European Partnership for Action Against Cancer (EPAAC)

D9: Reducing inequalities in cancer treatment and care through the use of clinical guidelines: A review and evidence-based recommendations

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Executive Summary

Context
Cancer is a considerable and growing public health challenge across Europe. In 2012, in the 40 countries of the four United Nations-defined areas of Europe and the 27 countries of the European Union (EU), there were an estimated 3.45 million new cancer cases and 1.75 million cancer deaths.

Significant variation in cancer control and care exist within and between EU Member States across the key areas of cancer care: screening, detection and early diagnosis (access); treatment and palliative care. Differences in survival rates are in part explained by differences in stage at diagnosis and accessibility to good care, different diagnostic intensity and screening approaches, and differences in cancer biology, as well as possible variations in socioeconomic, lifestyle, and general health between populations.

Clinical guidelines aim to minimise unacceptable variations in care provision by improving the quality of care provided to those who have accessed the health system (e.g. by improving access to screening and early diagnosis) through assisting practitioner and patient decision-making regarding care options. However, the application of clinical guidelines in practice can be hampered by, among other factors, organisational issues at the level of implementation.

Aim
This review aims to identify the key barriers and enablers to effective clinical guideline implementation located within the context of systems change and knowledge translation.

Methods
This narrative literature review entailed the searching of two electronic databases (i.e. PubMed and Science Direct) for work published in English during the previous 15 years using the broad thematic search terms of ‘evidence’, ‘cancer’, ‘guideline’ and ‘implementation’.

Recommendations
(i) Staff-related level
Guideline development should:

- Engage healthcare professionals, opinion leaders, patients and other stakeholders in the development and implementation of clinical guidelines to ensure buy-in, ownership and commitment.

- Employ a differentiated approach to engaging clinicians, with special attention given to those least receptive to guidelines.
• Demonstrate the anticipated benefits of the clinical guidelines, including any potential personal advantage arising from their implementation.

• Ensure that the guidance offered is specific and clear for those expected to implement them, indicating explicitly what, who, when, where and how.

• Frame the new guidance so that it demonstrates coherence with existing clinical guidelines, practice, norms and values.

• In light of Europe’s ageing population and the increasing prevalence of chronic health conditions, ensure that guidelines that are primarily disease-specific are located within a multi-morbidity narrative.

• Institute educational and training programmes and draw upon ‘local evidence’ where possible to support the advice being provided.

• Develop the guidelines using a credible, respected institution.

• Audit and provide feedback on the status of guideline compliance, in part to identify any factors that are negatively impacting upon their introduction. This would appear to be best undertaken using a group feedback approach, which can draw upon peer pressure.

(ii) Healthcare organisation-related

• Develop a dissemination strategy for the guidelines that is active rather than passive in nature.

• Develop a supportive working environment to complement the introduction of clinical guidelines, including the development of a positive culture of implementation that uses group pressure among colleagues to ensure compliance, as well as adequate communication channels between service providers and minimal paperwork to burden staff.

• Ensure that staff expected to implement clinical guidelines have the necessary resources and inter-service operability – where relevant – to effect the guidance.

(iii) External level

• Punitive sanctions to enforce guidelines’ implementation may be an increasingly popular option but should not sacrifice individual patient’s genuine health needs for cost-containment goals.

• Health care systems should view the role of patients as active, empowered and informed partners, from information generation to dissemination. This will help ensure the guidelines are relevant to those who are expected to use them or benefit from their use, rendering them more likely to be adopted in clinical practice.
An effective monitoring and evaluation plan should supplement the introduction of the guidelines, to ultimately determine their impact and the extent to which they achieved the anticipated changes in clinical practice and in reducing health inequalities.
Acknowledgements

Anna Carter and Elisabeth Jeffs for drafting earlier versions of this document, EHMA Board members and EPAAC partners for their comments on earlier versions, Olivia Dix, EHMA, for editing of the final version.

This report has been produced in the scope of the “European Partnership for Action Against Cancer Joint Action” (EPAAC) which has been funded by the European Union in the framework of the Health Programme.
Foreword

The European Partnership for Action Against Cancer (EPAAC) was launched in 2009, after the European Commission (EC) published its Communication on Action Against Cancer: European Partnership. The Partnership brings together the efforts of different stakeholders in a united response to prevent and control cancer through a Joint Action, co-financed by the European Union (EU) Health Programme. The National Institute of Public Health in Slovenia has assumed the role of leader of the EPAAC Joint Action, which encompasses 36 associated partners from across Europe and over 100 collaborating partners.

The main objective of this initiative was to assist countries in developing National Cancer Control Plans (NCCPs), as part of the EC’s push to reduce cancer incidence by 15% by 2020 and reach out to patients and the general public, but also included were supportive activities in: health promotion and prevention; screening and early diagnosis; healthcare; research and data and information. The primary target groups were EU Member States and governmental and key non-governmental organisations, but scientific organisations and professional associations were also targeted.

In terms of its primary objective, by late 2011 all but four Member States had some type of NCCP, programme or strategy in place, with the remaining four working towards the finalization of their plans. The EPAAC Joint Action ends in early February 2014, with a publication produced with its key findings: *Boosting Innovation and Cooperation in European Cancer Control: Key Findings from the European Partnership for Action Against Cancer.*

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Reducing inequalities in cancer treatment and care through the use of clinical guidelines: A review and evidence-based recommendations

1. Background

1.1 The scale of the problem
Cancer is a leading cause of morbidity and mortality worldwide, with an estimated 14.1 million new cases and 8.2 million deaths in 2012. Cancer accounts for a significant percentage of all fatalities and is a considerable public health issue. Lung (1.6 million, 19.4% of the total), liver (0.8 million, 9.1%), and stomach (0.7 million, 8.8%) malignancies are the cause of most cancer deaths annually. It is projected that by 2030, mortalities from cancer worldwide will rise to 13.2 million, attributable to an increasing and aging population and the adoption of risk factor lifestyles.

In 2012, in the 40 countries of the four United Nations-defined areas of Europe and the 27 countries of the European Union (EU), there were an estimated 3.45 million new cancer cases – excluding non-melanoma skin cancer – and 1.75 million cancer deaths. This was despite reductions in its incidence and mortality due to advances in early detection, diagnostic approaches, treatment, lifestyle changes and the development of prevention vaccines for selective cancers. The most common causes of death were cancers of the lung (353,000), colorectal (215,000), breast (131,000) and stomach (107,000). Indeed, in 2008 cancer was the second most common cause of death in the EU – 29% of deaths among men and 23% among women.

1.2 Inequalities
Significant variation in cancer control and care exist within and between EU Member States. Eurostat data shows that in 2008 the lung cancer mortality rate in men was over three times

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higher in the worst performing Member State compared with the best and nearly four times higher for cervical cancer mortality.\textsuperscript{8} Similarly, estimated colorectal cancer incidence was three times higher in the worst performing Member State than in the best.\textsuperscript{9}

This variation in incidence is matched by variation in mortality and survival both within and across the Member States. In a retrospective observational study of 107 cancer registries for more than 10 million patients with cancer diagnosed up to 2007, and followed up to 2008 across 29 European countries, De Angelis et al and the EUROCARE group found that, while 5-year relative survival generally increased steadily over time for all European regions, survival in eastern Europe was generally low and below the European mean, and highest for northern, central, and southern Europe.\textsuperscript{10} The authors postulated that likely explanations of survival differences between countries included: differences in stage at diagnosis and accessibility to good care; different diagnostic intensity and screening approaches; differences in cancer biology and possibly variations in socioeconomic, lifestyle, and general health between populations.

In the United Kingdom inequalities in survival between rich and poor are estimated to account for 7,122 avoidable cancer-related deaths. This is 11\% of the nearly 65,000 excess deaths recorded annually between 2004-06,\textsuperscript{11} with additional research suggesting inequalities in minority migrant groups’ mortality.\textsuperscript{12} Similarly, substantial socio-demographic inequalities in advanced stage at diagnosis (i.e. stage III/IV) was found to exist for seven cancers, with deprived patients more likely to be diagnosed in advanced stage for melanoma, prostate, endometrial and (female) breast cancer.\textsuperscript{13} Examining survival trends between 2000-04 for 20 common cancers, Gondos et al found that among the 12 participating cancer sites major geographical differences in patient prognosis persisted, with a lower survival observed in Eastern European countries.\textsuperscript{14}

\begin{itemize}
\item \textsuperscript{11} Ellis L, Coleman MP, Rachet B. How many deaths would be avoidable if socioeconomic inequalities in cancer survival in England were eliminated? A national population-based study, 1996-2006. \textit{European Journal of Cancer} 2012; 48: 270-278.
\end{itemize}
However, not all variation is attributable to income differentials. For example, Bray et al reported that prostate cancer is the most frequent cancer amongst men in Europe,\(^{15}\) with the highest mortality rates reported in the Baltic region (Estonia, Latvia and Lithuania) and in Denmark, Norway and Sweden. Indeed, while prostate cancer mortality has been decreasing in 13 of the 37 European countries studied by Bray et al – predominantly in higher-resource countries – there is considerable variability in the size of the annual declines, from approximately 1% in Scotland (from 1994) to over 4% for the more recent declines in Hungary, France and the Czech Republic.

Differences also exist in service provision and access across the key areas of cancer care: screening, detection and early diagnosis (access); treatment; and palliative care.\(^ {16}\)

### 1.3 Screening, detection and early diagnosis

Screening is the systematic application of a test in an asymptomatic population that aims to identify people with abnormalities suggestive of a specific cancer or pre-cancerous condition. This screening enables them to be referred promptly for diagnosis and to access appropriate treatment, thereby striving to prevent progression in the disease. Effective screening of populations has been shown to reduce mortality among a number of cancers, including breast and colorectal cancer.\(^ {17,18}\)

However, variation by education and income also exists in early diagnosis. Investigating cutaneous malignant melanoma among 27,235 Swedish patients between 1990-2007, Eriksson et al found lower levels of education were associated with reduced survival, and attributed it in part to a more advanced disease stage at diagnosis, meriting the need for improved early detection strategies.\(^ {19}\) This has since taken forward as part of an EU-wide agenda in a series of campaigns, and within the UK in the ‘Be Clear on Cancer’ drive that seeks to raise awareness of breast cancer among women over 70 in lower socio-economic categories.\(^ {20}\)

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\(^{16}\)Health promotion and prevention are additional important pillars in the response to cancer but not discussed in this section.


Similar findings were reported by Low et al who found awareness of risk factors for cervical cancer symptoms was lower among younger British women with lower education and also those from ethnic minority groups.\textsuperscript{21}

1.4 Treatment
Curative cancer treatment requires the selection of one or more interventions, such as surgery, radiotherapy and chemotherapy with the goal of curing the disease or considerably prolonging patients’ lives. Some of the most common cancer types – e.g., breast, cervical, oral and colorectal – have higher cure rates when detected early and treated according to best practices.\textsuperscript{22}

Aarts et al’s review of mass screening for colorectal cancer found treatment, as well as survival and mortality, was less optimal for people from lower socio-economic backgrounds, meriting the need for higher participation in detection programmes.\textsuperscript{23} Similar findings were reported by Møller et al in their study of colorectal cancer survival between socio-economic groups in England between 1996-2004.\textsuperscript{24} Given variations in infrastructure across Europe, it is also contended that health systems can impact upon patients’ cancer outcomes through three mechanisms: coverage, innovation, and quality of care, with inadequate service provision excluding patients from accessing needed assistance.\textsuperscript{25}

1.5 Palliative and end-of-life care
Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”\textsuperscript{26}

Palliative and end-of-life (EOL) care is increasingly seen as an essential component of cancer care,\textsuperscript{27} addressing what has been estimated as a median of 11 symptoms among people with advanced disease, and up to 1.6 million patients with pain annually.\textsuperscript{28} However,
despite the epidemiology of progressive cancer and its associated mortality across Europe, and the need for high quality palliative and EOL care, the discipline has been historically under-researched and under-funded. This deficiency has in part been addressed by the PRISMA project, a pan-European co-ordinating action funded under Framework Programme 7 of the European Commission with 12 partners in nine countries with the aim of promoting best practice in the measurement of EOL care, setting a research agenda and guidance that reflects European cultural diversity, and is informed by public and clinical priorities.²⁹ Consensus has since been reached on core priorities for EOL cancer care research in Europe: symptomatology – including pain, fatigue, cachexia, delirium and breathlessness – issues related to care of the dying, and policy and organisation of services.³⁰

Inequalities in outcome may also be at least partly attributable to differing cultural attitudes among the diverse communities and ethnicities of the EU. Personal narratives and coping mechanisms – including spiritual beliefs – can mediate, for example, how pain is interpreted,³¹ and how an effective psychological adjustment to a diagnosis of cancer and its progression is achieved.³²

### 1.6 Costs of cancer care provision

This variation in disease burden and care provision is reflected in a substantial societal economic burden. In a recent population-based cost analysis of all cancers – including those associated with breast, colorectal, lung, and prostate cancers – using country-specific aggregate data for morbidity, mortality, and healthcare resource use, Luengo-Fernandez et al estimated cancer cost EU countries €126 billion in 2009. Healthcare costs – including doctors’ time and drug costs – accounted for €51·0 billion (40% of total cancer costs), equivalent to €102 per citizen across the region, ranging from €16 per person in Bulgaria to €184 per person in Luxembourg, while lung cancer bore the highest economic cost (€18·8 billion, 15% of overall cancer costs), followed by breast cancer (€15·0 billion, 12%), colorectal cancer (€13·1 billion, 10%), and prostate cancer (€8·43 billion, 7%).³³

some of the study’s per person economic cost variations are partly explained by differences in inpatient care costs (for lung and colorectal cancers) and medicines costs for prostate and breast cancers.³⁴ However more generally this inter-country variation in disease burden and

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associated care costs is a function of the complex confluence of three key domains—science, policy and practice— all of which exert a critical impact on all aspects of cancer care provision: health promotion and prevention, screening and early diagnosis, treatment and palliation.

1.7 Clinical guidelines
Rigorously developed, comprehensive clinical guidelines use high-level evidence to provide guidance on everyday clinical management by integrating strategies for early detection, diagnosis, and treatment. These aim to minimise unacceptable variations in care provision by improving the quality of care through assisting practitioner and patient decision-making regarding care options.\(^{35,36}\)

Consequently, for people who manage to access health systems— and not all can for various reasons— clinical guidelines can reduce inequalities. While strategies and actions exist that can improve health service access by disadvantaged communities, some social determinants of health cannot be changed by health systems, instead necessitating collaborative work between public and social sectors.

Moreover, the application of clinical guidelines in practice, and thereby the effective translation of knowledge to daily clinical settings, has often proved problematic in cancer care— as it has in other health disciplines— with professional and organisational changes lagging behind the evidence. Whilst the influence of science and policy have been explored, practice has received varying coverage— specifically the organisational factors and training requirements that are potential impediments to the effective implementation of clinical practice guidelines across the EU.

This narrative review of the literature aims to identify the key barriers and enablers to effective clinical guideline implementation— using examples of cancer where possible but drawing upon other disease groups as needed— located within the context of systems change and knowledge translation. It recognises, however, that clinical guidelines do not, of themselves, reduce inequalities.

1.8 Structure of the report
The report is divided into the following sections:

- Review methodology;


- Clinical guidelines and cancer guidelines across and beyond the EU;
- A model of guidelines’ implementation;
- Implementing practice guidelines: the lifecycle
- Barriers and facilitators to implementing guidelines
- Patient empowerment, and;
- Monitoring and evaluation.
2. Review methodology

This literature review has had several iterations. The original title of the review was ‘Addressing inequalities in cancer care through clinical guidelines’. However, it became clear there was minimal evidence to explore in this field and that, of themselves, clinical guidelines cannot impact significantly on inequalities and health systems. They cannot alone mitigate all the reasons underpinning inequality of service access or treatment. The decision was therefore made to explore organisational challenges to implementing clinical guidelines.

In the development of this report, a narrative review of existing literature was undertaken. Two electronic databases (i.e. PubMed and Science Direct) were searched for work published in English during the previous 15 years using the broad thematic search terms of ‘evidence’, ‘cancer’, ‘guideline’ and ‘implementation’. Emphasis was placed on primary data studies – but included descriptive and discursive papers where appropriate – from within and outside Europe in economically developed nations and included studies of clinical practice guideline implementation from non-cancer fields where useful.

However, many of the barriers faced in the field of knowledge translation and the strategies for addressing them are not readily available in the public domain. This is because the relevant reporting does not fit the traditional paradigm for publication.\(^{37}\) Consequently, and given its proven use,\(^ {38}\) these literature searches were supplemented by recommendations for additional literature received from expert members of the European Health Management Association and its network following an open call.

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3. Clinical guidelines and cancer guidelines across and beyond the EU

3.1 Clinical guidelines
For many years, confusion existed regarding the definition of a clinical guideline. Clinical guidelines – also referred to as medical guidelines, clinical recommendations, clinical practice guidelines and clinical protocols – have been defined as “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific circumstances.”

They are positioned under the wider umbrella of a guideline programme, which is “a structured and coordinated programme designed with the specific aim of producing several clinical practice guidelines.” Kitson echoes the case for the ‘assisting’ role of guidelines, conceptualising them as “flexible, interpretative pieces of information that contain a mixture of factual evidence, evidence that requires interpretation and evidence that will be shaped and moulded by the particular context into which it will be introduced”. She concludes that guidelines are not ‘literal’ objects but instead complex communication vehicles used as catalysts to stimulate discussion, learning and debate across knowledge boundaries.

According to Pavlidis et al., the main purposes of clinical guidelines are to:

- Improve the quality of patient care and healthcare outcomes;
- Make clinical decisions more transparent;
- Promote efficient use of resources;
- Provide guidance for involved stakeholders – health professionals, patients, industry, health care providers and policymakers – and;
- Support quality control.

Clinical guidelines are a constituent part of the evidence-based medicine and practice paradigm initiated in the 1990’s, defined as the conscientious and judicious use of current best evidence from clinical care research in the management of individual patients. They

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are premised on the rigorous identification, summarization and evaluation of the highest quality current evidence available within a health discipline regarding prevention, diagnosis, prognosis, therapy (including dosage of medications), risk and benefit, and cost-effectiveness. Clinical guidelines aim to unite identified points in the clinical decision-making process, with evidence-based related courses of action, and the clinical discretionary judgment and professional experience of health practitioners.

Improving clinical decision-making in healthcare systems by underpinning it with the best available evidence, advice and guidance is one method by which governments seek to reduce variation in the quality of care provided and unacceptable health inequalities, especially among the socially disadvantaged.46 However, clinical guidelines per se do not necessarily result in superior patient outcomes. In Ontario, Canada, for example, an investigation of the knowledge-to-action translation in the area of cancer distress screening found that, while a significant uptake in screening had occurred following the introduction of guidelines, desired improvements in patient outcomes (i.e. reduced distress) were less certain.47 Practice guidelines cannot guarantee reductions in health inequalities – which can be impacted upon negatively by the domains of science, policy and politics (as arguably was the case with the UK Liverpool Care Pathway guidelines for EOL care48) and practice. Indeed they can be undermined in their authority by methodological weaknesses in their development, conflicts of interest, or recommendations that are unsupported by available evidence.49

Lastly, and in the context of variation in socio-economic development across the EU Member States, where resource abundance is contrasted with resource constraints – e.g. inadequate personnel resources, underdeveloped infrastructure, limited access to pharmaceuticals – there is an argument that guidelines must be resource-stratified in nature, as has been shown in other regions globally.50 Clinical guidelines that propose optimal clinical management strategies and approaches for settings where clinicians cannot deliver them, may be seen as irrelevant by clinicians struggling with inadequate facilities and

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an underfunded cancer programme. As Anderson noted: “Resource-stratified guidelines provide a framework for gap analysis to identify when important resources are missing and to create a platform to assess when aggressive treatment is unlikely to achieve improved outcome as measured by disease-free survival or overall survival. Often, palliative rather than curative approaches should be used, thereby reducing morbidity for the patient and saving valuable resources for use in a case where the likelihood of a successful outcome is more realistic.”

3.2 Cancer guidelines across and beyond the EU

Clinical guidelines are normally developed at national or international levels by medical associations, or professional or governmental bodies. In Europe, the leading organizations are the National Institute for Health and Clinical Excellence (NICE) (United Kingdom), the Dutch College of General Practitioners (NHG) and the Dutch Institute for Healthcare Improvement (CBO) (The Netherlands), the German Agency for Quality in Medicine (ÄZQ) (Germany) and, for specifically cancer-related clinical guidelines, the European Society of Medical Oncology (ESMO). All these organizations are members of the Guidelines International Network (G-I-N), an international network of organisations and individuals involved in clinical practice guidelines that hosts the International Guideline Library and promotes best practice.

A list of the 20 clinical practice guidelines for oncology professionals currently available from ESMO are outlined in Appendix A, as are those from the USA-based National Comprehensive Cancer Network, and those produced by the European Palliative Care Research Collaborative, specifically addressing cancer in a palliative care context.

Following the collective commitment of the EU Member States to population-based cancer screening, the European Commission has also produced European guidelines for quality assurance in screening and diagnosis for the three cancers concerned; breast, cervical and colorectal cancer.

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4. A model of guidelines’ implementation

There is a growing recognition among both practitioners and researchers that the transfer and effective implementation of knowledge into practice is a complex, and organic, rather than mechanical, phenomenon, involving multiple factors. However, for many years conceptual models that elaborated this process depicted it as uni-dimensional in nature, implying linearity and rational logic. These models were often characterised by the generation and provision of information, development of resulting guidelines, and patient impact mediated through the overall practice environment.

The implementation of clinical guidelines mirrors the implementation of research. In the late 1990s, Kitson et al.\textsuperscript{56} proposed that successful implementation of research into practice was a function of the interplay of three core elements: the level and nature of the evidence; the context or environment into which the research is being placed; and the mechanisms by which that change process is implemented or facilitated, with all three having equal importance. As Figure 1 shows, all three elements consist of sub-elements that can be rated on a scale from low to high, with high ratings on each factor more likely to produce implementation results.

From this initial conceptualization, there were five propositions: knowledge translation is a necessary but not sufficient mechanism to transform systems; the ‘system-as-machine’ metaphor is unhelpful to knowledge translation; the healthcare system is best viewed as a complex entity; successful innovation is a function of the level of local autonomy experienced by individuals, teams and the unit involved; and innovation is most effective when it involves key stakeholders.\textsuperscript{57}

The following section, in discussing the guideline lifecycle – from development to dissemination, implementation, and monitoring and evaluation – will explore some of the contextual or environmental factors, and the implementation or facilitation methods, indicated by Kitson et al that can have a critical impact upon successful knowledge transfer.

\begin{footnotesize}
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### Figure 1: Conditions for evidence, context and facilitation

**A. Evidence**

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<td>Anecdotal evidence</td>
<td>Randomised controlled trials</td>
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<tr>
<td>Descriptive information</td>
<td>Systematic reviews</td>
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<tr>
<td>Evidence</td>
<td>Evidence-based guidelines</td>
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<th>High</th>
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<td><strong>Clinical experience</strong></td>
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<tr>
<td>Expert opinion divided</td>
<td>High levels of consensus</td>
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<tr>
<td>Several ‘camps’</td>
<td>Consistency of view</td>
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<td>Patients not involved</td>
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**B. Context**

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<td>Task driven</td>
<td>Learning organisation</td>
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<td>Low regard for individuals</td>
<td>Patient centred</td>
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<td>Low morale</td>
<td>Valuing people</td>
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<tr>
<td>Little or no continuing education</td>
<td>Continuing education</td>
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<tr>
<td>Diffuse roles</td>
<td>Clear roles</td>
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<tr>
<td>Lack of team roles</td>
<td>Effective team work</td>
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<tr>
<td>Poor organisation or management of services</td>
<td>Effective organisational structure</td>
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<tr>
<td>Poor leadership</td>
<td>Clear leadership</td>
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**C. Facilitation**

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Reproduced with permission from Kitson et al.\(^{58}\)

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5. Implementing practice guidelines: the lifecycle

A significant and critical body of literature exists on the successful implementation of clinical guidelines. This is a multi-staged and iterative process that follows the pathway outlined in Figure 1: development; dissemination; implementation; and monitoring and evaluation.

**Figure 2: Guideline lifecycle**

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5.1 Phase 1: Development

This first phase in the clinical guidelines lifecycle is the point at which the decision is taken to initiate a clinical guideline and its contents are determined. This phase concerns:

- Identification of the topic;
- Gathering input;
- Establishing if existing guidelines exist on the same topic;
- Discussion of how to set the standard and its form, and;
- The drafting of the document.

Although this is a relatively unproblematic phase compared to the complexities of implementation, the manner in which the design phase is undertaken is central to the guidelines’ subsequent adherence by healthcare professionals.

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Critically, this phase should focus on outcomes, e.g. cancer survival rates. It should be based on the best contemporaneous evidence, graded according to its level, quality, relevance and strength (with the highest entailing a randomised controlled clinical trial); gathered in a transparent, systematically conducted and reported manner and include a statement about the strength of the recommendations.

5.2 Phase 2: Dissemination
Dissemination of clinical practice guidelines is the process of raising awareness of their existence and content to three core groups: the public, patients and professionals.

If one reason for inequalities in cancer diagnosis and care is lack of education and understanding, then public education could mitigate this. A recent UK example of this is the campaign by the country’s National Health Service that encourages people with a persistent cough to see their doctor in case it is an early sign of lung cancer, to improve early diagnosis and survival rates. One of the most effective ways of public dissemination is to involve individual patients and carers – as experts of their own lived experiences – in interactions with the media, enabling them to recount their personal stories to help raise awareness of the primary recommendations arising from the guidelines and their importance in the clinical decision-making process.

Patient-focused guidelines can be promoted in the traditional media of patient organisations and charities – e.g., newsletters, annual reports, conferences – as well as via social media – Facebook, Twitter, etc – and the internet. Traditional pathways for guidelines dissemination to healthcare professionals include professional bodies, their related materials and conferences but also increasingly via social media.

5.3 Phase 3: Implementation
Katterhagen noted that while 10% of time spent on clinical guidelines is focused on their drafting, almost 90% is devoted to their implementation and in this phase the clinical guidelines are disseminated to their target audience for implementation in a clinical setting. It includes all efforts made to introduce the guidelines and ensure compliance with them.

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61 Kennedy I. Patients are experts in their own field. British Medical Journal 2003; 326: 1276-1277.


and involves implementation work by healthcare providers and promotional campaigns by organisations. This phase is elaborated upon in Section 6.

5.4 Phase 4: Monitoring & evaluation

Often regrettably neglected, the fourth phase in the clinical guidelines lifecycle is their monitoring and evaluation. This entails gaining feedback from implementing clinicians, auditing their use and instigating a process that enables the updating and evolution of the guideline as appropriate so it continues to be supported by the best available evidence. This phase is elaborated upon in Section 7.
6. Barriers and facilitators to implementing guidelines

The effective implementation of clinical guidelines is influenced by multiple factors – all of which need to be managed successfully\textsuperscript{64} – that can be grouped into three broad types: staff-related, healthcare organisation-related and external factors.\textsuperscript{65}

**Staff-related factors** are primarily those relating to the engagement and commitment of the professionals to whom the clinical guidelines are directed and who will be expected to implement it.

**Healthcare organisational factors** arise from the context of the healthcare organisation – or organisations if a guideline spans different care settings – in which a clinical guideline is implemented.

**External factors** are those that lie outside the healthcare organisation.

This section discusses the key barriers and enablers to the implementation of clinical guidelines, focussing on organisational challenges and training needs.

6.1 Staff-related factors impacting guidelines’ implementation

There are nine distinct factors under this thematic area: the importance of professional, opinion leader and stakeholder engagement; clarity; coherence; change to existing practice; development by a credible institution; answering concerns on clinical autonomy; training and education; understanding existing values and practice, and; gaining and giving effective feedback.

6.1.1 The importance of professional, opinion leader and stakeholder engagement

Engaging healthcare professionals\textsuperscript{66} opinion leaders\textsuperscript{67} and other stakeholders\textsuperscript{68} in the implementation of clinical guidelines is critical for two reasons: first, engaging those intended to use the guidelines in everyday working experience ensures the guidance is developed with a thorough understanding and appreciation of the issues involved and the guidelines are in a format that meets practitioners’ needs.\textsuperscript{69} Indeed, from a cognitive theory


\textsuperscript{67} Wong RK, Brierley J, Brouwers M. What is the best way to produce consensus and buy in to guidelines for rectal cancer? *Current Colorectal Cancer Reports* 2012; 8: 83-89.


perspective, Grol and Grimshaw suggest professionals are more willing to implement a new policy or standard when they have actively contributed to highlighting the problem to be addressed, discussed it with their peers and proposed a solution.\textsuperscript{70} Second, not limiting engagement solely to doctors and nurses but extending it to other stakeholders (e.g., IT problems etc.) helps anticipate barriers that can occur at other implementation levels.

Moreover, after a review of 756 clinicians’ ratings of 84 Cancer Care Ontario, Canada, clinical practice guidelines between 1999 and 2005, Brouwers et al concluded there is a need to focus on engaging clinicians who are least receptive to guidelines since, over time, these clinicians most improved their practice, as demonstrated in practice guidelines’ quality ratings.\textsuperscript{71}

Additionally, demonstrating the benefits of clinical guidelines can influence professionals’ personal feelings towards them, including their willingness to implement and adhere to them over the long-term. Knops et al demonstrated that the expectation of personal advantage, both for professionals themselves – e.g., in terms of safety and gaining time, and for patients, such as superior care outcomes – improves not just the short-term compliance rate with clinical guidelines but secures professionals’ adherence to them in the longer term, too.\textsuperscript{72}

\textbf{6.1.2 Clarity}

Michie and Johnston suggest that the more specific and clear the guideline offered, the easier it is for doctors and nurses to implement it, influencing comprehension, recall, planning and behaviour.\textsuperscript{73} The authors suggested rewriting text in behaviourally specific terminology, indicating what, who, when, where and how as a method to boost guidelines’ compliance. This research is supported by earlier findings reported by Grol et al, who analysed the compliance rate of 47 recommendations from 10 national guidelines developed by the Dutch College of General Practitioners and recommended that clinical guidelines should always include specific advice on actions and decisions, describing them at different levels for the different professionals involved.\textsuperscript{74}


\textsuperscript{71} Brouwers M, Hanna S, Abdel-Motagally M et al. Clinicians’ evaluations of, endorsement of, and intentions to use practice guidelines change over time: A retrospective analysis from an organized guideline programme. \textit{Implementation Science} 2009; 4: 34.

\textsuperscript{72} Knops AM, Storm-Versloots MN, Mank APM et al. Factors influencing long-term adherence to two previously implemented hospital guidelines. \textit{International Journal for Quality in HealthCare} 2010; 22; 421-429.

\textsuperscript{73} Michie S, Johnston M. Changing clinical behaviour by making clinical guidelines specific. \textit{British Medical Journal} 2004; 328: 343-345.

6.1.3 Coherence

Grol et al suggested that coherence within the different guideline recommendations positively influences healthcare providers’ adherence, their study demonstrating compatibility with existing clinical guidelines, practice, norms, values, as well as the clarity and coherence of the guidelines, exert a positive effect on the compliance rate.\(^{75}\)

Fortin et al in 2011 noted that disease-specific guidelines can be confusing for clinicians and patients when the latter have one or more co-morbidity, as guidelines for one condition can contradict those for another.\(^{76}\) With ageing European populations – it is estimated that older persons will account for an increasing share of the total population, with those aged 65 years or over accounting for 29.5 % of the EU-27’s population by 2060, compared to 17.5 % in 2011\(^{77}\) – and longer survival rates associated with chronic health conditions, the number of people with co-morbidities will grow and pose an increasingly important consideration for healthcare providers and systems. The authors noted that clinical guidelines addressing co-morbidities are better supported by clinicians and consequently have a higher compliance rate.

6.1.4 Change to existing practice

Clinical guidelines compatible with the existing values and norms in physicians’ clinical practices are more likely to be complied with.\(^{78}\) Compliance can be influenced to some extent by the skills, training and equipment necessary to implement new procedures being available, and these issues need to be addressed at the healthcare organisation level during the guidelines’ planning phase. If they are not, guidelines seeking to change practice in line with new scientific evidence, rather than simply codifying currently accepted best practice, are not necessarily going to result in changed practices. Also, if the guidelines contain ‘local evidence’, there is a greater chance they will be integrated into practice.\(^{79}\)

6.1.5 Development by a credible institution

Guidelines developed within the framework of a structured and coordinated programme led by a credible institution – defined as the extent to which it is recognised as a source of reliable information in its field – were significantly strengthened, in terms of their credibility

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\(^{79}\) Harrison MB, Graham ID. Roadmap for a participatory research-practice partnership to implement evidence. *Worldviews Evidence Based Nursing* 2012; 9: 210-220.
and diffusion.\(^{80}\) This view was echoed by Mc Dermott et al’s study in primary care in the UK which found that doctors stressed the importance of the credibility of the guidelines’ source, with some reporting that the name of a known and respected institution was sufficient to guarantee their implementation.\(^{81}\)

However, this association is not necessarily consistent. For example, evidence exists that adoption of guidance from the UK’s National Institute of Clinical Excellence (NICE) is variable, despite the fact that the organisation is both well known and respected. Sheldon et al\(^ {82}\) audited the implementation of 11 sets of NICE guidance across 20 acute trusts, 17 mental health trusts, 21 Primary Care Trusts and all primary care and hospital prescribing and found their uptake varied depending on the subject matter: prescribing often changed as a result of NICE guidance, as long as clinicians agreed with NICE’s interpretation of clinical effectiveness – e.g. taxanes for breast cancer and ovarian cancer. But guidelines requiring a change in practice were variably successful; NICE guidance either codified an existing trend in procedures – e.g., ceasing to remove asymptomatic wisdom teeth – and consequently did not exert significant impact on the trajectory of change – or suggested a new technique or type of equipment, for which uptake was more variable.

Similarly, the perceived need for the introduction of such innovations is an influencing factor in the implementation process.\(^ {83}\) Unsurprisingly, when guidelines change something staff already perceived as obsolete and introduce a process that will render their work easier, they are more likely to be adopted and applied in the long term. In contrast, guidelines that are seen to complicate the decision-making process, or introduce new technologies not perceived as necessary, or which are initially difficult to use, will face greater implementation challenges.\(^ {84}\)

### 6.1.6 Answering concerns on clinical autonomy

A major source of concern regarding clinical guidelines is their perceived potential threat to healthcare professionals’ autonomy.\(^ {85,86,87,88}\) If guidelines aim at simplifying the clinical

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\(^{82}\) Sheldon T, Cullum N, Dawson D et al. What’s the evidence that NICE guidance has been implemented? Results from a national evaluation using time series analysis, audit of patients’ notes and interviews. *British Medical Journal* 2004; 329: 999.


\(^{84}\) Knops AM, Storm-Versloots MN, Mank APM et al. Factors influencing long-term adherence to two previously implemented hospital guidelines. *International Journal for Quality in HealthCare* 2010; 22; 421-429.


choice spectrum and ensuring patients with identical clinical conditions receive the same
treatment, concerns can arise that they are impinging upon the autonomy of doctors and
nurses, reducing the range of available interventions. Evidence suggests a correlation
between the experience a healthcare worker has and their eagerness to assert their
autonomy. Tunis et al, for example, found in their study of internists’ familiarity with,
confidence in, and attitudes towards clinical guidelines, that although the majority
recognised their importance and benefits, they worried they could erode their clinical
autonomy.\textsuperscript{89}

Whilst the implementation of clinical guidelines must address potential concerns concerning
professional autonomy, not all professionals share such concerns. Indeed, some findings
suggest that doctors use the discourse of clinical guidelines’ implementation to \textit{defend}
their professionalism.\textsuperscript{90}

\textbf{6.1.7 Training and education}

The need for adequate training and education on clinical guidelines is unanimously
recognised as important for their implementation by health professionals.\textsuperscript{91,92,93,94} More
specifically, there are two critical aspects: first, recipients’ knowledge of the guidelines, and
an understanding of why they exist and are important and, second, their skill levels to
implement them effectively.

Cabana et al contended the lack of familiarity with guidelines is a knowledge barrier to the
successful application of, and adherence to, them.\textsuperscript{95} Higher levels of familiarity with
guidelines’ content will arguably result in changed attitudes, and eventually behaviours,
among health professionals in line with the recommendations.

\textsuperscript{87} Katterhagen G. Physician compliance with outcome based guidelines and clinical pathways in oncology. \textit{Oncology}
\textsuperscript{90} Spyridonidis D, Calnan M. Are new forms of professionalism emerging in medicine? The case of the implementation of NICE guidelines, \textit{Health Sociology Review} 2011; 20: 394-409.
In their 2001 literature review, Smith and Hillner\textsuperscript{96} cited a study conducted in the US demonstrating that physicians with recent and superior cancer training had a comparably better record in treating patients according to most recent guidelines. They also discussed other US and French studies where protocols were implemented successfully because of, among other factors, the education of all providers and the availability of specific training interventions.\textsuperscript{97,98,99}

In 2011 Seoane et al evaluated university students’ diagnostic accuracy in oral cancer screening and effectiveness in implementing the related clinical guidelines and highlighted the importance of training in implementing cancer guidelines correctly.\textsuperscript{100} They found that when students were familiar with the protocols and recognised the importance of applying the correct standards, the chances of diagnostic delay or failure to refer the cancer case correctly were dramatically reduced.

\subsection*{6.1.8 Understanding existing values and practice}
While observing adherence to two guidelines implemented in 2000 in their hospital, Knops et al found that in surgical wards the guideline that abolished the practice of body temperature measurement twice per day in the absence of signs and symptoms of a postoperative infection, was not correctly applied. Nurses claimed the body temperature measurement was a more reliable tool than their clinical judgements, despite evidence to the contrary.\textsuperscript{101} This was reflected in the 2010 study by Carlfjord et al which found that one of three teams observed found it difficult to implement a new standard because they felt it was incompatible with their routine and believed there were better ways to address the issue,\textsuperscript{102} suggesting the need for awareness training amongst health professionals of why they need to change their practice.

\subsection*{6.1.9 Gaining and giving effective feedback}
Audit and feedback have been found to be important means of ensuring health professionals follow guidelines. By analysing and reflecting upon the data provided by

\begin{thebibliography}{99}
\bibitem{102} Carlfjord S, Lindberg M, Bendtsen P et al. Key factors influencing adoption of an innovation in primary care: A qualitative study based on implementation theory. \textit{BMC Family Practice} 2010; 11: 60.
\end{thebibliography}
feedback, health professionals and other stakeholders can determine the reasons preventing them from following guidelines and refine their practice accordingly. Medves et al found audit and feedback had utility in enhancing clinical guidelines’ implementation in 38 of 86 examined studies.103

This concurs with other studies, including a review of 118 trials searched through the Cochrane register,104 which found their success was in part associated with a high intensity of audit and feedback. Moreover, since these processes assess professionals’ performance, they have often been linked to quality of care improvement.105,106,107 Hysong et al conducted a cross-sectional, qualitative study of six Veterans Affairs Medical Centres with high and low adherence to six clinical guidelines, and concluded that actionable feedback should encompass timely, individualised, non-punitive and customisable information.108 However, a study of NICE recommendations found group feedback may be more effective than individualised feedback, since it may strengthen peer pressure and consensus on the new guidance to be followed.109

6.2 Healthcare organisation-related factors impacting guidelines’ implementation

Although it is common to analyse compliance with clinical guidelines from the healthcare professionals’ perspectives, the organisational context is crucial. There are two distinct factors under this thematic area: developing effective dissemination strategies and developing supportive work environments.

6.2.1 Developing effective dissemination strategies

In their study of physician adherence to clinical guidelines, Cabana et al found that in 46 identified studies, lack of awareness was a barrier to their correct implementation110 and the simple publication and passive dissemination of clinical practice guidelines are usually ineffective in changing how clinicians care for patients. For example, in 2006 Schrader et al

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reported attempts to minimise marked and variable excess mortality among German patients with testicular germ cell tumours by introducing evidence-based diagnostic and therapeutic guidelines in 1996 were undermined by a solely passive dissemination strategy, which exacerbated organisational, social and professional barriers.\(^\text{111}\)

What does effective dissemination look like? Medves et al’s 2010 analysis of 89 studies concerning dissemination and implementation approaches found that 60 dealt with dissemination strategies that included educational material and the distribution of small, laminated cards, and the hanging of poster and guideline abstracts where care was delivered. In 43 instances, these approaches were successful in enhancing healthcare providers’ adherence to the guidelines.\(^\text{112}\)

However, in a study of clinical guidelines’ implementation, Davis and Taylor-Vaisey identified two dissemination strategies: primary strategies – which include mailing or publishing the actual guidelines – and secondary strategies – which aim at reinforcing guidelines. Traditional continuing medical education and mailings were found to be weak, audit and feedback, especially concurrent, targeted to specific providers and delivered by peers or opinion leaders were moderately effective, while relatively strong approaches were reminder systems, academic detailing and multiple interventions.\(^\text{113}\)

Considered more patient-oriented and less passive than educational campaigns, the use of reminders has been reported in 28 studies, with 24 proving successful. Examples of effective reminders are common in the literature.\(^\text{114,115}\) Dartnell et al analysed compliance with the initiation of anticoagulation in patients with thrombotic disorders before and after the circulation of pocket-sized, laminated reminders and the display of posters promoting their use and found improved guidelines’ implementation.\(^\text{116}\) Similarly, Smith et al’s study of the French regional cancer network, where practitioners collectively review the clinical guidelines they have to implement and receive specific mailed remainders, found that from

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1994-1996 the adherence rate was raised by 25 per cent for breast cancer treatment and by 31 per cent for colon cancer.\textsuperscript{117}

Evidence demonstrates the effectiveness of embedding such reminders in the flow of care and in disseminating guidelines broadly.\textsuperscript{118} Indeed, some studies have advocated for the use of computer-based clinical guidance. A study cited in Boaz et al demonstrated the efficacy of computerised decision-making support in boosting clinicians’ confidence when prescribing.\textsuperscript{119} The same conclusions were reached by a number of studies appraised by Langton et al on the effects of computer-based clinical decision support systems on clinical performances and patients’ outcomes\textsuperscript{120} and more recently echoed by Patkar et al’s\textsuperscript{121} and Folkes et al’s\textsuperscript{122} studies of physician compliance with breast cancer guidelines in the clinical setting. Following Fervers et al’s advice, such use of computer technology is a highly targeted dissemination strategy that is essential to achieving a high compliance rate.\textsuperscript{123}

6.2.2 Developing supportive work environments
The work environment has an important impact on guidelines’ implementation. For example, in 2010 Nirenberg et al carried out a cross-sectional survey of oncology nurses’ use of National Comprehensive Cancer Network clinical practice guidelines for two specific neutropenia cases and found they reported the work environment strongly influenced their willingness to use evidence and consensus-based protocols and guidelines.\textsuperscript{124} More specifically, respondents were more likely to use clinical practice guidelines when they were expected to by physician and nurse colleagues and they perceived fewer barriers.

Organisational constraints generated by the operational context were included in the barriers map that Oxman et al (2001) drafted.\textsuperscript{125} In their analysis, characteristics of a poor working environment – such as poor communication and burdensome paperwork – directly affect compliance with clinical guidelines. This finding is also supported by a recent

qualitative study conducted in Sweden by Carlfjord et al on innovation in primary care. As well as such factors as assessment of staff expectations and compatibility with existing routines, their study also highlighted high workload and concurrent organisational changes as important factors in reducing compliance.

Lastly, existing resources and inter-service operations can exert an effect. For example, in Australia, and despite the existence of the Australian Therapeutic Guidelines – Palliative Care, palliative care physicians reported some of the main barriers to effective cancer pain management was insufficient access to non-pharmacologic interventions, poor coordination between services, amongst others.

6.3 External influences impacting on guidelines’ implementation
There are four areas under this theme: relevance and levels of consensus; financial incentives and sanctions; patients and families; the mass media, and; opinion leaders.

6.3.1 Financial incentives and sanctions
Katterhagen suggested financial rewards as one of driving forces shaping healthcare workers’ responses to guidelines, although evidence for the effectiveness of monetary incentives is problematic to source.

While Grol and Grimshaw found a greater use of incentives compared to sanctions, governments have imposed sanctions to enforce clinical guidelines’ compliance. Callens et al analysed examples of policies that used financial incentives. They reported the case of Belgium where, through the Health Insurance Act, financial sanctions in cases of overconsumption have been introduced, regulating physicians’ prescription behaviour with the threat of a fine equivalent to 150 per cent of the value of the treatment to ensure guidelines compliance. The authors concluded that, whereas in the past clinical guidelines focussed on improvements in the quality of care provided, the move towards sanctioning or restricting physicians for non-compliance with clinical guidelines introduced a cost-containment goal that could result in tensions between individual patients’ needs and the physicians’ treatment options (e.g., withholding expensive treatments that could later be seen as unnecessary).

6.3.2 Patients and families

Modern health care systems no longer view patients as passive recipients of care interventions, but rather as active, empowered and informed partners in the production of their healthy wellbeing. Quality of care’s traditional focus on issues of effectiveness and safety is now augmented by an interest in patient centredness. This approach is embodied in the definition of quality of care proposed by the US Institute of Medicine, which is: “doing the right thing, at the right time, in the right way, for the right person, and having the best possible results”.

Patient empowerment elevates patient centredness to another level. For some health practitioners and policy makers it constitutes a new paradigm that has the potential for improving medical outcomes while lowering treatment costs as patients assume some of responsibility for managing their own condition.

This ability to take co-ownership of their medical conditions is partly made possible by the increased opportunities that patients have to access medical information through, for example, their health providers, support groups, and the internet.

Whilst patient empowerment is especially relevant to the long-term self-management of chronic conditions, such as cancer, it is a paradigmatic shift in the relationship between health professionals – and the health system – and the patient. Patients are also involved in evidence generation as researchers and patient experience is informing public education on health.

Evidence-based health care, and the clinical guidelines they inform, requires not only the integration of best available benchmarking literature, but patient preferences, rights and values. This will help ensure the guidelines are relevant to those who are expected to use them or benefit from their use, rendering them more likely to be adopted in clinical practice. Guidelines should not be overly rigid, but be adaptable to varying local conditions, be relevant to different target populations and geographic and clinical settings, and take into consideration patients’ different values and preferences.

These different values and preferences can exert a significant impact on successful guidelines’ deployment where, for example, treatment recommendations that reflect what patients consider important can affect their uptake. This is particularly the case in clinical areas such as screening, where guidelines may focus on a particular demographic group. Analysing factors influencing levels of compliance with Mammography Screening Guidelines,

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for example, Phillips et al.\textsuperscript{132} found individual patient characteristics and environmental features are strong determinants affecting women’s inclination to be screened. Inaccurate beliefs about cancer risks have also been demonstrated to be a significant factor underpinning people’s rejection of screening calls.\textsuperscript{133}

Similar examples exist in EOL care. In their telephone survey of treatment, care and information preferences among over 9,000 respondents across seven European countries when faced with a hypothetical serious illness, like cancer, with limited time to live, most chose to ‘improve quality of life for the time they had left’, ranging from 57 percent in Italy to 81 percent in Spain, with only between 2 percent in England and 6 percent in Flanders replying that extending life was most important.\textsuperscript{134} This sentiment is echoed by a citizenry call for improved quality of end-of-life and palliative care for patients,\textsuperscript{135} and a preference among at least two-thirds of people in all but one country studied preferring a home death.\textsuperscript{136} However, health services can only determine what patients’ priorities and preferences are when they are in contact with those services.

Patient and family pressures can also have a negative impact on healthcare providers’ compliance with clinical guidelines.\textsuperscript{137,138} The risk is that, in order to satisfy their patients, a team chooses a different clinical path than that prescribed by protocols and guidelines.\textsuperscript{139} However, patients also represent a facilitator for clinical guidelines’ implementation, particularly when they provide the team with information that positively affects the timing and the typology of interventions.\textsuperscript{140}


6.3.3 Mass media

Whilst there is minimal evidence specifically on the impact of mass media interventions on clinical guidelines’ compliance, Grilli et al’s analysis of 20 studies on mass media interventions’ effects concluded these communication channels may have an important role in influencing the use of specific healthcare interventions and the non-use of ineffective interventions,\(^{141}\) with the potential to positively or negatively affect patient uptake.

6.3.4 Using opinion leaders

Research on the use of opinion leaders to support the use of clinical guidelines has shown their positive impact on compliance. Usually, local opinion leaders are healthcare professionals or experts in a specific topic area whose remit is to disseminate clinical guidelines broadly and assist practitioners in providing best evidence to inform their practice.\(^{142}\) A 2003 literature review investigating models of good guideline development conducted by Burgers et al, analysing 18 clinical guideline programmes across different countries – the USA, Canada, New Zealand and 10 EU states found that more than 55 per cent of guideline programmes involved the use of local opinion leaders as part of the strategy to promote and strengthen their use.\(^{143}\)

In their literature review, Medves et al identified 16 of 89 papers that described the role of opinion leaders, with 13 of them showing a significant impact.\(^{144}\) However, despite these positive findings, Boaz et al found evidence of the difficulty entailed in identifying opinion leaders.\(^{145}\)

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7. Monitoring and evaluation approaches

Monitoring and evaluating clinical practice guidelines is critical to ensure that they are making a positive difference to clinical practice health outcomes and if any discernible reductions in health inequalities can be attributed to their introduction. This requires a monitoring, evaluation and reporting (MER) system. The component parts of a MER system are:

Monitoring: this is defined as the systematic collection and analysis of information over time to track the efficiency of a project in achieving its goals. Monitoring provides regular feedback that helps track costs, personnel, implementation time, organisational development, and economic and financial results to compare what was planned to what actually took place.

Evaluation: this is the systematic collection and analysis of information to assess the effectiveness of the project in achieving its goals. Evaluation provides regular feedback that analyses the consequences, outcomes and results of actions – i.e., what impact was made.

Reporting: this is the systematic, timely and integrated reporting of operationally useful information at periodic intervals. Reporting is critical informing critical stakeholders on the progress of a project, as well as the challenges encountered, successes achieved, and lessons learnt from implementing it.\textsuperscript{146}

7.1 Why do MER for clinical guidelines?

In practical terms, implementing a MER plan has a number of benefits to the implementation of guidelines, enabling the implementer to:

- Foresee problems and mitigate risk as part of a well planned project cycle;
- Monitor progress to ensure the guidelines’ project is proceeding as planned or, if necessary, initiate corrective action to ensure success;
- Learn, both as a project lead and as an organisation – from the successes and failures – so future success is more likely to be ensured;
- Garner insights into best means of implementing guidelines;
- Build credibility, by documenting and sharing the success of the project, and;
- Determine their impact and the extent to which they achieved the anticipated changes.

\textsuperscript{146} McCoy KL, Ngari PN, Krumpe EE. \textit{Building Monitoring, Evaluation and Reporting (MER) Systems for HIV/AIDS Programmes Monitoring}. Washington DC: PACT.
7.2 What are MER plans comprised of?
A monitoring and evaluation (M&E) plan for the evaluation of clinical practice guidelines typically has six components:147

- An assessment of guideline dissemination;
- An assessment of whether or not clinical practice is moving towards the guidelines’ recommendations;
- An assessment of whether or not health outcomes have changed;
- An assessment of whether or not the guidelines have contributed to any changes in clinical practice or health outcomes;
- An assessment of the guidelines’ impact on consumers’ knowledge and understanding, and;
- An economic evaluation of the guideline process.

7.2.1 Evaluation of dissemination
This component is relatively simple, and can include such questions as:

- How many copies of the guidelines were requested?
- How many copies of the guidelines have been mailed out?
- Of those disseminated, how many have been received, opened, read in part / full, and understood?
- How many posters were sent out?
- How many were displayed in appropriate and prominent places?
- How many articles have been published, or interviews broadcast, about the guidelines?
- How many consumer inquiries have there been?

These relatively easy criteria can be used to assess the success of a guidelines’ dissemination strategy.

7.3 Evaluation of changes in clinical practice and health outcomes
Based upon a pre-intervention baseline benchmark – either from an existing national dataset or specifically generated data – an evaluation to determine changes in clinical practice and any associated positive changes in health outcomes could entail repeated data collection and analysis following the introduction of the guidelines. This can take the format of clinical audit and other quality assurance activities.

The evaluation plan should be focussed on assessing whether the guidelines improved the desired health outcomes. The evaluation should not be a one-off exercise but repeated approximately every three years to avoid becoming outdated,\textsuperscript{148,149} and more frequently in subject areas prone to rapid change.

### 7.4 Evaluation of guidelines’ contribution to changes in clinical practice and health outcomes

Changes in clinical practice and patient health-related outcomes cannot necessarily be attributed to the introduction of related guidelines. They could have been the result of a combination of factors and require more complex study designs than that provided by a simple clinical audit to isolate the relative impact of these variables.

Possible approaches to evaluate the impact of the guidelines include:

- Comparing changes in clinical practice or health outcomes, or both, in areas of exceptionally high guideline promotion with changes in areas of exceptionally low guideline promotion;

- Comparing health outcomes in areas of exceptionally high guideline uptake with outcomes in areas of exceptionally low guideline uptake—focus group testing can be useful to elucidate factors that have influenced this uptake.

### 7.5 Evaluation of clinical guidelines

A number of approaches to be considered in the evaluation of clinical guidelines include:

- Their accessibility;
- Their clarity and lucidity;
- The acceptability of the amount of information they contain, particularly compared with the amount of information contained in the professionals’ guidelines;
- Their relevance to different patient groups, and;
- Patients’ overall level of satisfaction – or dissatisfaction – with the guidelines.

In accord with the patient empowerment agenda, these evaluations need to be undertaken with extensive patient input and direction.


7.5.1 Economic evaluation
In this component of the evaluation process, a number of guideline-related cost factors need to be known, including:

- Process costs – the costs of development, dissemination and implementation;
- Pre-implementation costs – the costs associated with existing practice patterns, including testing, pharmaceutical and surgical interventions, and;
- Post-implementation costs – the costs and cost savings resulting from observance of the guidelines (e.g. from the elimination of unnecessary tests).

7.5.2 Reporting on the evaluation
The findings arising from the evaluation of clinical practice guidelines – be they positive or negative – should be included in a final report and ideally include an indication of avoidable outcomes for quality assurance purposes that include:

- Unforeseen consequences of the guidelines;
- Outcomes that suggest the guidelines were not being followed that would be useful in monitoring the extent to which guidelines were being implemented, and;
- Outcomes that suggest the guidelines were not being implemented correctly or the quality of care was deficient.

The results of such reports will help inform any necessary revisions to the original guidelines.
8. Conclusion and Recommendations

8.1 Conclusion

Inequalities in accessing screening and diagnosis, treatment, aftercare and palliative care exist in-country and across countries in Europe. Clinical practice guidelines have the potential to help reduce those inequalities – but only if there is equal access to that screening, early diagnosis and care – by minimising differences in how care is provided and its quality. However, the development of practice guidelines is not an endpoint in itself; the implementation of guidelines requires training and organizational guidelines. There are multiple factors that can impact upon their effective introduction and all need to be addressed.

Implementation science studies how healthcare policy can be translated into real-world settings, with comparative effectiveness research and pragmatic research trials increasingly used to assess interventions. But currently there is insufficient evidence of the best methods of implementing clinical guidelines.

More research is needed to explore the barriers encountered in the field of knowledge translation and the strategies for addressing them, so that we do what Browman referred to as “telling the ‘stories behind the story’” to enhance our understanding in this field.\textsuperscript{150} Given the multiple variations in culture, setting, resources etcetera across the EU states, this research should strive to identify the commonalities and differences that exist so that solutions are tailored to the specific challenges in specific locations.

8.2 Recommendations

From this narrative review of the literature, a number of recommendations arise:

8.2.1 Staff-related level

Guideline development should:

- Engage healthcare professionals, opinion leaders, patients and other stakeholders in the development and implementation of clinical guidelines to ensure buy-in, ownership and commitment.

- Employ a differentiated approach to engaging clinicians, with special attention given to those least receptive to guidelines.

\textsuperscript{150} Browman GP. Challenges in knowledge translation: The early years of Cancer Care Ontario’s Programme in Evidence-Based Care. \textit{Current Oncology} 2012; 19: 27-35.
- Demonstrate the anticipated benefits of the clinical guidelines, including any potential personal advantage arising from their implementation.

- Ensure that the guidance offered is specific and clear for those expected to implement them, indicating explicitly what, who, when, where and how.

- Frame the new guidance so that it demonstrates coherence with existing clinical guidelines, practice, norms and values.

- In light of Europe’s ageing population and the increasing prevalence of chronic health conditions, ensure that guidelines that are primarily disease-specific are located within a multi-morbidity narrative.

- Institute educational and training programmes and draw upon ‘local evidence’ where possible to support the advice being provided.

- Develop the guidelines using a credible, respected institution.

- Audit and provide feedback on the status of guideline compliance, in part to identify any factors that are negatively impacting upon their introduction. This would appear to be best undertaken using a group feedback approach, which can draw upon peer pressure.

### 8.2.2 Healthcare organisation-related

- Develop a dissemination strategy for the guidelines that is active rather than passive in nature.

- Develop a supportive working environment to complement the introduction of clinical guidelines, including the development of a positive culture of implementation that uses group pressure among colleagues to ensure compliance, as well as adequate communication channels between service providers and minimal paperwork to burden staff.

- Ensure that staff expected to implement clinical guidelines have the necessary resources and inter-service operability – where relevant – to effect the guidance.

### 8.2.3 External level

- Punitive sanctions to enforce guidelines’ implementation may be an increasingly popular option but should not sacrifice individual patients’ genuine health needs for cost-containment goals.
• Health care systems should view the role of patients as active, empowered and informed partners, from information generation to dissemination. This will help ensure the guidelines are relevant to those who are expected to use them or benefit from their use, rendering them more likely to be adopted in clinical practice.

• An effective monitoring and evaluation plan should supplement the introduction of the guidelines, to ultimately determine their impact and the extent to which they achieved the anticipated changes in clinical practice and in reducing health inequalities.
Appendix A

Twenty clinical practice guidelines for oncology professionals currently available from ESMO are outlined below. Each guideline includes information on the incidence of the malignancy, diagnostic criteria, staging of disease and risk assessment, treatment plans and follow-up designed to help oncologists deliver an appropriate quality of care to their patients.151

Breast cancer
1. Primary breast cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Gynaecological malignancies
2. Newly diagnosed and relapsed epithelial ovarian carcinoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
3. Endometrial cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
4. Gestational trophoblastic disease: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Gastrointestinal cancer
5. Oesophageal cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Gastric cancer:
6. ESMO–ESSO–ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow-up
7. Early colon cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
8. Familial risk-colorectal cancer: ESMO Clinical Practice Guidelines
9. Rectal cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Lung cancer
10. Early and locally advanced non-small-cell lung cancer (NSCLC): ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
11. Small-cell lung cancer (SCLC): ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Genitourinary cancers
12. Prostate cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

13. Penile cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
14. Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Haematological malignancies
15. Multiple myeloma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
16. Acute myeloblastic leukaemias in adult patients: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
17. Gastric marginal zone lymphoma of MALT type: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
18. Primary cutaneous lymphomas: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up
19. Waldenström’s macroglobulinaemia: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

Supportive care
20. Cancer, pregnancy and fertility: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up

The guidelines of the USA-based National Comprehensive Cancer Network are outlined below (www.nccn.org/professionals/physician_gls/f_guidelines.asp#site):

By site
1. Acute lymphoblastic leukaemia
2. Acute myeloid leukaemia
3. Anal carcinoma
4. Bladder cancer
5. Bone cancer
6. Breast cancer
7. Cancer of unknown primary
8. Central nervous system cancers
9. Cervical cancer
10. Chronic myelogenous leukaemia
11. Colon/rectal cancer
12. Colon cancer
13. Rectal cancer
14. Cutaneous melanoma
15. Endometrial cancer
16. Oesophageal and oesophagogastric junction cancers
17. Fallopian tube cancer
18. Gastric cancer
19. Head and neck cancers
20. Hepatobiliary cancers
21. Hodgkin lymphoma
22. Kidney cancer
23. Malignant pleural mesothelioma
24. Melanoma
25. Multiple myeloma/ other plasma cell neoplasms
26. Multiple myeloma
27. Systemic light chain amyloidosis
28. Waldenström's macroglobulinemia / lymphoplasmacytic lymphoma
29. Myelodysplastic syndromes
30. Neuroendocrine tumours
31. Non-Hodgkin's lymphomas
32. Non-melanoma skin cancers
33. Basal and squamous cell skin cancers
34. Dermatofibrosarcoma protuberans
35. Merkel cell carcinoma
36. Non-small cell lung cancer
37. Occult primary
38. Ovarian cancer
39. Pancreatic adenocarcinoma
40. Penile cancer
41. Primary peritoneal cancer
42. Prostate cancer
43. Small cell lung cancer
44. Soft tissue sarcoma
45. Testicular cancer
46. Thymomas and thymic carcinomas
47. Thyroid carcinoma
48. Uterine neoplasms

For detection, prevention and risk reduction
49. Breast cancer risk reduction
50. Breast cancer screening and diagnosis
51. Cervical cancer screening
52. Colorectal cancer screening
53. Genetic/ familial high-risk assessment: breast and ovarian
54. Lung cancer screening
55. Prostate cancer early detection

For supportive care
56. Adult cancer pain
57. Antiemesis
58. Cancer- and chemotherapy-induced anaemia
59. Cancer-related fatigue
60. Distress management
61. Myeloid growth factors
62. Palliative care
63. Prevention and treatment of cancer-related infections
64. Survivorship
65. Venous thromboembolic disease

For age-related recommendations
66. Adolescent and young adult (AYA) oncology
67. Senior adult oncology

The three guidelines produced by the European Palliative Care Research Collaborative are outlined below:

1. Use of opioid analgesics in the treatment of cancer pain.\textsuperscript{152}
2. Management of depression in palliative care.\textsuperscript{153}
3. Cancer cachexia in advanced cancer patients.\textsuperscript{154}