

EUROPE'S BEATING CANCER PLAN ROADMAP FEEDBACK

ECL's response to consultation by 3 March 2020

BCP should aim to organise our society and economy to benefit EU citizens, cancer patients and survivors. The goal should be to close the inequalities gaps between and within MS, focusing on key areas where Europe should work together to improve cancer control and care. BCP should complement and amplify the impact of national and regional cancer control plans.

PREVENTION

Tackling modifiable risk factors have additional benefits for all NCDs. Priority should be given to translating messages of the European Code Against Cancer into policy action, incl. re environmental and workplace carcinogens, and immunisation against HPV and hepatitis B. BCP should take the lead to regulate artificial tanning devices as a public health problem and not as a commercial device.

BCP must focus intensely on early detection of cancer as timely diagnosis greatly increases chances for successful treatment and increased understanding of possible warning signs of cancer, among HCPs and the public. Support is required to establish a permanent platform for competent authorities and independent experts to monitor, evaluate and propose evidence-based recommendations to improve population-based cancer screening programmes.

Lack of clarity on or commitment to the implementation of optimal strategies to bring about improvements in public health through behavioural change or policy and regulatory measures should be addressed.

RESEARCH

R&I investments should be driven by public health and patients' needs, abiding to the highest transparency standards and involving patients and civil society. Public R&I should be accountable and result in health technologies that are available in a timely manner to those who need them and at a price that individuals, health systems and providers can afford.

Focus should be given to behavioural research underpinning lifestyle patterns that increase cancer risk and management of long-term side-effects of treatments and interventions improving the quality of life of survivors.

Effective research efforts are conditioned by the possibility of sharing high-quality individual health data across the EU, EEA and as part of global collaborations. BCP should support such collaborations and address challenges posed by heterogeneous interpretation of GDPR across MS.

TREATMENTS

The Roadmap rightly identifies that treatment costs for many cancer therapies are high, with often limited analysis of the overall social and economic benefit of such treatments, there are large inequalities in terms of patient access to treatments and that innovation may further increase those gaps.



BCP should include concrete measures to safeguard the sustainability of healthcare systems and patient access to treatment such as ensuring robust regulatory framework to avoid its misuse (incl. accelerated approvals where sufficient evidence on safety and efficacy is missing; patent protection and IP incentives - e.g., orphanisation of cancer treatments) and support MS in their cooperation in horizon scanning, HTA and information sharing on pricing. BCP should include measuring the extent and causes of medicines shortages and suggest coordinated approach among MS.

CARE & SURVIVORSHIP

BCP should provide funds to build capacity in MS, particularly in the CEE region, to ensure structural investment in workforce, technologies and specialised centres of excellence. BCP should be patient-centred with overall focus on quality of life of patients and survivors. Best practices, particularly in terms of full integration of supportive care and psycho-social services in cancer care and protection against financial toxicity of cancer for both patients and carers shall be promoted.

For more detailed information about priorities and effective cancer control and care interventions, please consult attached ECL's position papers on Europe's Beating Cancer Plan and HEU Cancer Mission. Also available here:

<https://www.europeancancerleagues.org/policy-hub-ecl-advocacy-action/>

Public consultation on the Commission's Europe's Beating Cancer Plan (Online Questionnaire)

Fields marked with * are mandatory.

Introduction

Cancer concerns all European citizens. 40% of us are likely to be affected at some stage in our life and we all know someone who developed the disease. This is why the President of the European Commission announced [Europe's Beating Cancer Plan](#) to be carried forward by the Commission, under the stewardship of the [Commissioner for Health and Food Safety](#).

Europe's fight against cancer is ongoing ([link](#)). But beating cancer requires everyone's involvement. The Commission wants to place European citizens at the centre of this plan. This is why we want to hear your views as we embark on this journey. Whether you are a concerned citizen, a patient or one of his/her relatives, a healthcare worker, a researcher, an employee in the pharmaceutical sector, or a policy maker, we want to hear from you. Share your experience. Tell us where you think Europe should focus its efforts.

We see the cancer problem as three-fold. First, cancer can cause huge suffering to individuals and their families. The citizen, and patient and his/her immediate family is the starting point and epicentre of Europe's Beating Cancer Plan. The second element is the burden that cancer imposes on society as a whole, stretching health systems. The third dimension is the significant inequalities that exist across Europe in terms of access to high-quality cancer-related services. Access to screening programmes varies significantly throughout Europe. And once diagnosed, patients don't always get access to the treatment that might make a vital difference for them.

With an estimated 40% of cancers being attributed to avoidable causes, we need to do better when it comes to cancer prevention. And as we get better at ensuring people survive cancer, our societies also need to do better at helping survivors with the problems they face subsequently. Therefore, the Commission intends to design the plan to cover the entire cycle of the disease. Actions should span all steps of the disease, including prevention, early diagnosis, treatment, and the social dimension of cancer (encompassing life after cancer, carers and palliative care). We published a roadmap describing this approach under this [LINK](#). Please let us know if you think we have missed something important, be it in terms of problems, objectives, or areas of EU action to explore.

Drawing on your input, the Commission will go on to complement this initial public consultation with further targeted interactions with specific stakeholder groups.

The contributions to this public consultation are not considered to relate to your own personal health situation but may relate to the health experience or situation of family and/or friends.

Thank you for helping us shape the European Cancer Plan!

About you

* Language of my contribution

- Bulgarian
- Croatian
- Czech
- Danish
- Dutch
- English
- Estonian
- Finnish
- French
- Gaelic
- German
- Greek
- Hungarian
- Italian
- Latvian
- Lithuanian
- Maltese
- Polish
- Portuguese
- Romanian
- Slovak
- Slovenian
- Spanish
- Swedish

* I am giving my contribution as

- Academic/research institution
- Business association
- Company/business organisation
- Consumer organisation
- EU citizen
- Environmental organisation
- Non-EU citizen
- Non-governmental organisation (NGO)
- Public authority
- Trade union
- Other

* First name

Wendy

* Surname

YARED

* Email (this won't be published)

ecloffice@europeancancerleagues.org

Gender

- Male
- Female

Age

- 14 or less
- between 15 and 24
- between 25 and 39
- between 40 and 54
- between 55 and 64
- 65 or more

Highest degree obtained

- Basic education
- Secondary education
- Vocational training
- University degree

* Organisation name

255 character(s) maximum

Association of European Cancer Leagues (ECL)

Postal address of your organisation

* Country of origin

Please add your country of origin, or that of your organisation.

- | | | | |
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| <input type="radio"/> Afghanistan | <input type="radio"/> Djibouti | <input type="radio"/> Libya | <input type="radio"/> Saint Martin |
| <input type="radio"/> Åland Islands | <input type="radio"/> Dominica | <input type="radio"/> Liechtenstein | <input type="radio"/> Saint Pierre and Miquelon |
| <input type="radio"/> Albania | <input type="radio"/> Dominican Republic | <input type="radio"/> Lithuania | <input type="radio"/> Saint Vincent and the Grenadines |
| <input type="radio"/> Algeria | <input type="radio"/> Ecuador | <input type="radio"/> Luxembourg | <input type="radio"/> Samoa |
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| <input type="radio"/> Andorra | <input type="radio"/> El Salvador | <input type="radio"/> Madagascar | <input type="radio"/> São Tomé and Príncipe |

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- Belgium
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- Benin
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- Bhutan
- Bolivia
- Bonaire Saint Eustatius and Saba
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
- British Indian Ocean Territory
- British Virgin Islands
- Brunei
- Bulgaria
- Burkina Faso
- Equatorial Guinea
- Eritrea
- Estonia
- Eswatini
- Ethiopia
- Falkland Islands
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- French Southern and Antarctic Lands
- Gabon
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guam
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Honduras
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte
- Mexico
- Micronesia
- Moldova
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar /Burma
- Namibia
- Nauru
- Nepal
- Netherlands
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Sint Maarten
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia and the South Sandwich Islands
- South Korea
- South Sudan
- Spain
- Sri Lanka
- Sudan
- Suriname
- Svalbard and Jan Mayen
- Sweden
- Switzerland
- Syria
- Taiwan
- Tajikistan
- Tanzania
- Thailand
- The Gambia
- Timor-Leste
- Togo
- Tokelau

- Burundi
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Clipperton
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
- Cook Islands
- Costa Rica
- Côte d'Ivoire
- Croatia
- Cuba
- Curaçao
- Cyprus
- Czechia
- Democratic Republic of the Congo
- Denmark
- Hong Kong
- Hungary
- Iceland
- India
- Indonesia
- Iran
- Iraq
- Ireland
- Isle of Man
- Israel
- Italy
- Jamaica
- Japan
- Jersey
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- Kosovo
- Kuwait
- Kyrgyzstan
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- Peru
- Philippines
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- Portugal
- Puerto Rico
- Qatar
- Réunion
- Romania
- Russia
- Rwanda
- Saint Barthélemy
- Saint Helena Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks and Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States
- United States Minor Outlying Islands
- Uruguay
- US Virgin Islands
- Uzbekistan
- Vanuatu
- Vatican City
- Venezuela
- Vietnam
- Wallis and Futuna
- Western Sahara
- Yemen
- Zambia
- Zimbabwe

* Organisation size

- Micro (1 to 9 employees)
- Small (10 to 49 employees)

- Medium (50 to 249 employees)
- Large (250 or more)

Transparency register number

255 character(s) maximum

Check if your organisation is on the [transparency register](#). It's a voluntary database for organisations seeking to influence EU decision-making.

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* Publication privacy settings

The Commission will publish the responses to this public consultation. You can choose whether you would like your details to be made public or to remain anonymous.

Anonymous

Only your type of respondent, country of origin and contribution will be published. All other personal details (name, organisation name and size, transparency register number) will not be published.

Public

Your personal details (name, organisation name and size, transparency register number, country of origin) will be published with your contribution.

In the interest of transparency, organisations and associations have been invited to provide the public with relevant information about themselves by registering in Transparency Register and subscribing to its Code of Conduct.

I agree with the [personal data protection provisions](#)

Please indicate if you have work experience in any of these areas

- Cancer care
- Pharmaceutical industry
- Social care sector
- Healthcare sector
- Education sector
- Health/social insurance sector
- Public administration

Are you a healthcare professional?

- Yes
- No

General Questions

1. On a scale from 0 to 10, how present is cancer in your life? (0 is not at all present and 10 very present)

Only values between 1 and 10 are allowed

10

2. What do you think is needed to beat cancer?

● What do you think citizens can do to help beat cancer?

600 character(s) maximum

- Follow messages of the European Code Against Cancer (www.cancercode.eu)
- Be aware of early-warning signs (e.g., <https://www.cancer.ie/cancer-information-and-support/cancer-information/early-detection/spot-cancer-early>)
- Follow advice of their health professionals, cancer societies and health authorities
- Participate in citizen dialogues and consultations, voicing their support for public health/environmental interventions of their governments

● What do you think health professionals can do to help beat cancer?

600 character(s) maximum

- Ensure proper communication with patients regarding prevention, treatment options, side effects and supportive and palliative care
- Refer patients to appropriate specialists
- Follow new scientific evidence related to prevention, treatments and care
- Learn new skills throughout their career (e.g., digital, social, leadership)
- Ensure well-functioning communications within multi-disciplinary teams
- Network and gain new knowledge/skills through European/global networks of HCPs and other relevant health and research societies
- Participate in health decision-making at the political level

● What do you think public authorities/national governments can do to help beat cancer?

600 character(s) maximum

- Legislate to ensure high protection of public health throughout all policies
- Evaluate efficiency of health systems and ensure smart investments and implementation of best practice
- Assess the cost-effectiveness of new interventions in health before uptake
- Collaborate with other governments (within EU/EEA/globally) to avoid duplication of efforts, where appropriate (e.g., horizon scanning, HTA, research funding)
- Consult experts (public health groups, academia, patients, HCPs etc.) to ensure policy changes ultimately lead to greater well-being of citizens

3. Do you support the idea that the EU should do more to address cancer?

- Yes
- No
- I don't know

In which areas do you think the EU should prioritise its efforts (choose top 3):

at most 3 choice(s)

- Prevention
- Screening and early diagnosis
- Treatment and quality of life of patients and carers
- Life after cancer
- Research and collection of information
- Other
- I don't know

If you chose "Other", please describe it

600 character(s) maximum

All above mentioned areas should be prioritised, to the extent where it makes most sense for the EU to work together in order to increase the well-being of EU citizens. Hence it is less about the areas but more about concrete policies where the EU has a clear mandate or where it can make the largest impact. From ECL's perspective, this can be achieved in the areas of primary prevention as a lot of goods are regulated by the single market, ensuring safety, efficacy and affordability of approved treatments, collaboration in research and integration and standardization of health data sources.

Which actions would you consider most useful in the areas indicated below

STEP I: PREVENTION- Preventing cancer by addressing risk factors

Many things related to our lifestyle, and the environment around us may increase or decrease our risk of getting cancer. About 40% of cancer cases could be avoided through prevention measures that have proved to be successful.

Some of the most effective measures are:

- lifestyle changes (healthy diet, physical activity, reduction of obesity, avoidance of tobacco and alcohol consumption),
- vaccination against viruses that cause diseases such as cervical or liver cancer (Human papillomavirus, Hepatitis B),
- avoidance of excessive exposure to sunlight (including sunbeds)
- protection from exposure to certain chemicals that can cause cancer.

More recommendations are available in the [European Code Against Cancer](#), a joint initiative between the European Commission and the World Health Organization's International Agency for Research on Cancer.

4. Do you have enough information about how to prevent cancer?

- Yes
- No
- I don't know

What information would you need?

600 character(s) maximum

There is enough information about HOW TO PREVENT cancer, however, we need more behavioural research in order to know how to best communicate this information to the general public in order to achieve change lifestyle habits

5. Which of the actions below do you think would have the biggest impact on your lifestyle habits (e.g. diet, physical activity, tobacco or alcohol consumption)? (choose top 3)

- Measures on prices (including both taxation and/or incentives)
- Advertising
- Information campaigns
- Legislation
- Other

Please describe

600 character(s) maximum

Legislation (which includes taxation and price levels) and a well-informed public is key. Please see WHO's 'best buys' on how to prevent NCDs for more information: <https://www.who.int/ncds/management/best-buys/en/>

STEP II: EARLY DIAGNOSIS - Preventing avoidable cancer cases through cancer screening

An early cancer diagnosis can often significantly increase the chances of successful treatment. The European Union has issued [recommendations](#) for the screening of [breast](#), [cervical](#) and [colorectal](#) cancer.

6. Do you think the EU should extend recommendations for screening of other types of cancer, beyond breast, cervical and colorectal cancer?

- Yes
- No
- I don't know

To which types of cancer in priority?

- Lung cancer
- Gastric cancer
- Prostate cancer
- Ovarian cancer
- Other types of cancer

Other types of cancer

600 character(s) maximum

We need more evidence before recommending further screening, this is a very dangerous questions, especially in a questionnaire that will largely not be answered by screening experts
The decision to extend the recommendation would be premature as recent evidence on some of the cancer sites mentioned need to be further investigated and analysed in a pragmatic, "real-life" context. The priority must be delivering high quality re the already recommended programmes. Please see recent paper in the Int. Journal of Cancer on this topic: <https://onlinelibrary.wiley.com/doi/abs/10.1002/ijc.32885>

7. What could influence your decision to take part in a cancer screening programme?

- Information about the usefulness of screening and early diagnosis
- Convenience (proximity, ...)
- Cost
- Expertise and skills of healthcare workers
- The safety and quality of the equipment
- Other

Please explain

600 character(s) maximum

All factors are important for citizens. Special attention should be paid to people of lower socio-economic status and vulnerable groups who participate at a lower rate in screening. Specific challenges may inhibit their ability to find, access and understand the screening offer, thus potentially exacerbating existing inequality in health. Information on BOTH benefits and risks related to cancer screening needs to be well communicated; citizens should not feel coerced but should make an informed decision about participation.

STEP III: TREATMENT - Best available care, treatment and quality of life for all cancer patients

Finding out you have cancer can be quite a shock. It can be difficult in these circumstances to decide how to approach your treatment. And then there is the question of whether you can get the treatment you need, and how much of it will be covered or provided by your health system. As with diagnosis, the best and most effective treatment should be available to all EU citizens. And, whilst our current treatments are indeed effective, new innovative treatments offer us even greater possibilities – yet this innovation can come at a very high cost.

8. What could Europe do to ensure that cancer patients across Europe receive the best available treatment at an affordable price, independently of where they live?

600 character(s) maximum

- Foster research collab., add conditions to public funding - ensure products from publicly funded projects are available at a fair/affordable price;
- Ensure robust regulatory env. for safety and efficacy of meds coming to the market;
- Prevent misuse of IP protection/incentives, ensure fair competition for generics and biosimilars;
- Support MS to pool resources to ensure high quality HTA, horizon scanning, knowledge on pricing/prices & joint procurement;
- Assess the extent, causes and impact of shortages, develop EU strategy to secure sustainable supply of meds (prevention & crisis management)

9. Do you believe that you know where to find sufficient information about available cancer treatment services where you live?

- Yes
- No

How can this be improved?

600 character(s) maximum

Info re availability of medicines in different MS is scattered and the access to databases of national medical agencies and clarity of information, including reimbursement levels and availability, differs greatly. Info provided by national agencies and contact points is often difficult for patients to find/understand. Easily accessible and up-to-date unbiased information about the availability of treatments and whether they are reimbursed should be available to patients in their national language, as well as centrally gathered by the EMA to enable swift comparison between European countries

10. Do you consider sufficient written information regarding cancer diagnosis and possible treatments is available to patients ?

- Yes
- No
- I don't know

11. Do you consider adequate support, both inside and outside of the healthcare setting, is available to cancer patients?

- Yes
- No
- I don't know

What additional support do you consider could be made available?

600 character(s) maximum

While some MS provide excellent free-of-charge support services to patients to guide them through the cancer pathway, it is not the case in most EU countries. The BCP should provide guidance to MS on how to implement best practices and address inequalities in access to high quality supportive care. Integration of psycho-social services in oncology, including psychological counselling, rehabilitation, advice on work issues and access to financial services, should be encouraged.

12. In your experience, do cancer patients receive treatment from a multidisciplinary team of health professionals (oncologists, researchers, psychologists)?

- Yes
- No
- I don't know

13. Do you consider that adequate means are available to help families and friends caring for cancer patients?

- Yes
- No
- I don't know

What additional support do you consider could be made available?

600 character(s) maximum

Both the financial and mental impact of cancer on informal caregivers is largely under discussed. Caregivers should be able to access psycho-social counselling (incl. sexual and relationship issues) and have sufficient flexibilities at the workplace to be able to tend to their loved one. Addressing financial hardship for households related to cancer should be measured and compared between MS. MS should then implement appropriate measures to address financial and emotional toxicity of cancer on both patients and their families.

STEP IV: SOCIAL INTEGRATION - Quality of life with and after cancer

The good news is that the number of cancer survivors has increased substantially in the EU over the past decades. However, many of these survivors experience disabilities or long-term side effects of cancer treatment, including emotional distress.

In addition, cancer patients and cancer survivors often face hurdles in the workplace and in matters such as access to employment, insurance, or credit.

14. In your country/region, do cancer survivors receive follow-up and support after treatment?

- Yes
- No
- I don't know

15. Do you consider that cancer survivors experience significant challenges in their daily life?

- Yes
- No
- I don't know

Please indicate in which areas challenges are particularly significant:

- Lack of social rehabilitation, including employment
- Lack of education and training on self-management of your daily life (empowerment of cancer survivors)
- Lack of psychological support to address distress and depression
- Lack of training and support of your informal carers
- Lack of capacity of physicians and nurses to recognise your distress and depression
- Problems linked with medical follow-up, including management of the late effects of treatment
- Problems linked with other diseases (co-morbidity)
- Others

Please describe

600 character(s) maximum

In addition to the above - financial toxicity of cancer, supportive care for both patients and carers, referral to specialists (incl. rehabilitation, social workers, sexologists, psychologists etc.), support and flexibilities at the workplace, early integration of palliative care services, lack of time of healthcare professionals (incl. insufficient communication between patients and their HCPs, and HCPs among themselves - ultimately leading to lower quality of care)

16. Do cancer patients and survivors receive psychosocial support during or after their treatment?

- Yes
 No
 I don't know

17. Do you know or have experience of any particularly good practice in supporting cancer survivors, or do you have any suggestions as to how this could be done?

600 character(s) maximum

Counselling centres financed by the Danish Cancer Society and danish municipalities are houses where patients can go and without appointment receive free psychological support, participate in rehabilitation programmes (exercise, cooking classes etc), or spend time with others (books, board games etc. available); <https://www.cancer.dk/international/patient-support/>

GENERAL QUESTIONS:

18. Tell us what a successful cancer plan means to you. 10 years after we implement the plan, what should have improved in the lives of European citizens?

600 character(s) maximum

- Key risk factors, such as tobacco and alcohol consumption, rates decreased
- Growth in cancer incidence has slowed down
- Improved survival rates with narrower gaps between MS;
- Lower inequalities in terms of access to prevention, diagnosis, treatment and quality care (including supportive care services), also among marginalised populations.

19. Provided it is securely managed and in full respect of data protection would you share your personal health data in order to help others and contribute to health improvements (tick all that apply)

- With doctors?
 With researchers?
 With pharmaceutical industry?

20. Have you received information on or been informed about the possibility to take part in clinical trials, including their benefits and risks?

- Yes

- No
- Not applicable

21. How can you (or your organisation) contribute to the EU plan on cancer?

600 character(s) maximum

Provide input on necessary policy change/legislation towards better cancer control and care, see our recommendations here: https://www.europeancancerleagues.org/wp-content/uploads/ECL-vision-EU-Beating-Cancer-Plan_final.pdf

Support alignment between the Commission and the EP via MEPs Against Cancer group

Share best practices re cancer prevention, diagnosis, research, treatment and patient support from national cancer societies who work directly with patients/citizens

Support advocacy at national level in the Plan's implementation stage

Communicate about the Plan to stakeholders/general public

22. Is there anything else that you would like to add that has not been covered in this consultation?

600 character(s) maximum

-We wish to flag that phrasing of some questions in the consultation heavily oversimplified the situation. Questionnaire focused on 'competing' between different sectors (e.g., addressing risk factors tobacco vs alcohol) rather than on where EU has the largest potential and mandate to drive necessary change to improve cancer control and care

-Questions about extending cancer screening were inappropriately phrased and asked to the wrong audience. This could mislead governments into premature spending on interventions that have not yet proved to be (cost)effective or steer patients' false hope

Contact

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