The survivorship & quality-of-life national self-assessment tool

100 points across five domains, 20 questions split between the national assessment coordinator and the expert panel.

1. Survivorship care planning 10 pts · *Ensure cancer patients completing active treatment receive a survivorship needs assessment and a personalised survivorship care plan*
2. Quality-of-life screening 25 pts · *Ensure key physical, psychosocial, social and functional needs are screened during clinical appointments*
3. Quality-of-life measurement 20 pts · *Systematically measure and report on patient and survivor quality-of-life*
4. Multi-professional care 25 pts · *Include supportive care professionals fully within models of multidisciplinary care*
5. Social & legal protection 20 pts · *Legislate against financial discrimination, recognise cancer within disability frameworks, and support return to work and informal caregiving*

1. Survivorship care planning

Score out of 10 · Ensure cancer patients completing active treatment receive a survivorship needs assessment and a personalised survivorship care plan

COORDINATOR 1.1 Is survivorship care planning a national political commitment — for example included in the national cancer control plan?

0	There is no commitment to survivorship care planning in our national cancer plan
1	There was a commitment in a previous plan, but not in our current plan
2	It is not a commitment in our cancer plan, but the government appears to understand the importance of making more progress
3	It is not a commitment in our cancer plan, but is committed to in other health ambitions and statements of our government
4	It is a commitment in our cancer plan, but little actual progress has been made and little to no funding is available for this ambition
5	It is a commitment in our cancer plan, and progress is going well

Justification:

PANEL 1.2 On a scale of 0 to 5, how would you rate your country's implementation level on survivorship care planning?

0	No commitment and no funding for it
1	Some vague political commitments, but no concrete or tangible goals set
2	Some clear commitments have been made, but they are not clearly funded and implementation energy is missing
3	There are clear commitments and funding, but implementation is still not where it should be
4	There are clear commitments and funding, but implementation is only happening in some places
5	There is clear commitment, funding is in place, and matters are well implemented across the country

Justification:

2. Quality-of-life screening

Score out of 25 · Ensure key physical, psychosocial, social and functional needs are screened during clinical appointments

COORDINATOR 2.1 Is the routine screening of physical, psychosocial, social and functional needs a national requirement in your country — for example mandated in national clinical guidelines, the national cancer control plan, quality standards, or accreditation criteria for cancer centres?

0	There is no national requirement, guideline or commitment on screening for these needs
1	Screening is mentioned as a general aspiration in policy documents, with no standard, tool or expectation attached
2	National guidelines recommend screening, but it is not a requirement, is not monitored, and no funding is attached
3	Screening is a formal requirement in national guidelines or quality standards, but compliance is neither monitored nor enforced
4	Screening is a requirement and is monitored through accreditation or audit, but only for some needs or at some points of the pathway
5	Screening across physical, psychosocial, social and functional needs is a monitored national requirement, with designated tools and defined points along the pathway

Justification:

PANEL 2.2 To what extent are cancer patients routinely screened for physical and functional needs — fatigue, pain, neuropathy, malnutrition, bowel and sexual dysfunction, and loss of physical function or activity levels — using validated tools?

0	There is no routine screening; these needs surface only if the patient raises them
1	Clinicians ask about physical symptoms informally during consultations, with no structured screening and no validated tool in use
2	Some centres screen systematically for one or two needs, typically pain or nutrition, with very limited coverage of other needs or of functional capacity
3	Structured screening for physical symptoms is reasonably common, but functional capacity, physical activity and treatment burden are rarely captured
4	Most centres screen systematically across physical and functional needs using validated tools, though not at all points of the pathway
5	Systematic screening across physical and functional needs, including physical function and treatment burden, is standard practice nationally and repeated at key points of the pathway

Justification:

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PANEL 2.3 To what extent are cancer patients routinely screened for psychological and emotional needs — distress, anxiety and depression — using validated tools such as the Distress Thermometer?

0	There is no routine screening for psychological needs
1	Psychological needs are addressed only when a patient is visibly in crisis or explicitly asks for help
2	A small number of centres, usually the larger or research-active ones, screen systematically; elsewhere it depends on the individual clinician
3	It is patchy. Leading cancer centres screen routinely with validated tools, but a majority of centres do not
4	Most, but not all, centres screen routinely using validated tools, although often only at a single point such as diagnosis
5	Routine screening with validated tools is standard practice nationally, repeated at diagnosis, during treatment and in the survivorship phase

Justification:

PANEL 2.4 To what extent are cancer patients routinely screened for social, practical and financial needs — financial toxicity, employment and income loss, caring responsibilities, and practical barriers to reaching care?

0	These needs are not screened for at all within the cancer care system
1	They are raised only informally, and typically by patient organisations or charities rather than by the care team
2	Social workers or navigators identify these needs in some centres, but there is no structured screening and coverage depends entirely on local staffing
3	Some centres use a structured social or financial needs assessment, but this is the exception rather than the norm
4	Most centres screen for social and practical needs in a structured way, although financial toxicity specifically is inconsistently captured
5	Structured screening for social, practical and financial needs, including financial toxicity, is a standard and funded part of cancer care nationally

Justification:

PANEL 2.5 Where needs are identified through screening, to what extent do they lead to timely, needs-based support integrated within the care pathway, rather than ad hoc referral?

0	Identified needs rarely lead to any structured response; results are recorded but not acted upon
1	Any response depends entirely on the individual clinician's initiative and personal contacts
2	Referral pathways exist on paper, but waiting times, capacity limits or cost mean most patients never receive the support identified
3	Identified needs usually lead to a referral, but the response is ad hoc, external to the cancer team, and not followed up
4	In most centres, identified needs trigger a defined pathway to support within an agreed timeframe, though follow-up and re-screening are inconsistent
5	Identified needs reliably trigger timely support embedded in the care pathway, with documented follow-up and re-screening to confirm the need has been met

Justification:

3. Quality-of-life measurement

Score out of 20 · Systematically measure and report on patient and survivor quality-of-life

COORDINATOR 3.1 Is the systematic measurement of quality of life a national political commitment in your country — for example included in the national cancer control plan or other public government documents?

0	There is no commitment to systematic quality-of-life measurement in our national cancer plan or other government documents
1	There was a commitment in a previous plan, but not in our current plan
2	It is not a commitment in our cancer plan, but the government appears to understand the importance of making more progress
3	It is not a commitment in our cancer plan, but is committed to in other health ambitions and statements of our government
4	It is a commitment in our cancer plan, but little actual progress has been made and little to no funding is available for this ambition
5	It is a commitment in our cancer plan, and progress is going well

Justification:

PANEL 3.2 To what degree are PROMs and PREMs being used across your country to support cancer research?

0	Not at all
1	Some research centres make use of PROMs/PREMs for cancer research, but it is irregular and the tools used may not be validated or standardised across the country
2	There are earnest efforts underway to make better use of PROMs/PREMs in cancer research, but there is still some way to go before use is regular, systematised and standardised
3	There has been good progress in recent years, and the trajectory towards systematised, standardised and regular use is positive
4	Most, but not all, centres of cancer research in our country make good use of validated PROMs/PREMs, with clear evidence of intent for the system to become systematised and standardised
5	Our country is advanced in PROMs/PREMs use, close to or at a level of standardised, systematised and regular use

Justification:

PANEL 3.3 To what degree are PROMs and PREMs being used across your country to support improvements in daily oncology practice?

0	Not at all
1	I have heard of some centres using PROMs/PREMs to improve clinical practice, but I have little direct experience or knowledge of it
2	A small number of centres are known to be using PROMs/PREMs to improve clinical practice, and other centres are considering these developments closely
3	It is patchy. Leading cancer centres use PROMs/PREMs to improve clinical practice, but a majority of centres do not
4	Most, but not all, centres of cancer research in our country make good use of PROMs/PREMs to improve clinical practice
5	Our country is advanced in PROMs/PREMs use for the improvement of clinical practice; most cancer centres use PROMs/PREMs for this purpose

Justification:

DRAFT

COORDINATOR 3.4 To what degree are PROMs and PREMs being used in your country to inform evidence-based decision-making at national level — for example reimbursement decisions, HTA, and decisions on the standard patient pathway?

0	PROMs/PREMs have no role in national-level decision-making about cancer patient treatment and care
1	PROMs/PREMs are rarely used in national-level decision-making about cancer patient treatment and care
2	The government has general commitments to make more use of PROMs/PREMs in national-level decision-making, but they are far from realised
3	Things are moving in a good direction, with the maturity of the country's systems for PROMs/PREMs use on a positive trajectory
4	Some relevant categories of national-level decision-making are well guided by PROMs/PREMs, such as HTA, but not all
5	PROMs/PREMs are highly integrated into all relevant national-level decision-making structures affecting cancer care delivery

Justification:

4. Multi-professional care

Score out of 25 · Include supportive care professionals fully within models of multidisciplinary care

COORDINATOR 4.1 Are supportive care disciplines — palliative care, rehabilitation, pain medicine, sexual medicine and fertility, clinical nutrition, psycho-oncology — formally recognised, funded and reimbursed as part of standard cancer care?

0	These disciplines have no formal recognition or dedicated funding within cancer care
1	One or two disciplines are recognised, typically palliative care, but the others have no funded status
2	Several disciplines are recognised in policy, but funding is project-based, time-limited or dependent on charitable sources
3	Most of these disciplines are recognised and reimbursed, but funding does not cover the staffing levels guidelines recommend
4	These disciplines are recognised and reimbursed as a standard component of cancer care, with some gaps remaining — commonly sexual medicine, fertility or rehabilitation
5	All of these disciplines are formally recognised, funded and reimbursed as an integral component of standard cancer care

Justification:

PANEL 4.2 To what extent are supportive care professionals embedded members of the multidisciplinary team — attending tumour board or MDT meetings and shaping the care plan — rather than accessed through external referral?

0	Supportive care professionals play no part in multidisciplinary team working
1	Contact with supportive care happens only by referral, after treatment decisions have already been taken
2	Supportive care professionals are occasionally invited to MDT meetings for complex cases, but are not standing members
3	It is patchy. Leading centres include supportive care professionals as MDT members, but most centres operate a referral model
4	Most centres include supportive care professionals as standing MDT members, though typically only a subset of the relevant disciplines
5	Supportive care professionals across the relevant disciplines are standing MDT members, and their input shapes the care plan from diagnosis onwards

Justification:

PANEL 4.3 To what extent does your country have sufficient trained workforce capacity in supportive care disciplines to meet the needs of cancer patients and survivors?

0	There is effectively no trained workforce in these disciplines within cancer services
1	A very small number of professionals exist nationally, concentrated in one or two institutions
2	There is some capacity, but it falls far short of need and there is no national plan to expand it
3	Capacity is improving and workforce planning has begun, but shortages remain severe in several disciplines
4	Capacity is adequate in most disciplines and most regions, with recognised shortages in specific areas such as sexual medicine, fertility or rehabilitation
5	There is sufficient trained capacity across supportive care disciplines, supported by national workforce planning and recognised training pathways

Justification:

PANEL 4.4 To what extent does access to supportive care professionals continue beyond the end of active treatment, into follow-up, survivorship and the management of long-term and late effects?

0	Access to supportive care ends with active treatment
1	Support after treatment is available only through patient organisations or charities, not the health system
2	Some support continues after treatment, but it is time-limited and usually restricted to a single discipline
3	Continued access exists in some centres, but there is no defined mechanism for re-entry once a patient is discharged from oncology
4	Most patients can access supportive care during follow-up and survivorship, though re-entry pathways after discharge are inconsistent
5	Access continues throughout follow-up and survivorship, with clear pathways to re-enter services when long-term or late effects emerge

Justification:

PANEL 4.5 To what extent is access to multi-professional supportive care equitable across your country — across regions, between specialist centres and general hospitals, and across cancer types?

0	Access is available in only one or two locations nationally
1	Access is concentrated in the capital or in a small number of comprehensive cancer centres
2	There are significant disparities between regions, and patients outside specialist centres have little or no access
3	Specialist centres provide reasonable access, but general hospitals and rural areas lag substantially behind
4	Access is broadly comparable across most of the country, with recognised gaps for certain regions or rarer cancers
5	Patients receive comparable access to multi-professional supportive care wherever they are treated and whatever cancer they have

Justification:

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5. Social & legal protection

Score out of 20 · Legislate against financial discrimination, recognise cancer within disability frameworks, and support return to work and informal caregiving

COORDINATOR 5.1 To what extent does your country provide binding protections against financial discrimination affecting cancer survivors in access to insurance, mortgages, loans and other financial services?

0	There are no legal, or right-to-be-forgotten, protections in place
1	There are only some non-legal protections
2	The government and elected representatives are actively considering legal protections
3	There are some legal protections in place, but they are not well implemented
4	There are some legal protections in place, but they are not to the European standard — for example the right to be forgotten becomes effective more than five years after the end of active treatment
5	Our country has well-implemented legislation that is at the European standard — five years or less after the end of active treatment

Justification:

PANEL 5.2 To what extent are the rights of cancer patients and survivors protected by national legislation, including disability legislation?

0	Not at all. There is little to no protection for the rights of cancer patients and survivors in national legislation
1	To a limited extent. There are some basic rights under employment legislation, such as not losing your job, but nothing specific to the needs and experiences of cancer patients and survivors
2	To some extent. There is a patchwork of legal rights across different legal instruments, but it is not cohesive or complete
3	In some areas the legal protections are strong, such as disability, but in many other fields there is much more to be done, such as employment and return to education
4	In most areas, cancer patients and survivors receive good levels of legal and regulatory protection for their employment, social and other rights, though some areas for improvement remain
5	There are strong and comprehensive legal protections for cancer patients and survivors, including for employment, disability, and return to education

Justification:

PANEL 5.3 To what extent does your country provide structured return-to-work and rehabilitation support for patients and survivors?

0	Not at all
1	To a limited extent. It is not a centralised requirement, and cancer centres and other service providers that support these needs do so under tight budgetary constraint
2	To some extent. Some parts of the country provide this support well, but most do not
3	A large number of centres and service providers meet this need, but by no means all
4	Our country is close to making return-to-work and rehabilitation support a standard part of cancer care in all parts of the country
5	Return-to-work and rehabilitation support is a standard part of cancer care in all parts of the country

Justification:

PANEL 5.4 To what extent do informal carers have the right to legal recognition, access to support, and recognition within national social security systems in your country?

0	Informal carers in our country have hardly any, and maybe no, legal recognition, access to support, or recognition within national social security systems
1	To a limited extent. There is some basic access to support, often from non-governmental sources, but little legal recognition
2	To some extent. The government has some formal support policies for informal carers in place, but they are far from comprehensive and legal rights are lacking
3	The government and elected representatives recognise that there is more to do to support informal carers, but implementation of fresh measures is not yet advanced
4	To a large extent. There are some good and useful legal protections in place to support informal carers, but there is more to do
5	Informal carers are well protected in legislation, and the government provides helpful support mechanisms

Justification:

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