



The work of CANCON – from the patient perspective

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Our role

- To review the work of CANCON as an observer, to look at the outcomes and to assess needs in the future
- The question was where to start, bearing in mind its almost over and we haven't been closely involved
- We approached this review from the perspective of what a patient might expect
- As we understand it, all patients want to get the best possible treatment; treatment that will give them a good quality of life and extension where ever possible

Europe of Disparities

- Where ever we look one finds inequalities in access to best treatment and care, not only between countries but also within countries
- Estimated life expectancy between European countries is more than eight years! Much of this can be avoided
- CANCON is looking at between countries, sadly they haven't assess the internal inequalities also
- The UK had a *postcode* lottery that showed that in South of England you lived up to 10 years longer than in the North, not just because of more sunshine!

The Passive Patient

Patient care can be very disempowering



*"When we want your opinion,
we'll give it to you"*

Table 1. Number of guidelines and their focuses concerning after-care guidelines and providers

Cancer location	Number of guidelines	Countries with guidelines	Specific to after-care	Scientific reference to after-care	Guide for GPs
Breast cancer	24	19	7	17	2
Colorectal cancer	21	16	6	12	1
Lung cancer	17	11	3	9	1
Melanoma	15	13	1	12	1
Prostate cancer	18	14	4	14	1

Differences in engagement

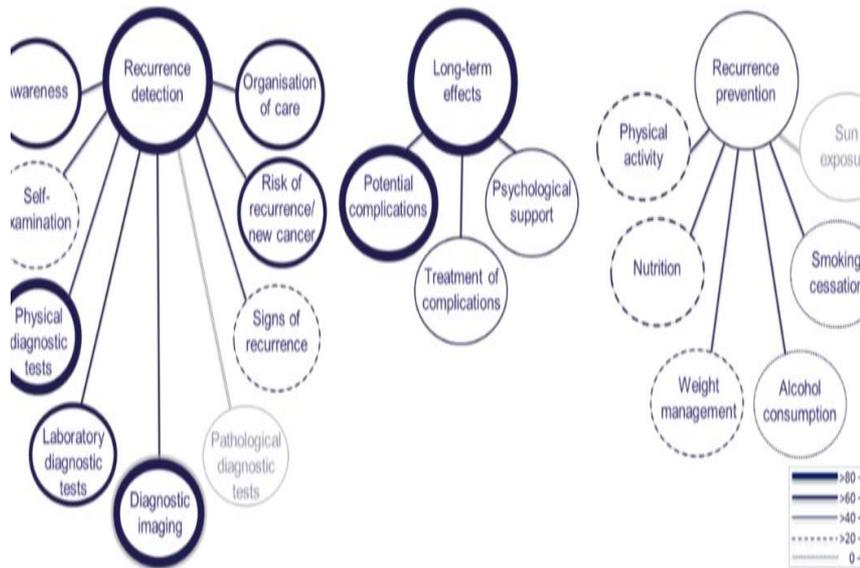


Figure 1. Overview of categories and topics on after-care for breast cancer derived from 24 guidelines. Note. Topics shown in grey were not discussed in the breast cancer guidelines.

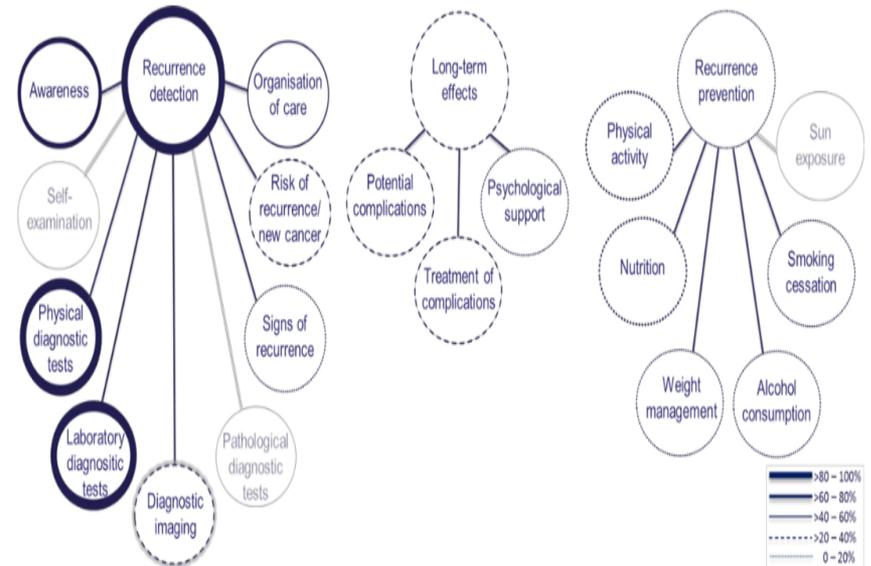


Figure 2. Overview of categories and topics on after-care for colorectal cancer derived from 20 guidelines. Note. Topics shown in grey were not discussed in the colorectal cancer guidelines.

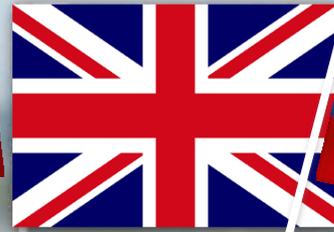
**Have
done
well....**



Italy



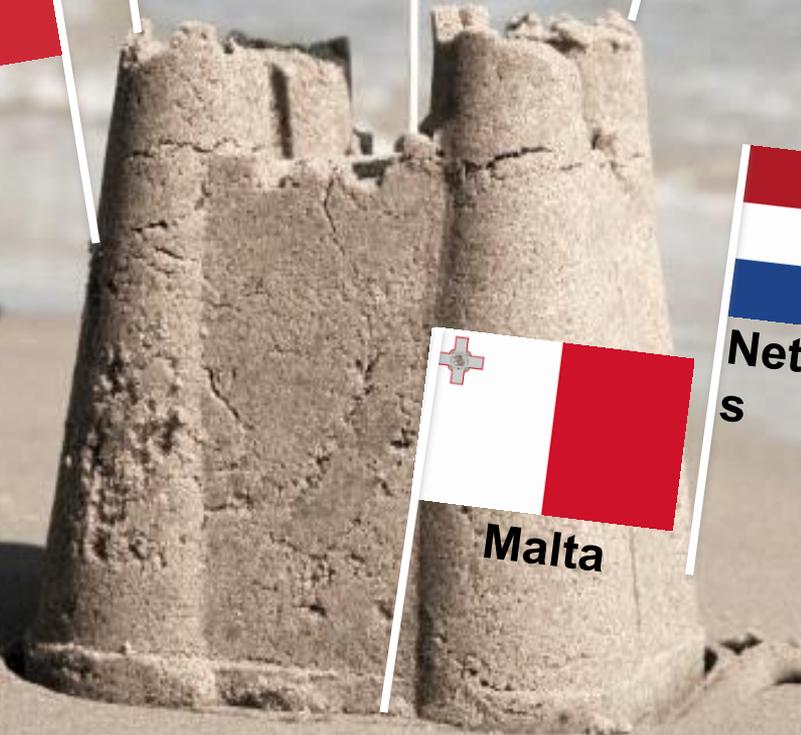
France



UK



Slovenia



Malta



Netherlands

Survivorship



- Aims to set bench marks for the delivery of a service that is integral to every cancer patients experience of the disease.
- However there is a **huge** question – Who will pay for this service.
- Currently there is little or no support for survivorship in most national budgets, in fact few NCCPs even mention it
- Next to early diagnosis and successful surgery, this is probably the most important issue for patients because its about their daily lives and how to manage them.

Observations



- The management of cancer requires continuous review - EPAAC and CANCON have shown this, each project has offered new insights and advanced our understanding
- However, without a strong financial justification for making change and disinvesting we believe you might struggle to introduce the good suggestions from CanCon
- Treating cancer in the community will be essential for patient management in the future. **BUT** with so few Guidelines for PCPs this could be a stumbling block
- More work needs to be done on this aspect of cancer care as more people survive and live longer and PCP need to be included in models of care for cancer patients

Raising the Profile of Health



- We would like to see a coalition of all patient organisations in every MS, this stronger health voice could bring about change
- We would like to see greater engagement between patients; supporting each other on their journey
- Closer interaction between clinicians, nurses, patient organisations and patients
- In Bulgaria a Standing Committee on Health involves all stakeholders and seems a good model to generate a united voice
- Too often cancer is seen as the disease that gets all the resources but joined up campaigning by all diseases would raise the profile of health and the needs of all patients



Financial Imperative



- We need greater clarity about the costs and benefits of change to argue our case
- Governments might embrace these suggestions more willingly if they see a financial saving
- We are all challenged by today's financial climate and so our case needs to be strong – with clear justification for any costs
- Hospital managements tend to be on the front line, they are more likely to accept the need for change to help manage their budgets and are possibly our best allies here

Unmet needs of patients



Expectations
Information
Support
Patient Reported Outcome Measures
Financial guidance



Conclusion



1. The interests of patients should be central, with patient organisations actively involved in all health discussions
2. More work needs to be done within MS with greater collaboration between patient organisations to ensure best access to health resources
3. Patient organisations should be treated like professionals and funded suitably so that they can support patients and relieve pressure on clinicians
4. Finally, we would like to see a long term monitoring of the outcomes of this excellent work to see if CanCon recommendations are being heard and being followed through

Thank you



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