



Improving the efficiency of cancer care

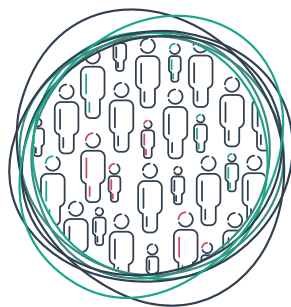
A focus on information, support and shared decision-making

About this focus brief

This brief is the second of a series focused on four key themes emerging from the All.Can patient survey, which aimed to obtain patients' perspectives on where they encountered inefficiency in their care, looking at the entire care continuum as well as the broader impact of cancer on their lives. The survey was open to current or former patients with any type of cancer; caregivers were also able to fill in the questionnaire on behalf of the patient, if needed. Nearly 4,000 cancer patients and caregivers responded to the survey, providing insights into which aspects of their care could be improved. The survey used the All.Can definition of inefficiency, namely resources that are not focused on what matters to patients.

This document focuses on what respondents said about information, support and shared decision-making. For more information about the survey methodology and a full report on the survey findings, please visit <https://www.all-can.org/what-we-do/research/patient-survey/>





Introduction

Providing patients with appropriate information and support and involving them in shared decision-making throughout their care are well known components of high-quality cancer care.¹⁻⁴

Information provision is essential to supportive cancer care.⁵ Information needs vary from one patient to another and change at each stage of the care pathway – but evidence suggests the majority of patients want access to as much information as possible throughout their cancer care and treatment.⁵⁻⁸

Patients also need appropriate supportive care throughout the entire care pathway to help them manage and cope with their condition. Multidisciplinary care teams, and integrated care models, are means of achieving this and can appropriately address ongoing symptoms and side effects of cancer (i.e. pain, fatigue, malnutrition, depression, anxiety, etc).

In addition to information and support, shared decision-making and positive patient–doctor communication are essential. Shared decision-making involves: listening to and discussing patients’ treatment goals; providing evidence-based information about treatment options, side effects and late effects, and their impact on daily life; and having systems for recording and implementing patients’ treatment preferences so they can get the care they need, in line with their desired treatment outcomes.^{9 10}

In the All.Can patient survey, it was found that these important aspects of quality cancer care were not always provided to patients. One clear opportunity to improve efficiency in cancer care from the patients’ perspective is thus to improve information sharing, support and shared decision-making.

What the survey told us about information, support and shared decision-makings*

Respondents reported that too much information being given at once was overwhelming.

Some respondents indicated that they would rather be given information at relevant points during their care pathway, rather than being told everything at the point of diagnosis.



'It would have been good to have access to resources at appropriate points during treatment (i.e. before surgery and radiation). I found I was given all the information at once, which was too much.' [Respondent from Australia](#)

Respondents were not always adequately involved in shared decision-making. Only half of respondents (53%) felt they were sufficiently involved in making decisions about their care. Nearly a third (31%) felt they were not given adequate information about their cancer care and treatment in a way that they could understand.



'The disconnect between the language my haematologist uses and common language has been frustrating.' [Respondent from Canada](#)

Respondents needed more and better support dealing with ongoing symptoms and side effects. Nearly four in ten respondents (39%) felt they had inadequate support to deal with ongoing symptoms and side effects. A third of respondents (31%) felt that they lacked adequate support for dealing with pain.



'I think we do not take the aftermath into account enough. Treatments help heal cancer but destroy other things. Life becomes different after.' [Respondent from Belgium](#)

Respondents wanted more information on what to expect after the phase of 'active treatment' was over. Over a third of respondents (35%) felt inadequately informed about how to recognise whether their cancer might be returning or getting worse.

Information on available peer support groups was not always provided. Over two-fifths (41%) of respondents were not given information about available peer-support groups by their care team.

Gaps in information and support were more prevalent for people with advanced cancers. Specifically, respondents with an advanced cancer reported being less involved in shared decision-making, having less information about their cancer care and treatment, and having less support in dealing with ongoing symptoms and side effects compared to patients with earlier-stage cancers.

How do information, support and shared decision-making contribute to greater efficiency in cancer care?

Information

Providing information in line with patients' needs can help them to feel more in control of their disease, increase overall care satisfaction, reduce anxiety and depression, create realistic expectations of care and encourage engagement in care.^{4-6 11 12}

Information provision is associated with improved symptom management, treatment adherence, clinical outcomes, and quality of life for patients.^{5 6 13 14}

Support

Supportive cancer care can reduce complications, the frequency and number of unscheduled hospitalisations, length of hospital stay and readmissions, emergency room visits, and overall hospital costs.^{15 16}

Cancer symptoms that are not managed properly may worsen patient outcomes and increase the cost of care. For example, malnutrition increases patients' risk of mortality and lowers their quality of life, and may significantly increase healthcare costs.¹⁶

Other types of patient support, such as patient support groups, can improve quality of life, as well as physical and psychological wellbeing.¹⁷

Shared decision-making

Shared decision-making can improve people's knowledge about their condition and treatment options; this, in turn, can improve their own involvement in their care, self-confidence and self-care, and care satisfaction.⁹

Effective communication enabling shared decision-making contributes to better relationships between patients and professionals, and may improve patient outcomes.^{9 18} More, earlier and better conversations between advanced cancer patients and their oncology clinicians have been shown to lead to significant reductions in emotional suffering.¹⁹ Further, patients' treatment decisions may change after receiving appropriate information – with many choosing fewer or less aggressive treatments.²⁰

What are the barriers to provision of information, support and shared decision-making?

There are several barriers to provision of information, support, and shared decision-making. Barriers may be patient-related, related to healthcare professionals or to the care system itself. The most common barriers defined in the literature are outlined below.

Limited health literacy

Many studies have shown that patients often do not fully comprehend what their diagnosis, prognosis and/or treatment mean. This may be due to not understanding the medical terminology, misinterpreting the benefits and harms of a treatment, or inability to recall what was said at an appointment.^{6,21,22}

Anxiety and psychological distress

Anxiety can inhibit a person's ability to process information, and may lead to more difficulty in understanding and remembering the information given during consultations.⁵ Emotional distress can also lead to difficulties in communicating during medical consultations.²³

Hesitancy to ask questions

Patients may not always ask enough questions. This may be because they mistakenly assume their doctor will tell them everything they need to know about their disease, they are afraid to ask questions, or they are concerned about taking up too much of the doctor's time.^{7,24,25}

Failure by healthcare professionals to provide relevant information

Clinicians often tend to underestimate the information patients require or are reluctant to speak openly about cancer to protect the patient, and may choose to censor information to protect their patients from bad news.⁷ For example, a study conducted by the European Society for Medical Oncology found that nearly two thirds of young oncologists found it hard to be truthful about prognosis with patients they liked.^{7,8,26} In addition, information and support has been found to be less impactful for patients with advanced disease than for those with earlier-stage diseases.²⁷

Lack of written information

Written information on treatment options is extremely important, as research suggests there is a mismatch between what oncologists believe they have said in a consultation and what patients believe they have heard.^{28 29}

Communication breakdown between doctor and patient

Good communication is necessary for patients' education, decision-making around treatment options, psychosocial adjustment, adherence to treatment and satisfaction with care.^{8 30} Positive communication may decrease stress and burnout and increase job satisfaction for physicians.³⁰ Evidence shows that a substantial gap exists between the outcomes patients prefer and the outcomes that doctors think patients prefer – necessitating the need for clear communication.²⁰ Factors affecting a physician's ability to communicate effectively include: lack of time, skills and tools; incorrectly interpreting what the patient wants; personal bias; and the use of medical jargon.^{3 28 30-34}

Poorly coordinated care and follow-up

Studies have shown that patients' information needs are often highest, and least well met, during the phase following active treatment.¹⁴ Without ongoing supportive care and appropriate follow-up from a multidisciplinary care team, patients may be left to deal with consequences of treatment that could have been managed or avoided altogether.³⁵

Lack of multidisciplinary care teams

Multidisciplinary care teams (MDTs) comprise a number of different healthcare professionals to support a broad range of patients' needs throughout the care pathway. MDTs should include oncologists, cancer nurse specialists, nutritionists, psychologists, physiotherapists, general practitioners, community pharmacists, caregivers, and other primary or community professionals.²⁴

Lack of information on patient support groups

Some healthcare professionals may not feel comfortable or able to distribute information about patient support groups. This presents a missed opportunity to address patients' needs, as doctors are usually the main source of information connecting patients to these groups.³⁶

What can be done to improve efficiency in this area?

By eliminating common barriers to information provision, support and shared decision-making, we could see dramatic improvements in cancer care for patients.

Providing patients with easy-to-understand, appropriate information is the key starting point.

Information should be adapted to where patients are in their care pathway, based on available resources, and tailored to their diagnosis and specific information needs. Information given during consultations should also be provided in writing, and patients should be encouraged to bring a loved one to these visits to ensure that they have adequate recall of information on diagnosis, cancer care and treatment.

A number of tools can facilitate doctor–patient communication and information exchange.³⁰

These include patient-reported outcome measures (PROMs), question prompt lists, patient-held records, tape recordings of consultations, decision aids and survivorship care plans.³⁰ Benefits of PROMs alone include improved pain management, doctor–patient communication, symptom detection and control, and increased use of supportive care and patient involvement in care.^{30 37} Physicians' engagement with these tools, as well as adequately resourced healthcare systems, are essential to ensure benefits are fully achieved.³⁰

Evidence-based communication courses have been shown to help oncologists communicate in a clear, honest and empathetic way while remaining realistic about clinical outcomes.²⁶

Education courses have also been shown to create more patient-centred behaviour among doctors, and make them more responsive to patient needs.⁷

Multidisciplinary care is essential. Having a full MDT and integrated care pathways to appropriately manage patients' symptoms and support needs throughout the entire care pathway is crucial for comprehensive and holistic cancer care.²⁴ Moreover, an effective handover from secondary care to primary care, with regular and timely follow-up, is necessary to ensure patients' information and support needs are met – particularly after their 'active treatment' phase is over.^{24 35}

A key contact person, such as a cancer nurse specialist and/or care coordinator, is enormously beneficial for patients. This person can help patients navigate all stages of care, as well as offering a more individualised approach to follow-up rather than a one-size-fits-all approach.³⁵

Some examples are presented as case studies below.



Case study 1. 'Just Ask' campaign, Denmark: facilitating positive patient–doctor communication

The Danish Society for Patient Safety created a handbook to help guide patients and their families through hospital care. The handbook is linked to an online tool where patients can view prompts for questions to ask their doctor. As well as printing a list of questions to ask at their own consultation, patient can suggest questions for other patients to use.

It is estimated that 10% of households have a copy of the handbook and that 86% of citizens who received and used the tool when they encountered their healthcare providers had an improved dialogue and asked more questions.¹



Case study 2. 'No decision about me, without me', England: legal framework for shared decision-making

Under the Health and Social Care Act 2012, the UK government has tasked the National Health Service (NHS) Commissioning Board with making shared decision-making commonplace in the NHS. The initiative, called 'no decision about me, without me', aims to give patients a say over their care and treatment by enabling more opportunity for informed choices, as a means of providing better care and improving patient outcomes.

The Department of Health and Social Care will create a 'Choice Framework' to outline where people have the legal right to make choices in their care, where they can find information and support to make these choices, and where they can go if they are not offered the choices to which they are entitled.³⁸



Case study 3. Supportive care service, Italy: supporting cancer patients in an outpatient clinic

In 2012, the Azienda Ospedaliero-Universitaria Pisana outpatient clinic introduced a supportive care service (SCS) in oncology containing a medical oncologist, nurse, psychologist and spiritual assistant. The clinic was set up for cancer patients who had ongoing treatment, to help them deal with issues related to their disease or treatment.

Preliminary results showed that after the introduction of the SCS for patients undergoing treatment, unplanned hospitalisations decreased by 3%, emergency room visits decreased by 5%, days in hospital decreased by 15% and cancer-related hospital costs decreased by 2%.¹⁵ decreased and diagnosis waiting times shortened.^{24 25}

Conclusion

Meeting patients' information and support needs and involving them in shared decision-making are key components of high-quality cancer care.^{1-5 23} This was an area where respondents to the All.Can patient survey felt there were notable inefficiencies in their care, and represents an important opportunity for improvement. Policymakers should consider these findings in future healthcare plans and investment decisions to ensure all patients benefit from information, support and shared decision-making. Failure to act on these findings will result in higher costs of care and poorer patient outcomes, quality of life and survival for people diagnosed with cancer.

References

1. All Party Parliamentary Groups (APPG). 2014. Patient empowerment: for better quality, more sustainable health services globally. London: APPG on Global Health
2. European Health Parliament. 2015. Patient empowerment and centredness. Available from: http://www.healthparliament.eu/wp-content/uploads/2017/09/EHP-papers_Patients-empowerment.pdf [Accessed 01/04/19]
3. European Patients' Forum (EPF). 2017. EPF Campaign on Patient Empowerment: Roadmap for Action. Available from: http://www.eu-patient.eu/globalassets/campaign-patient-empowerment/roadmap/roadmap_patient-empowerment_epf_2017.pdf [Accessed 10/07/19]
4. Rutten LJJ, Arora NK, Bakos AD, et al. 2005. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Educ Couns* 57(3): 250-61
5. Husson O, Mols F, van de Poll-Franse LV. 2010. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 22(4): 761-72
6. Jefford M, Tattersall MHN. 2002. Informing and involving cancer patients in their own care. *The Lancet Oncology* 3(10): 629-37
7. Jenkins V, Fallowfield L, Saul J. 2001. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer* 84(1): 48-51
8. Fallowfield L. 2019. Communicating with patients with advanced and metastatic cancer. Available from: <https://cancerworld.net/e-grandround/communicating-with-patients-with-advanced-and-metastatic-cancer/> [Accessed 04/11/19]
9. The Health Foundation. 2013. The MAGIC programme: Evaluation. London: The Health Foundation
10. Elwyn G, Durand MA, Song J, et al. 2017. A three-talk model for shared decision making: multistage consultation process. *BMJ* 359: j4891
11. Treacy JT, Mayer DK. 2000. Perspectives on cancer patient education. *Semin Oncol Nurs* 16(1): 47-56
12. Ross L, Petersen MA, Johnsen AT, et al. 2013. Satisfaction with information provided to Danish cancer patients: Validation and survey results. *Patient Educ Couns* 93(2): 239-47
13. Tokdemir G, Kav S. 2017. The Effect of Structured Education to Patients Receiving Oral Agents for Cancer Treatment on Medication Adherence and Self-efficacy. *Asia Pac J Oncol Nurs* 4(4): 290-98
14. Halbach SM, Ernstmann N, Kowalski C, et al. 2016. Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Educ Couns* 99(9): 1511-18
15. Antonuzzo A, Vasile E, Sbrana A, et al. 2017. Impact of a supportive care service for cancer outpatients: management and reduction of hospitalizations. Preliminary results of an integrated model of care. *Support Care Cancer* 25(1): 209-12
16. Arends J, Baracos V, Bertz H, et al. 2017. ESPEN expert group recommendations for action against cancer-related malnutrition. *Clin Nutr* 36(5): 1187-96
17. Lindemalm C, Strang P, Lekander M. 2005. Support group for cancer patients. Does it improve their physical and psychological wellbeing? A pilot study. *Support Care Cancer* 13(8): 652-57
18. Kehl KL, Landrum MB, Arora NK, et al. 2015. Association of Actual and Preferred Decision Roles With Patient-Reported Quality of Care: Shared Decision Making in Cancer Care. *JAMA Oncology* 1(1): 50-58

19. Ariadne Labs. 2019. New study on Serious Illness Care Program underscores significant benefit of more, better, and earlier conversations between clinicians and patients. Available from: <https://www.ariadnelabs.org/resources/articles/news/new-study-on-serious-illness-care/> [Accessed 04/11/19]
20. Mulley A, Trimble C, Elwyn G. 2012. Patients' preferences matter. London: The King's Fund
21. K, Abraham C, Jenkins V, et al. 2003. Lay understanding of terms used in cancer consultations. *Psychooncology* 12(6): 557-66
22. Epstein AS, Prigerson HG, O'Reilly EM, et al. 2016. Discussions of Life Expectancy and Changes in Illness Understanding in Patients With Advanced Cancer. *J Clin Oncol* 34(20): 2398-403
23. Campbell-Enns HJ, Woodgate RL, Chochinov HM. 2017. Barriers to information provision regarding breast cancer and its treatment. *Support Care Cancer* 25(10): 3209-16
24. Banks I, Weller D, Ungan M, et al. 2019. ECCO Essential Requirements for Quality Cancer Care: Primary care. *Crit Rev Oncol Hematol* 142: 187-99
25. Henselmans I, Heijmans M, Rademakers J, et al. 2015. Participation of chronic patients in medical consultations: patients' perceived efficacy, barriers and interest in support. *Health Expect* 18(6): 2375-88
26. Fallowfield L, Guarneri V, Ozturk MA, et al. 2014. Blurring of boundaries in the doctor-patient relationship. *The Lancet Oncology* 15(13): 1423-24
27. Breast Cancer Network Australia. 2018. State of the Nation Report. Camberwell: BCNA
28. Coulter A. 2017. The global reach of shared decision making. *BMJ opinion: patient perspectives*. Available from: <https://blogs.bmj.com/bmj/2017/07/13/angela-coulter-the-global-reach-of-shared-decision-making/> [Accessed 22/08/19]
29. Jenkins V, Solis-Trapala I, Langridge C, et al. 2011. What Oncologists Believe They Said and What Patients Believe They Heard: An Analysis of Phase I Trial Discussions. *J Clin Oncol* 29(1): 61-68
30. Licqurish SM, Cook OY, Pattuwage LP, et al. 2019. Tools to facilitate communication during physician-patient consultations in cancer care: An overview of systematic reviews. *CA Cancer J Clin* 0(0): 1-24
31. Kunneman M, Engelhardt EG, ten Hove FL, et al. 2016. Deciding about (neo-)adjuvant rectal and breast cancer treatment: Missed opportunities for shared decision making. *Acta Oncol* 55(2): 134-39
32. Kunneman M, Branda ME, Hargraves I, et al. 2018. Fostering Choice Awareness for Shared Decision Making: A Secondary Analysis of Video-Recorded Clinical Encounters. *Mayo Clinic Proceedings: Innovations, Quality & Outcomes* 2(1): 60-68
33. Engelhardt EG, Pieterse AH, van der Hout A, et al. 2016. Use of implicit persuasion in decision making about adjuvant cancer treatment: A potential barrier to shared decision making. *Eur J Cancer* 66: 55-66
34. Légaré F, Ratté S, Gravel K, et al. 2008. Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Educ Couns* 73(3): 526-35
35. National Cancer Survivorship Initiative (NCSI). 2013. Living with and beyond cancer: taking action to improve outcomes. London: NHS England
36. Oliver K. 2019. Personal communication: 13/03/19
37. Brown RF, Butow PN, Dunn SM, et al. 2001. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer* 85(9): 1273-9
38. Department of Health and Social Care. 2012. Liberating the NHS: No decision about me, without me - government response to the consultation. London: Department of Health and Social Care