# Additional file 9 – Recommendations published in the Action Guide per cluster of metrics

## CLUSTER 1: TIMELINESS OF CARE – KEY RECOMMENDATIONS TO OPTIMISE METRICS IMPLEMENTATION

### At national, federal, regional levels

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **National cancer control plan** | • Ensure the **development and timely updating** of long-term national strategic cancer plans. These should prioritise the inclusion of supportive care, palliative care and end-of-life care within standard care pathways, thus ensuring comprehensive support for people with cancer throughout their care trajectories.<br>• Institutionalise **standardised cancer care pathways** per cancer type, including:<br>- the regulation of **issues affecting timeliness of care** and<br>- the existence of mechanisms for **monitoring and ensuring timeliness**. |
| | **National health data ecosystem, including a national approach to cancer data collection** | • Invest in the development of **national health data governance frameworks**, specifying the purpose and use of health data by different users.<br>• Develop **efforts to legislate and regulate cancer data collection** at the national or federal level.<br>• Ensure that **funding** is available to develop the cancer data infrastructure as part of the overall health data infrastructure.<br>• Ensure **alignment of national or federal and regional regulations** pertaining to cancer data registration and cancer care performance. |
| Data governance | **Interoperability among databases** | • Invest in **developing and promoting the maturity of electronic health records (EHRs)** and in particular: |

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| | | - the implementation of a **unique patient identifier** at national level to **enable linkage of healthcare databases** and notably the **interoperability** of cancer registries with other health and care databases<br>- the creation of an integrated data infrastructure **linking primary and secondary care**<br>- the **linkage of EHRs with patient portals** that patients can access and contribute to. |
| Data use and performance monitoring | **Mechanisms of feedback and learning** | • Invest in the **availability of near real-time performance data**, underpinned by **specified purposes and uses** – notably, quality assurance and improvement mechanisms across the cancer care pathway at national or federal, organisational and clinical levels.<br>• Develop data collection that facilitates the **monitoring of inequalities** in both access to and quality of cancer care.<br>- This includes prioritising the collection and analysis of data as well as the capability of disaggregating data, for instance by geographical area, sex, gender, education, employment status and disability.<br>• Ensure transparency and accountability by **publicly reporting cancer care performance data**, whilst developing mechanisms for people to exercise a voice.<br>• Co-design action **plans to improve patient safety in cancer drug administration by leveraging digital solutions**, such as e-prescription, e-preparation and e-administration, and by ensuring interface with electronic health records. |

## At organisational level

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **Data ecosystem to monitor timeliness of care** | • Invest in your organisation's data ecosystem to effectively **monitor the timeliness of the care pathway**. This includes recording key dates along the cancer care pathway, such as:<br>- the date of cancer pathology diagnosis<br>- the date of the first cancer treatment and the dates of all subsequent treatments<br>- the date of first contact with an oncology nurse specialist.<br>• Establish mechanisms to identify and track people newly **diagnosed with cancer in the emergency department**. |
| | **Coordination with primary care** | • Prioritise **strengthening the coordination and communication between healthcare professionals** involved in the cancer care pathway, particularly those working in primary and secondary care, to ensure timeliness of care. |
| | **Availability of supportive and palliative care** | • Make **workforce training and patient and carer training** available for supportive, palliative and end-of-life care.<br>• Ensure that mechanisms are available to **activate such resources** in an effective and timely manner. |

## By communities and patient advocates

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **Cancer control plan or strategy** | • Advocate for **timely access** to **supportive care, palliative care and end-of-life care** as policy priorities in national oncology policies. |
| | **National health data ecosystem** | • Advocate for enhancing both the **health data ecosystem** and the **timeliness of care delivery** at national, regional and local levels. This may include:<br>- advocating for legislation and regulation supporting cancer data collection, while ensuring that aspects related to data ownership and people’s rights to authorise use of their personal data for care and research are considered<br>- implementing transparent reporting systems<br>- setting measurable targets for improvement<br>- creating oversight bodies to monitor progress and ensure that political leaders are held accountable for driving positive change. |

## CLUSTER 2: COORDINATION OF CARE – KEY RECOMMENDATIONS TO OPTIMISE METRICS IMPLEMENTATION

# At national, federal, regional levels

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Workforce capacity | **Monitoring and addressing workforce shortages in the cancer care ecosystem** | • Ensure that the **monitoring and improvement of cancer workforce capacity and capabilities are a national priority**. This entails:<br>- monitoring workforce capacity on a regular basis<br>- documenting in detail workforce shortages that compromise care delivery, so as to determine whether specific policies are needed<br>- developing strategies to improve the retention of workforce, concentrating on improving working conditions and promoting safety and well-being<br>- evaluating compliance with regulations governing oncology nurse specialists and cancer patient navigators within your context. |
| Oncology nurses and cancer patient navigators | **Regulation of the professional role of oncology nurses** | • Establish a **legal framework** for the **role of oncology nurse specialists and cancer care navigators** and their fit in the cancer care pathway to enhance coordination of care.<br>- If applicable, ensure that they have similar roles, mandates and power at subnational levels.<br>• Broaden the **engagement of these professionals** along the cancer care pathway in **discussing policies** to address the burden of cancer and to improve efficiency in cancer care. |

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| Task sharing and substitution | **Regulation concerning task sharing and substitution** | • Implement **regulations for task sharing and substitution** to enable seamless care experiences along the cancer care pathway.<br>- Ensure harmonisation of task sharing and substitution regulations across regions and jurisdictions. |
| Multidisciplinary tumour boards | **Regulation of multidisciplinary tumour boards** | • Regulate the **composition of and access to multidisciplinary tumour boards** within the cancer care pathway to ensure that quality standards are met.<br>- Ensure harmonisation of regulations across regions and jurisdictions. |
| Comprehensive cancer centres (CCCs) | **Centralisation of cancer care in specialised centres** | • Regulate the **centralisation of cancer care delivery** in certified CCCs.<br>• Monitor **patient access** to specialised care in certified CCCs, ensuring equal access to care in these centres. |

# At organisational level

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Workforce capacity | **Monitoring and addressing workforce shortages** | • **Co-develop strategies** to make the organisation sufficiently competitive **to attract and retain talent**, notably by nurturing a workplace underpinned by a robust safety culture. |
| Oncology nurses and cancer patient navigators | **Capacity building for oncology nurses and care navigators** | • Facilitate **specific training for oncology nurse specialists and cancer care navigators** that enables them to work in better coordination with other professionals along the care pathway.<br>• Establish the role of **cancer care navigators**, ensuring sufficient capacity and power for a meaningful impact on the care trajectories of people with cancer.<br>• Monitor **access of people with cancer to cancer care navigators** and the **impact of these professionals** on care outcomes and experiences. |
| Task sharing and substitution | **Regulation concerning task sharing and substitution** | • **Co-develop action plans** within your organisation to **implement task sharing and substitution** amongst professionals, underpinned by quality-of-care values. |
| Multidisciplinary tumour boards | **Regulation of multidisciplinary tumour boards** | • Ensure that the **composition** of multidisciplinary tumour boards in your organisation and/or the **access** to multidisciplinary tumour boards outside your organisation **conforms to national or international guidelines and good practices** per cancer type.<br>• Ensure the **functioning** of the multidisciplinary tumour boards, notably in terms of capacity and patient access. |

## By communities and patient advocates

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Workforce capacity | **Monitoring and addressing workforce shortages** | • Advocate for **safety culture improvements**, in particular regarding staff well-being and working conditions. |
| Oncology nurses and cancer patient navigators | **Regulation of oncology nurses and care navigators** | • **Co-design policies** that **leverage the utilisation of oncology nurses and cancer care navigators** in the care trajectories of people with cancer.<br>• Engage with **national associations of oncology nurses** so as to be actively involved in implementation efforts for utilisation of oncology nurses and cancer care navigators. |
| Multidisciplinary tumour boards | **Regulation of multidisciplinary tumour boards** | • **Co-design policies that enhance access** to multidisciplinary tumour boards. |

## At national, federal, regional levels

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **Political will and funding** | • Ensure **sufficient capacity and funding to initiate, monitor and assess pilot projects** aimed at implementing standardised and systematic collection of PREMs and PROMs across the entire cancer care pathway – from prevention to survivorship and including patient financial toxicity issues. Consider the **upscaling of these measures**. |
| | **National approach to patient-reported data collection** | • Develop a **national approach to people-reported data collection** such as patient-reported outcome (PROMs) and experiences of care (PREMs) measures, specifying clear purposes and uses in order to inform quality improvement initiatives. |
| | **Use of standardised tools for patient-reported data collection** | • Ensure **adequate alignment between national and regional approaches** to implementing the systematic collection of standardised PROMs and PREMs, including the feasibility of **utilising already existing national or international standardised instruments** to collect patient-reported measures. |
| | **Involvement of patient groups and non-governmental organisations** | • Actively **involve ordinary citizens and patients** in designing the health system and driving its performance (e.g. in developing medication safety action plans). Involve organisations representing patients, their families and communities in health policy making. |
| Data governance, use, and reporting | **Embedding of patient-reported metrics in cancer** | • Develop the health data infrastructure to ensure that capabilities for **collection of patient-reported data are embedded in electronic health records.** Ensure adequate capacity to enhance interoperability and |

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| | **registries or databases** | linkages to cancer registries and other public health databases, such as mortality databases. |
| | **Enforcement and feedback mechanisms** | • Consider the possibility of **enforcement mechanisms** for the systematic collection of patient-reported data and ensure that this data is considered in feedback mechanisms. |

# At organisational level

| **Key components for preconditions** | **Enablers** | **RECOMMENDATIONS** |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **Use of standardised tools for patient-reported data collection** | • Develop **partnerships to design and employ standardised questionnaires** to collect information about PROMs and PREMs. |
|  | **Involvement of patient groups and non-governmental organisations** | • Nurture the **engagement of organisations representing patients**, their families and communities in standards and guideline development. |
| Data governance, use and reporting | **Organisational will to include the patient perspective** | • Develop **initiatives to provide easy-to-understand information about patients' clinical situation** and to promote shared decision making.<br>• Develop **digital portals** to ensure patients' access to medical information from your organisation. |

## By communities and patient advocates

| Key components for preconditions | Enablers | RECOMMENDATIONS |
|---|---|---|
| Legal frameworks and strategy, policy context, funding | **Political will and funding** | - Advocate for **increased political will and funding allocation** that can help **improve patient-centredness** in the cancer care system, including synergies with broader measures such as patients' right to be forgotten and their return to work. |
| | **High levels of health literacy** | - Promote and develop **initiatives to promote patient empowerment and health literacy**, with a specific focus on fostering shared decision making. |
| Data governance, use and reporting | **Clear purpose and use of the metrics and linkage to other functions** | - Advocate for the **monitoring of equity** in access and quality of care, focusing particularly on vulnerable populations. |