Council is aware that whether or not physicians
38 use formal SDM processes, they routinely engage patients and their families in making health care
39 decisions, and are committed to preserving the patient-physician relationship.
40
41 Policy H-373.997 articulates a basic set of policies about the design and use of formal SDM
42 process and patient decision aids that will allow the AMA to comment effectively on developments
43 in this area. The majority of activity involving SDM is focused on the development of pilot
44 projects and other efforts to strengthen the knowledge base associated with the use of formal SDM
45 protocols, which is consistent with AMA policy. The Council believes that AMA policy remains
46 sufficient to address the role of formal SDM processes and patient decision aids in the current
47 health care environment.

References are available from the AMA Division of Socioeconomic Policy Development.