



**EUROPEAN CANCER ORGANISATION**

**Integrated Cancer Care:  
Bringing Primary Care and Secondary Care Together  
ECCO Position Statement**

May 2017

Acknowledgement: This position statement has been produced by the [European CanCer Organisation \(ECCO\)](#), a federation of 25 professional societies in oncology, in collaboration with the [ECCO Patient Advisory Committee \(PAC\)](#).

Through its 25 Member Societies - representing over 170 000 professionals - ECCO is the only multidisciplinary organisation that connects and responds to all stakeholders in oncology Europe-wide.

ECCO is a not-for-profit federation that exists to uphold the right of all European cancer patients to the best possible treatment and care, promoting interaction between all organisations involved in cancer at European level.

It does this by creating awareness of patients' needs and wishes, encouraging progressive thinking in cancer policy, training and education and promoting European cancer research, prevention, diagnosis, treatment and quality care through the organisation of international multidisciplinary meetings.

**Purpose of this position statement**

This position statement defines, in short summary, the views of ECCO, and its member organisations, on the necessity of integrated care to ensure the best care for cancer patients and what is required at the macro level to improve integration of care.

**Background and context of the position statement**

The position statement, and its accompanying annex, are drawn in large part from the bringing together of sector, profession and patient representatives at the primary care track of ECCO2017 Congress in Amsterdam.

For the first time at a European oncology congress, the roles for primary care in cancer prevention, screening and management as well as healthcare delivery approaches integrating primary and secondary care were presented and discussed.

The position statement of ECCO addresses all health care professionals involved in cancer control as well as EU and national policy makers influencing healthcare systems and the organisation of cancer care. It addresses all cancer types and the entire patient journey.



### **Position statement in summary**

ECCO and its member organisations call for:

- A multidisciplinary and patient-centric approach to integrated cancer care, in order to achieve best outcomes and quality of care for patients
- Predefined coordination of the total care process, with clearly defined roles and responsibilities for all involved healthcare professionals
- Concerted attention to the improvement of communication between differing professionals and sectors involved in cancer care, including via IT investment and improvement, and integration of education
- The development of integration models that reflect the differing patient needs associated with different cancer types (such as set out in the ECCO Essential Requirements for Quality Cancer Care documents)

### **Position statement**

The incidence of many cancers is increasing as a result of lifestyle and environmental factors and an ageing population. There is a very large increase in the burden of cancer. Cancer patients constitute a vulnerable group: 70% have comorbidities mostly due to age and many of these comorbidities are treated by primary care professionals.

During the follow-up period, patients have multiple interactions with their family doctor and other primary care professionals in parallel to interactions with specialists in secondary care. Patients have much more contacts with primary care professionals for the treatment of side effects of chemotherapy, radiotherapy or surgery as well as for the management of psycho-social events. Patients also seek the advice of primary healthcare professionals for cancer treatment decisions. However, primary healthcare professionals often feel they may not have the necessary specialised expertise to provide such advice.

Meanwhile primary care itself is evolving. It is now mostly delivered through multidisciplinary teams centred around general or family practices. These teams consist of up to thirty individual professionals who can contribute to the care of cancer patients (including physiotherapists, occupational therapists, psycho-oncologists, community nurses, community pharmacists, nutritionists, patient advocates and caregivers).

The strengths of primary care are particularly evident in prevention and diagnosis but also in shared follow-up, survivorship care and end of life care. Important reasons for improved integration of primary and specialist care during active cancer treatment include symptom control and management of toxicities to avoid emergency department visits and hospital admissions, management of patients with concurrent mental health problems and management of geriatric patients with multimorbidity as well as addressing the specific needs of children and adolescents with cancer. Patients and their families want reassurance, convenience, continuity of care, quality of life and psycho-social dimensions which are often lacking in hospital follow-up.

More work is needed to ascertain the most appropriate role for primary care during cancer treatment. The expertise of specialists in secondary care shall remain an indispensable part of integrated cancer care. Roles and responsibilities for all involved healthcare professionals must be clearly defined.



Healthcare staffing and resources need to be planned on the basis of the demand of interventions. Incidence and prevalence numbers of different malignancies should be taken into account.

Integration should not be substitution of care but rather “The creation and maintenance of a common health-care structure and connection between different providers to coordinate patient care, while retaining each provider’s unique role. (Source: Suter E et al. 2009).

Patients have a lot of interactions with the healthcare system and there is a lot of duplication of care but also many significant gaps in care. Despite many advances in cancer care, problems persist between the primary care and cancer sectors: fragmentation, poor communication, poor coordination and lack of clear role definition. Integration of care is key to optimising inter-sectorial/inter-disciplinary care. When acting as case managers, specialised cancer nurses play a central role in communication and coordination between primary and secondary care professionals.

Integrated care covers a complex and comprehensive field, and there are many different approaches to and definitions of the concept \*. The literature refers to different terms such as coordination of care, continuity of care and transitions of care but those are essentially the same concepts.

A number of elements are required to establish successful integration of care:

- Patient centricity
- Multidisciplinary/multiprofessional team based approach
- Pre-defined coordination of the total care process
- Clearly defined roles and responsibilities
- Good communication among all care providers
- Adequate education, clear guidelines/protocols on management/follow-up care
- Rapid access back to secondary care
- Adequate IT systems

IT solutions could potentially address problems of communication and information transfer between healthcare providers in the primary and secondary care settings. Patients’ access to their healthcare records could also facilitate access to all relevant healthcare providers.

The active engagement of patients and patient organisations including parents’ organisations in the case of paediatric malignancies is essential in achieving sustainable high quality health and cancer care. For this reason, ECCO’s work is rooted in a multidisciplinary approach with the patient at the centre, as an integral part of the team. Integrated models of cancer control must result in an improvement for patients and not something that is forced on them.

More research into integration during cancer treatment is needed. Various integration models will have to be designed for each type of cancer (or groups of cancers) and each healthcare system will need to take into account all the variables.

One of the areas where a change can be made is education. Undergraduate and postgraduate training of healthcare professionals should ensure they expect to work as an integral part of a team. This is already embedded in ECCO’s educational activities providing multidisciplinary perspectives and interdisciplinary clinical knowledge to cancer healthcare professionals. They should also be educated on the importance of patient’s expectations throughout the entire pathway, from initial diagnosis, staging, treatment, follow-up and end of life.



The most effective type of educational interventions to enhance integration of cancer care needs to be defined as well as training curricula across and between primary and specialist care.

Integration of care requires a cohesive collaborative effort not just on the part of healthcare providers but also on the part of people who organise care often outside of the capacity of the researchers or clinicians trying to improve care. It requires a pre-defined coordination of the total care process.

Policy and organisational commitments are needed to effect change. As a multidisciplinary organisation encouraging progressive thinking in cancer policy, training and education, ECCO seeks to be actively involved in the development of innovative integrated models of cancer control.

ECCO has already established collaborations with several European organisations in primary care and is reaching out to other relevant primary care and community care organisations representing healthcare professions involved in cancer care.

*\* Definitions*

Primary care

Primary Care is defined by the WHO as “first contact, accessible, continued, comprehensive and coordinated care. First-contact care is accessible at the time of need; ongoing care focuses on the long-term health of a person rather than the short term duration of the disease; comprehensive care is a range of services appropriate to the common problems in the respective population and coordination is the role by which primary care acts to coordinate other specialists that the patient may need.”  
*(Source: Framework for professionals and administrative development of general practice/family medicine in Europe. Copenhagen: World Health Organisation Regional office for Europe, 1998).*

Integrated care

"Integrated care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve services in relation to access, quality, user satisfaction and efficiency." (source: Gröne, O & Garcia-Barbero, M (2002): Trends in Integrated Care – Reflections on Conceptual Issues. World Health Organization, Copenhagen, 2002, EUR/02/5037864)

Expert Group on Health Systems Performance Assessment. Tools and methodologies to assess integrated care in Europe – Report by the ISBN 978-92-79-66679-7; March 2017

“Integrated care includes initiatives seeking to improve outcomes of care by overcoming issues of fragmentation through linkage or co-ordination of services of providers along the continuum of care.”

“The creation and maintenance of a common health-care structure and connection between different providers to coordinate patient care, while retaining each provider’s unique role. *(Source: Suter E et al. 2009).*



**Annex to the Position Statement: Integrated Cancer Care: Bringing Primary Care and Secondary Care Together**

**Report from the ECCO2017 Primary Care Track**

The ECCO2017 'Primary Care' track programme was led by Ian Banks, ECCO2017 Co-Chair, Chair of the ECCO Patient Advisory Committee (ECCO PAC) and David Weller, Chair WONCA Europe Special Interest Group on Cancer and Palliative Care.

**A. Background / Contextual factors**

What we learned:

- Increasingly cancer patients are living with multiple long term conditions, which adds complexity to the care pathway, and increases primary care dimensions
- Primary care roles in cancer are not related solely to prevention and diagnosis, but also in shared follow-up, survivorship care and end of life care
- Primary care practices increasingly collaborate in networks and federations to provide more cost-effective care at scale.

The incidence of many cancers is increasing as a result of lifestyle and environmental factors and an ageing population. There is a very large increase in the burden of cancer. Internationally ageing populations have led to a growing demand for complex medical care because an increased number of people are living with multiple long-term conditions. The majority of over-65s have two or more conditions, and the majority of over-75s have three or more conditions. People who have two or more conditions outnumber those who have only one. Therefore, cancer should not be viewed in isolation. Implementation of effective strategies is essential to counteract these trends. Measures must include improved adoption and accessibility of effective treatments to all patients within an integrated care system.

WHO has endorsed primary care as a leader in healthcare reform internationally.

Primary Care is defined by the WHO as "first contact, accessible, continued, comprehensive and coordinated care. First-contact care is accessible at the time of need; ongoing care focuses on the long-term health of a person rather than the short term duration of the disease; comprehensive care is a range of services appropriate to the common problems in the respective population and coordination is the role by which primary care acts to coordinate other specialists that the patient may need." (Source: WHO. *Framework for professionals and administrative development of general practice/family medicine in Europe*. Copenhagen: World Health Organisation Regional office for Europe, 1998).

There is evidence in all the key areas of cancer control that primary care has a major role. The Lancet Oncology has published a landmark summary of the evidence for primary care roles in cancer care. (Source: *The Lancet Oncology. The expanding role of primary care in cancer control Volume 16, No. 12, p1231-1272, September 2015*).

There is international evidence linking more developed primary care with better health outcomes (Source: *Starfield et al*).



Primary care lies between self-care and hospital (specialist care) and fulfils a range of functions. Cancer and its consequences will be an increasingly prominent part of the primary care workload in the future, while the breadth of involvement of primary care physicians in cancer care will also increase. The strengths of primary care are particularly evident in prevention and diagnosis but also in shared follow-up, survivorship care and in end of life care.

Primary care is evolving. Examination of national systems discovers a large range of differing models for primary care provision. Some involve gatekeeping, in others, general practitioners need to make referrals. In some countries, patients can access secondary care directly (*Source: European Commission (2010). Health systems institutional characteristics: a survey of 29 OECD countries. Health working paper No50, OECD 2010 + country Fiches.*)

There are multiple factors influencing primary care supply and demand: lack of access to social care, rising patient expectations, ageing populations, new providers/supply induced demand, rising prevalence of chronic disease and multi-morbidity, new technologies and treatments.

Primary care is now mostly delivered through multidisciplinary teams centred around general or family practice that consist of up to thirty individual professionals who could contribute to the care of cancer patients. Primary care practices increasingly collaborate in networks and federations to provide more cost-effective care at scale.

In addition to the general practitioner, the primary care team includes the following professions involved in cancer care:

#### Psycho-oncologists

A substantial number of cancer patients and survivors experience high levels of cancer-related distress (30-45), which negatively impact their clinical outcomes. Psycho-oncology interventions have proved to be effective in preventing and reducing severe distress and psychological morbidity and in improving patients' clinical outcomes including quality of life and survival. Specialised psychosocial care must be a central component of quality comprehensive cancer care. While psycho-oncologists are available in many cancer centres, this will not be the case at the primary care level. At this community level the likelihood of these services will rely on the generic specialty of clinical psychology or even better if on clinical health psychology.

Clinical health psychologists (as well as psycho-oncologists, a subspecialty within cancer care, which has its roots in clinical health psychology) are specialists in behavior and emotional change and have an important role at primary care level. They can collaborate closely with family physicians and nurses, integrating the primary care team, by developing and delivering psycho-educational and psychosocial intervention programs at the 4 prevention levels: primary, secondary, tertiary, and quaternary. These specialists are resourceful in providing a whole range of evidence-based interventions for addressing populations at risk, groups, families, and individuals' needs, which may go from risk-behavior change (e.g., smoking cessation, obesity reduction, physical inactivity, stress-management) to preventing or reducing excessive negative emotional symptoms or syndromes (e.g., anxiety and/or depression) and maladjustment disorders in patients and caregivers, to rehabilitation programs targeting cancer treatment side-effects and consequences at the psychological, social, sexual and cognitive levels. These programs promote risk reduction and self-management, emotional and physical recovery, adjustment and healing, of the person who has experienced or is experiencing cancer and its



treatment and also foster return to normal active life, including work. These programs have proven to be cost-effective as they reduce psychological morbidity and as such reduce healthcare-related costs. They also promote quality of life, an adaptive meaning and coping with adversity in life (resilience), foster post-traumatic growth in cancer patients, which helps them store/process this experience in a positive learning or less damaging way.

### Community nurses

Community nurses have a central role in proactively planning and organising a person-centred care plan for the person with cancer in the home by cooperating with other professionals (such as doctors, physiotherapists, occupational therapists, dieticians, social workers, psychologists, assisted living teams etc.). They play a key role in the following aspects:

- Recognising and relieving symptoms in all stages of the disease
- Supporting the patient in the lifestyle changes that can improve symptom control
- Involving and supporting the family and relatives of the patient

### Community pharmacists

Cancer patients live in a community and can decide more and more often where they seek advice and care. Community pharmacists are well integrated into the communities much like the general practitioners and other primary care professionals. Many patients prefer to stay in the communities that they know and be treated by the professionals they are familiar with.

Community pharmacists not only dispense medication, but more and more often they manage medications, provide pain management services, offer nutritional advice and promote screening and prevention services. Yet, too often primary care practitioners, including community pharmacists, do not have the full picture of patients' condition. This is often attributable to straight forward barriers such as lack of access to the patient's medication record. Collaborative care examples are rarely found. Lack of formal communication channels, time pressure, staff shortages, professional silos, outdated service remuneration models, as well as legal barriers (e.g. data access) are amongst the main barriers to be overcome.

### Physiotherapists

Physiotherapists are experts in finding the best ways for cancer patients to stay active. This may involve exercise programmes or advice on everyday activities, such as climbing stairs or getting dressed. Cancer patients often lose control and confidence in their body. Physiotherapists train them throughout the cancer journey.

With some cancers, research has shown that exercise can reduce the risk of recurrence and increase the chances of survival. Specialist physiotherapists can also help with the treatment of side effects such as tiredness, osteoporosis and lymphoedema.

Physiotherapists also support cancer patients with managing pain. This is important as pain can make patients reluctant to move or walk. Managing pain improves quality of life. For cancer patients of working age, physiotherapy can help them gain enough strength and mobility to return to work.

A recent systematic review concluded that supervised exercise by physiotherapists is crucial in all stages of the cancer journey.



### Occupational health specialists

Occupational health advisers are health professionals who specialise in workplace health issues. The professional and social roles of patients can be altered dramatically as a result of cancer.

Occupational therapists help patients to analyse the different roles they play as individuals (such as workers, parents, volunteers, etc.) and find ways to lead meaningful lives. This applies to cancer survivors but also to patients at end of life.

### Carers

Eurocarers, the EU platform working with and for carers, defines carers as persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal employment framework. Carers are an inherent and indispensable part of the provision, organisation and sustainability of health and social care systems. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty and chronic disease. However, this precious resource is under pressure and there is a need for actions aimed at building and strengthening carer resilience and putting support in place that enables them to continue to deliver care.

## **B. Enhanced roles for primary care in cancer prevention, screening and management**

### **What we learned:**

- To design high quality pathways to cancer diagnosis we must recognise that cancer diagnosis starts in primary care and acknowledge that different pathways are needed.
- Cancer survivors are a growing group and require attention in the future development of primary care cancer services.
- There are open opportunities to improve the role of primary care in respect to palliative care, including anticipatory care

### Reducing diagnostic delays

Earlier diagnosis is associated with better cancer outcomes. In 90% of cases, cancers are diagnosed based on symptoms. The selection of patients for onward referral or for diagnostic investigations is mostly predicated on the predictive values of symptoms. More than 80-85% of patients present in primary care and not at the hospital (*Source: Vedsted P, et al. Scand J Prim Health Care, 2009; 27: 193-4*).

Many cancers are diagnosed in a timely and efficient manner. Some diagnoses are easy for general practitioners (GPs), some are hard, some are nearly impossible. Diagnostic times vary significantly between health systems. For all cancers there is a very skewed distribution of diagnostic intervals. There are several parameters which can be changed in healthcare systems to improve the diagnostic pathway:

- Patients' awareness of cancer symptoms and ability to seek help when symptoms are experienced.
  - There have been many forms of public awareness of symptoms campaigns. There is evidence that these lead to improved outcomes in the short term but there is no evidence



of long term benefit (campaigns are typically of a short term nature and it is less well known what their long term impacts are).

- General Practitioners' consulting style: when presented with a symptom what can GPs do?
  - Ignore/reassure
  - Act as a safety net
  - Low level investigation
  - Start a more specific investigation
  - Refer the patient for a specialist opinion
  - Arrange urgent admission to hospital
  - Arrange assessment in Emergency

Healthcare systems can influence the following factors which impact the decision making process of GPs:

- Readiness to investigate and refer
- Dealing with uncertainty
- Safety netting practice: (process by which if the physician has the slightest concern, information is given so that the patient knows what to look out for, what to do about it and how to get back to the physician)
- Use of guidelines (physicians are not very good at following guidelines REF: international variations in adherence to referral guidelines for suspected cancers. Nicholson BD, Mant D, Neal RD et al., BR J Gen Pract 2016)
- Use of decision support tools
- GPs access to investigations, specialist opinion, other health services and the speed of such access
- Making better tests available to GPs
- Secondary care diagnostics

### **Designing better pathways to diagnosing cancer**

Many people who have symptoms which could indicate cancer will be found not to have it. There is a symptom continuum in primary care from 'trivial' to 'low but not no risk' up to 'serious' and 'alarm/referral' levels. The majority of symptoms will fall into the grey zone of 'low but not no risk'. If earlier diagnosis is to be achieved more patients need to be referred when they present with symptoms in "the grey zone".

A 3-legged pathway for cancer diagnosis is recommended:

- Urgent referral for a specific cancer (alarm symptoms)
- Urgent referral to diagnostic centre (serious, non specific symptoms)
- Fast and direct access to investigations (vague symptoms)

In 50% of cases, cancer patients present with alarm symptoms and follow the urgent referral pathway for specific cancers. Urgent referral is effective (shorter diagnostic interval, lower mortality, higher patient satisfaction) but is only applicable to the 40% of patients diagnosed through urgent referral.



Diagnostic centres have been established in Denmark to care for patients who cannot be allocated to a specific route by the GP. These centres are in fact multidisciplinary teams of specialists in hospitals. In 11% of cases, patients receive a cancer diagnosis while another 34% of patients receive another significant diagnosis.

General Practitioners have direct access to expedited investigations (cancer: “yes” or “no”). The GP is responsible for action and follow-up. In the Netherlands, for example, GPs are allowed to refer patients directly to colonoscopy. This has significantly reduced the days between diagnosis and treatment from 85.5 to 42 days. (Source: *Klemann et al. Dig Surg 2011; 28:15-21*).

To design high quality pathways to cancer diagnosis we must recognise that cancer diagnosis starts in primary care and acknowledge that different pathways are needed.

### **Using guidelines to improve cancer diagnosis and referral**

In the UK, NICE established the first guidelines for GPs for the diagnosis of symptomatic cancers in 2005. The guidelines can be evidenced as having achieved a reduced time to diagnosis (Source: *BJC – comparison of cancer diagnosis intervals before and after implementation of NICE guidelines ...*).

10 years later, in 2015, recognising that not every symptom can be tested, NICE issued new guidelines that set a threshold for investigation or referral by GPs of the patient meeting a 3% ‘Positive Predictive Value’ (a measurement of risk) for possible cancer. The decision to set a threshold of 3% was controversial, though based on the wishes of patients. Patients are understandably eager to be tested for cancer even if the overall chance of cancer diagnosis is considered to be low. (Source: *preferences for cancer investigation: a vignette-based study of primary-care attendees*).

Based on primary care evidence, the 2015 NICE guidance were generally popular with GPs whilst inviting some disquiet from members of the cancer specialist community.

National guidelines appear to have a positive effect on expediting cancer diagnosis. They may work best if seen to come from a General Practitioner source and need ‘buy in’ from secondary care and government.

### **Management of cancer patients in primary care**

Cancer survivors are a growing group. General Practitioners (GPs) have a role in detection, diagnosis and end of life care in cancer but research shows that they also have a role during treatment and in providing care to survivors.

For the purpose of this paper, the definition of a cancer survivor is the one used in the EU CanCon guide. A cancer survivor is defined as “anyone with a diagnosis of cancer and who is still alive. This includes patients having completed primary therapy and who are free of disease as well as those patients living with recurrent and/or advanced disease”.

(Source: *European Guide on Quality Improvement in Comprehensive Cancer Control (CanCon)*; Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke, 2017)

General Practitioners have much more contact with patients for the treatment of side effects of chemotherapy, radiotherapy or surgery, for the management of psycho-social events and for the prescription of medicines. (Source: *D. Brandenburg et al. Scand J Prim Health Care: 2014*).



Cancer patients constitute a vulnerable group: 70% have comorbidities which are mostly due to age and are often treated by GPs.

Because there is no formal role for GPs during cancer treatment and survivorship, the Dutch College of GPs issued a position paper in 2014.

([www.nhg.org/sites/default/files/content/nhg\\_org/uploads/final\\_nhg-standpunt\\_2014\\_webversie\\_met\\_bookmarks\\_sk\\_3\\_juli.pdf](http://www.nhg.org/sites/default/files/content/nhg_org/uploads/final_nhg-standpunt_2014_webversie_met_bookmarks_sk_3_juli.pdf)). The paper advocated for a pro-active attitude towards the patient who receives a diagnosis and called on GPs to maintain contact with the patient after diagnosis. GPs can play a role to help patients make decisions based on the options they receive from the hospital both for curative and palliative treatments. This can include supplying further information and answering questions patients may have formed subsequent to their hospital stay. The paper suggests that follow-up treatments might be performed by GPs for 4 (four) cancer types: breast, prostate, lung, colorectal where the evidence supports substitution of care.

Primary care can be holistic and include physical, psychological and some social aspects of cancer care. It can provide continuous care and care for co-morbidities. It can coordinate care between the patient and other agencies and include a focus on family members.

Primary care can offer screening for late effects and prevention (e.g. cardio toxic effects and osteoporosis). GPs might encourage patients to change their life style. They can help with the diagnosis of late secondary cancers.

Patients want reassurance, continuity of care and psycho-social dimensions which are often lacking in hospital follow-up. Hospital follow-up offers specialist knowledge and tests but can also create anxiety. Communication between providers is perceived as poor by the patients. Primary care is well placed to have an expanded role in caring for cancer survivors.

### **Comorbidity in cancer survivors in the 21<sup>st</sup> century**

Comorbidities are frequent in cancer patients and create many complications for care and patient wellbeing (Source: Deckx et al, J cancer epidemiol 2012). Co-morbidities can contribute towards a reduced quality of life for the patient, as well as an increased treatment burden. This also has impacts for the caregivers of a patient.

The top seven diseases that exist around the time of cancer diagnosis in a population aged 60+ are diabetes, lipid disorders, Ischemic Heart Disease + angina, IHD no angina, myocardial infarction, osteoarthritis knee. The types of diseases we see in cancer patients are similar to those of their counterparts in age and sex who have no cancer. There is the exception of COPD which is more frequent with cancer patients and can be explained by smoking.

Personality disorder and dementia are less frequent around the time of cancer diagnosis probably due to the fact that these diseases can mask the cancer symptoms.

After cancer diagnosis, there are no differences in frequency of many of the large disease groups between groups of people with cancer and similar groups of people with no cancer diagnosis. Some difference exists in thrombosis which is more frequent in cancer patients.

At the professional level, when patients have multiple considerations it might be more difficult to interpret new symptoms (e.g. dementia can mask symptoms of cancer) and diagnose a new disease. Once the disease is apparent it might be difficult to handle the various disease-specific guidelines



which may be in conflict with each other. Many regular medication therapies interact with chemotherapies. We need a guideline for each patient, not a guideline for each disease.

From the patient perspective, multiple treatments make it more difficult for patients to achieve compliance and adherence. Most professionals overestimate the level of compliance of patients to treatments and the results of treatments. It might be easier to ensure compliance when the patient is part of the decision-making process.

Comorbidity can be a problem in cancer prognosis. The different diseases mean an increased physiological burden of disease. Cancer treatment may affect the possibilities of treatments and the effectiveness of treatment is not so clear.

Comorbidities create specific problems in research. In the study population, cancer patients are a very heterogeneous group. With comorbidities the heterogeneity is even bigger. If these comorbidities are included in the study it might be difficult to get clear results. If only some of them are selected to make the group more homogeneous, the results will not count for the entire population and will have little external validity.

Clinical trials often exclude older people with severe comorbidities. Research results are then not generalisable to the patients in consultation who are often older patients with comorbidities. The study participants must be recruited in a vulnerable population with a high level of non response which reduces the possibility of generalising the results.

### **The need for joined up approaches between palliative care and primary care**

WHO recommends that palliative care should be integrated with cancer care from cancer diagnosis. This is even earlier than the early palliative care input advocated by palliative care studies such as Temel in the USA. Primary care is the place to do this.

Some years ago, palliative care was introduced after curative care once the person was dying. Nowadays the new model is that palliative care in cancer patients should start in parallel with the disease modifying treatment. (Source: Murray SA, Kendall M, Boyd K, Sheikh A., *Illness trajectories and palliative care. BMJ. 2005; 330:1007-1011*).

Studies show that palliative care comes late. This is a period during the patient journey about which more attention should be focused.

Palliative care does more to help the person. There are many dimensions to patients' needs. Dying can also be seen as a spiritual event rather than only a physical one. (Source: Grant E, Murray SA, Sheikh A. *Spiritual dimensions of dying in different cultures. BMJ 2010; 341: 4859*).

Dying of cancer is a journey along a multidimensional trajectory. The non-physical triggers must be considered. Social decline goes hand in hand with physical decline. There are certain times along the trajectory when patients are expected to be anxious (e.g. at diagnosis, upon returning home, in case of a recurrence). (Source: Grant L, Murray SA, Sheik A. *BMJ 2010; 341: bmj.c4859*).

A study in Scotland shows that many people now benefit from anticipatory care before they die. (Source: Tapsfield J, et al. *BMJ Supportive and Palliative Care; 0:1 -10. Doi: 10.1136/bmjspcare-2015-001014 1*).



Anticipatory means early palliative care or survivorship care. In that study, GPs were encouraged to identify candidates for palliative care earlier in their illness and to use new IT tools enabling medical records to be shared among healthcare professionals in primary care and secondary care. This made it possible to plan ahead (based on information sent to hospitals). Since then, more patients are included in the palliative care register and at an earlier stage. Anticipatory care is holistic care with conversations anticipating issues patients are likely to be worried about.

Evidence shows that it does make a difference where people die. Nursing care is one of the contributing factors in the preferred place of death (*Sources: Gomes et al. BMC Medicine (2015) 13:235 DOI 10.1186/s12916-015-0466-5*).

Several studies look at the role of community based nursing in palliative care provision. They show that people generally believe that the relationship between nurses and patients is critical to care. However, evidence shows that a prior relationship is not needed for patients to feel a difference. The psychosocial needs of patients are managed in equal numbers by nurses familiar or unfamiliar with the patients. The gift certain nurses have in intuitively responding to a patient's needs seems much more important than the presence of an ongoing relationship between nurse and patient. (*Source: International Journal of Nursing Studies 47 (2010) 1167-1183*).

Integrated team-based care at home enables people to die in their place of choice. However, studies show that people working together to provide palliative care at home do not always collaborate well and therefore we need to look at other models of care. (*Source: Palliative Medicine 2016 Vol. 30(6) 580-586*).

Current research is looking at how to cope well with advanced cancer. A qualitative interview study with patients and family carers has concluded that they want peer support. Therefore, thinking about primary care should be broadened beyond, doctors, nurses, pharmacists and allied healthcare professionals to include the community and people experiencing cancer. We should look at ways for them to help improve the quality of care of cancer patients. (*Source: PLOS ONE/DOI: 10.1371/journal.pone.0169071 20 January 2017*).

### **C. Integrated models of cancer management: bringing primary care and secondary care together - the Canadian example**

#### **What we learnt:**

- Studies show that patients seek the advice of primary care professionals about their cancer treatment after diagnosis and during treatment;
- Studies also evidence the difficulties that exist in respect to communication between primary care and secondary care professionals
- Improved utilisation of IT solutions can address some of these communication challenges

Evidence shows that patients on chemotherapy are significantly more likely to have at least one primary care professional visit compared to controls. Most of them are related to the management of toxicities induced by chemotherapy. (*Source: Bastedo et al. Curr oncol 2017*).

A focus group qualitative study evaluated the perception of primary care physicians and oncologists of their role in assisting treatment decisions and dealing with questions around precision medicine. This study showed that primary care physicians felt they did not have the expertise required to interpret the



gene profiling expression tests or to advise their patients on the treatment decision based on precision medicine. (Source: O'Brien, *Curr Oncol*: 2017 – Ontario).

However, patients do seek the advice of primary care physicians about their treatment decisions. A quantitative population based study (Ontario) showed that 42% of patients visited their primary care physician between the first oncology consultation and the start of chemotherapy. A US study showed that 35% of breast cancer patients reported their primary care physician participated in treatment decisions. (Source: US study, Wallner, *Journal of Clinical Oncology (JCO)*: 2016.)

During the follow-up period patients have multiple interactions with their family doctor in parallel to the interactions with their oncologists (Source: Grunfeld et al. *J Oncol Prac* 2010).

Patients have a lot of interactions with the healthcare systems and there is a lot of duplication of care but also many significant gaps in care. For example, patients are often not up to date with the screening recommendations for cancers other than their index cancer. The most important predictor of the frequency of visits to primary care doctors is the extent of their co-morbidities at the time of diagnosis.

The cancer care system has many fault lines in inter-sectorial and inter-disciplinary care. Integration of care is key to optimising inter-sectorial and inter-disciplinary care.

On average, 85% of primary care physicians are willing to provide exclusive follow-up care to patients up to 3 years after diagnosis (Source: Del Guidice, Grunfeld et al. *JCO* 2009).

The most important predictor of the willingness of family doctors to provide exclusive follow-up was their experience with cancer in the past. To provide this follow up, primary care physicians would need the following:

- Fast-referral of patients if specialist advice required
- Training and advice from the cancer team
- Tools and procedures for communication with the cancer team
- Access to appropriate investigations as per the recommendations for follow-up care

There is a mismatch between what patients, primary care physicians and oncology specialists expect from each other (Source Cheung et al. *JCO* 2009).

- Patients expect a much greater role of the oncologists in cancer screening, preventive care and management of comorbidities than the oncologists feel responsible for.
- Primary Care Physicians (PCPs) expect greater involvement of primary care in follow up than oncologists and patients.
- Both PCPs and oncologists expect to play a substantial role in primary care follow up, cancer screening and preventive care but the extent to which they are responsible varies substantially.

A study among patients, oncologists and primary care physicians on the perceptions of the most important role for primary care physicians in the healthcare system showed major problems of communication: unclear roles or access to patient information, lack of communication among healthcare providers. (Source: easley for canIMPACT: Canadian national program of research on integration between primary care and cancer specialist care; 2017).



### **Models of improved integration**

The literature refers to different terms such as coordination of care, continuity of care and transitions of care but those are essentially the same concepts.

Definition of integration: The creation and maintenance of a common health-care structure and connection between different providers to coordinate patient care, while retaining each provider's unique role. (Source: Suter E et al. 2009).

Elements of integrated care:

- a) Clinical: establish processes to coordinate patient care and clearly define clinical roles
- b) Vertical: establish structures and processes to support coordination in the delivery of cancer services between formal cancer care system and community-based care
- c) Functional: establish structures and processes to enhance coordination among providers through models of care that inform structuring of health services

Systematic reviews looked at models of integrated care for cancer. They identified 3 elements for successful integration of care:

- a) Patient-centred

Patients and their families are arguably the single-most underutilised resource for achieving sustainable health care (source: Catherine Craig and Eva Powell, Institute for Healthcare improvement Triple Aim faculty). The active engagement of patients is a common thread across numerous reports aimed towards achieving sustainable high quality health and cancer care (source: Schlisky, ASCO President, 2014; Leonard Kish, 2012).

- b) Multidisciplinary
- c) Organisation of care (pre-defined coordination of the total care process)

The study concluded that multifaceted interventions that address all elements are most likely to be effective on proximal outcomes. Very few interventions actually address all three elements. (Source: Ouwens et al, Int J Qual Health Care: 2009).

Integration of care requires a cohesive collaborative effort not just on the part of providers but also on the part of people who organise care often outside of the capacity of the researchers or the clinicians who are trying to improve care.

IT solutions could potentially address problems of communication and information transfer. Overall, most countries are behind in harnessing these IT solutions. However, a comprehensive approach to how IT solutions can improve integrated cancer care could go a long way.

Examples:

- Electronic medical record (EMR) in PCP practices
- Guidelines on follow-up integrated into EMR with a reminder system (decision support software)
- Electronic updates on new evidence automatically integrated into EMR
- Computer generated, disseminated and updated treatment summaries



In Ontario, survivorship care has been transferred to primary care. Despite the evidence, there was not a proper movement in that direction until the Ontario Cancer Agency felt it was vital to improve patient care and address the increased prevalence that was set to overwhelm the healthcare system. Cancer Care Ontario developed a work plan to strengthen the evidence base and standardise follow-up care. They recognised the complexity of trying to introduce the change and had to articulate all the elements and different steps in the process. They created a care map that described where care was expected to be provided. A policy commitment was made to effect the change.

There are many initiatives across Canada to improve integration mostly in the survivorship area but some do look at the entire cancer control continuum.

### **Conclusions**

- Involvement and better integration of primary care is essential to meet the demand of 40% increase in cancer incidence.
- The importance of integration is recognised internationally.
- Despite many advances in cancer care, problems persist between the primary care and cancer sectors: fragmentation, poor communication, poor coordination and lack of clear role definition.
- Improved integration is a complex process. It must be multifaceted, involving patients, professionals and organisation of care stakeholders.

### **Integrated models of cancer management: Key points from the panel discussion**

#### **Patient centeredness**

- Most of the therapeutic products produced by industry for the treatment of cancer require provision and administration in a hospital setting. Part of the answer to more sustainable models of care is to design treatments which can be more easily used in the community. This would facilitate collaboration and integration of care.
- It is striking to see the difference between the perceptions of the patients' needs by the healthcare professionals and the patients' perceptions and experiences. There is a necessity to address this now as well as the ability to return to normal life as much as possible.
- It should be a duty of the GP to seek contact with the patient who has received the cancer diagnosis.
- In order to be empowered as being at the centre of their own care, patients have educational needs to be met.
- In the Netherlands specialised nurses see patients immediately after the specialist has explained to the patient the surgical procedure and diagnosis. Thereafter the nurses have closer contact with the primary care physicians and the family of the patient. The nurse practitioner is usually the contact person between the different care interventions and plays an important role in the communication processes.
- GPs may not feel confident and qualified in being part of the decision making process for cancer treatment after diagnosis and need clarifications about what they should and should not discuss. They need to be convinced that it is not all about the medical content of the advice but also talking about knowing the patient, continuity of care and patients' priorities.



- The needs of those patients with more limited comprehension should not be forgotten. People vary in their capacity to understand. We can not empower all patients in the same way. However, patient centeredness is not necessarily equivalent to shared decision-making without regard to patient capacity.

#### Multidisciplinary/multiprofessional care

- In Switzerland some primary care professions have gained more competences in the area of cancer care. Examples include community pharmacists and nurses. In such circumstances however, it is possible for GPs to fear a loss of contact with the patient. The difficulty is to involve the patients. The GP's knowledge of the patient helps to empower the patient. The relationship does not start with the cancer.
- In the UK, nurses do a lot of the management of the doctors. GPs know all the patients registered in their practice. Other professions know the patients only when they are referred to them. From the patient perspective, the only person the patient knows how to get hold of is the GP. They do not know how to get hold of the nurses or the specialists.
- Each profession talks about what they can offer to patients in a one to one consultation, but few talk about being part of a team. One of the places where further change could usefully be made is in education. At the time they are being trained, at undergraduate or postgraduate level, students must clearly visualise and understand the way in which they will be expected to operate professionally as part of a team.
- In other disease areas, such as diabetes, moves towards providing more care in the primary care sector are more long-established. Previously diabetes care was almost the sole remit of endocrinologists. Lessons from this include knowing that clarification on the roles of, and the expectations from, differing professions in providing care to cancer patients will be of much assistance. Oncologists need to reach out to primary care, and to welcome increasing interactions with primary care. The complex part is during the treatment.



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