

“Macmillan Values Based Standard”™

Overview

In 2009 Macmillan Cancer Support commissioned work to research and develop a standard for cancer care services, expressing human rights principles as specific behaviours. The Macmillan Values Based Standard has been developed through an 18 month engagement process with over 300 healthcare staff and people living with and affected by cancer across the country. In *Improving Outcomes: A Strategy for Cancer Care* the government has confirmed its support for the Macmillan Values Based Standard, recognising that the application of human rights to the delivery of cancer care focuses on ‘what matters’ to patients, and has the potential to create more equitable care outcomes by changing the nature of the relationship between patients and professionals.¹

Why behaviours?

The Macmillan Values Based Standard identifies specific **behaviours**. Practical things staff and patients *can do* on a day to day basis, to ensure people’s rights are protected across the care pathway.

Why ‘behaviours’? These are ‘moments that matter’ to people affected by cancer and healthcare staff. It became evident that while patients find it hard to define ‘dignity’ or ‘respect’, they are nonetheless very aware of **behaviours** that signify their opposite. Our work across the country identified similar failures in the *care relationship* which should exist between staff and patients, rather than ‘big system failures’ or strategic issues.

There was a high level of agreement between these groups about what the behavioural standards should look like, about what care entitlements were practical and reasonable and about where things are ‘going wrong’ in relation to protecting basic rights. Patients, carers and families were very aware when they had not been treated with dignity and respect. Staff too were acutely aware of instances in which circumstances had prevented them meeting their own vocational standards.

So rather than ‘top-down’, the Macmillan Values Based Standard is **staff, patient and carer-led**. Rather than performance benchmarks ‘imposed’ from above, the Macmillan Values Based Standard emphasises **co-productive behaviours** between staff and patients. This reflects the wider shift emerging in health policy towards a more equitable relationship between the citizen and the NHS, and the use of **patient experience** as a key lever in both judging and raising quality and effectiveness in care services.

Achieving the Macmillan Values Based Standard can be seen as process of change within an organisation. The role of **leadership and governance** is emphasized because it can support staff to enact positive, pro-patient

¹ *Improving Outcomes: A Strategy for Cancer* (2011), p.69.

behaviours that support and uphold care rights. Similarly, the Macmillan Values Based Standard contains a **'vocational-nudge'** to help staff to (privately) interrogate their own behavior and to articulate and judge progress against their own care-related goals (e.g. 'today I won't tell a lie to patients').

The Macmillan Values Based Standard in brief...

The Macmillan Values Based Standard is therefore structured around eight behaviours that can be used as indicators of service quality. They are designed to effect positive change in staff/patient relationships, to drive up performance – especially in patient experience, satisfaction and outcomes – and protect care rights. The eight behaviours are described as:

- Naming – “I am the expert on me”.
- Private communication – “My business is *my* business”.
- Communicating with more sensitivity – “ I’m more than my condition”
- Clinical treatment and decision-making – “I’d like to understand what will happen to me”
- Acknowledge me if I’m in urgent need of support – “I’d like not to be ignored”.
- Control over my personal space and environment – “I’d like to feel comfortable”.
- Managing on my own – “I don’t want to feel alone in this”.
- Getting care right – “My concerns can be acted upon”.

For each of these areas, the Macmillan Values Based Standard includes an associated list of:

- ‘Behaviours’ (things staff and those affected by cancer should do in a care setting) to ensure basic entitlements are met
- ‘Vocational nudge’ (a set of prompts to encourage staff to set themselves personal goals that challenge what they do on a day-to-day basis in order to achieve the Macmillan Values Based Standard)
- ‘Leadership behaviours’ (things leaders need to do to ensure staff do too)

The benefits of this approach

By focusing on standards of behaviour chosen for their potential to improve staff/patient relationships and the care experience, the Macmillan Values Based Standard provides a credible method for understanding and measuring patient experience, and makes explicit the link between delivery of care outcomes and the patient’s entitlement to be treated with dignity, respect and equity by those who deliver their care.

In this respect, the Macmillan Values Based Standard is closely aligned with the NHS Outcomes Framework, with the Health and Social Care Act 2012, as well as *Improving Outcomes: A Strategy for Cancer Care* 2011 and NICE Patient Experience Guidelines 2012.

By building on convergent views and aspirations of patients, carers and professionals and ‘measuring what matters’ to these groups, there is likely to be:

- More trust and improved relationships between staff and patients/carers – leading to more opportunities for disclosure to identify problems earlier and to higher patient satisfaction.
- Increased motivation amongst professionals to deliver on standards that relate closely to their personal ethics and views of their vocation (‘the reason I got into healthcare in the first place’).

The business case

The Macmillan Values Based Standard is therefore focused on behaviours which will improve patient experience. This is ‘what matters’ to patients but it is also what matters to health professionals, reinforcing their sense of vocation and personal/professional ethics and in this sense is more accurately described as person-centred because it is about both staff and patients. Evidence is beginning to suggest that patient-centred care is associated with good health outcomes and cost effectiveness, with lower costs and shorter in patient stays.²

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² Charmel PA, Frampton SB (2008) ‘Building the business case for patient-centered care,’ *Healthcare Financial Management* March, vol 62(3), pp 80-5

MACMILLAN VALUES BASED STANDARD/PLEDGES

<p>Naming – “I am the expert on me”</p>	<p>Leadership Behaviour</p>	+	<p>Vocational ‘Nudge’ examples</p>	+	<p>Behavioural Standard for improving cancer care</p>
	<p>Leaders create a personable and approachable environment across the staff structure, they want ideas and innovation to emerge from the frontline reinforcing the importance of all roles in the organisation.</p> <p>Leaders ‘role model’ behaviours that emphasise the importance of relationship building because leaders want to encourage staff to develop better relationships with all patients.</p>		<p>“I want to know who patients really are.”</p> <p>“I recognise the need to understand what is important to patients and that this information can be of assistance to me in understanding how to care for patients.”</p>		<p>Staff ensure that patients are asked how they want to be addressed in every new staff/patient interaction and act upon this information.</p> <p>Staff ensure that this initial introduction supports the gathering of essential information, such as: language, support requirements, disability issues, religious and dietary needs.</p> <p>Patients help staff understand what is factual and what is presumption and take greater responsibility for the information they provide.</p> <p>Staff are open to correcting incorrect patient information.</p>
<p>= Outcome:</p> <p>Patient can disclose information which will help staff to understand them and act on their needs.</p>					

	Leadership Behaviour		Vocational 'Nudge' examples		Behavioural Standard for improving cancer care
<p>Private communication – “My business is my business”</p>	<p>Plans are drawn up to address confidentiality issues, especially where private space is not easily available.</p>	+	<p>“I want to give you the space you need.”</p> <p>“I recognise that however many times I have conveyed this type of information, this is your news and your first time hearing it.”</p>	+	<p>Staff ensure that consultations with patients are made private and that patients are informed when this isn't possible.</p>
	<p>Staff are supported in their endeavours to provide private consultation to patients.</p> <p>Leaders discourage inappropriate communication between staff or between staff and patients.</p>				<p>Patients may have to acknowledge that complete privacy is not always possible.</p> <p>Staff ensure that patients are involved in decisions about the onward communication of information about them and their condition.</p> <p>Patients take greater responsibility for determining disclosure.</p>
<p>= Outcome:</p> <p>Patient has space to listen and hear information and can be secure in their reaction to information received. Patient decides if they wish information to be shared and with whom.</p>					

	Leadership Behaviour		Vocational 'Nudge' examples		Behavioural Standard for improving cancer care
Communicating with more sensitivity – 'I'm more than my condition'	Leaders communicate regularly with staff and consider how they use communication to motivate and encourage staff to do the best job.	+	"I want to understand the impact of my communication so that I can alter my approach to respond to your needs."	+	Staff ensure that the seriousness of intended communication is explained, and observe and respond appropriately to the emotional, physical and psychological impact of information.
	Leaders put plans in place that support staff more holistically in carrying out their roles.		"I will respond patiently to your questions and concerns."		Patients are enabled to share their concerns.
= Outcome:					
Patients are empowered to share any concerns about what they have been told. Patients receive better support based on their reaction to information.					

	Leadership Behaviour		Vocational 'nudge' examples		Behavioural Standard for improving cancer care
<p>Clinical Treatment and decision making – “I’d like to understand what will happen to me”</p>	<p>Leaders listen to staff and involve them appropriately in negotiation of decisions which impact on their roles.</p> <p>Leaders appraise and understand patient data, noticing in particular who is likely to receive the best and worst outcomes within their care.</p> <p>Leaders use a range of data sources, especially those that relate to patient and staff feedback.</p> <p>Leaders encourage staff to represent patient concerns, especially where this conflicts with achieving the Macmillan Values Based Standard.</p>	<p>+</p>	<p>“I want you to know – even when telling you is challenging or uncomfortable for me – I will be supportive in your need to understand the options.”</p> <p>“I have knowledge and you have knowledge: we will explore the options and negotiate the decisions.”</p> <p>“It’s important that I put aside my personal values and ‘health beliefs’ when they collide or conflict with the wishes of a patient.”</p>	<p>+</p>	<p>Staff ensure that the next stages in clinical processes are explained, including timescales, type of support required to help patients through the treatment process, how the treatment will make them feel and any consequences of the treatment – short, medium or longer term.</p> <p>Patients contribute by asking questions and sharing concerns.</p> <p>Staff ensure that patients’ practical support requirements are discussed.</p> <p>Staff ensure that patients are given both the space and opportunity to raise questions – including those relating to alternative treatment options.</p> <p>Staff ensure that patients are involved in negotiating their treatment.</p>
<p style="text-align: center;">= Outcome:</p> <p>Patients understand what options have been considered and why recommendations for a particular course of treatment have been made. They know how to prepare for the treatment and have a better understanding of associated short, medium and longer-term treatment consequences. Patients feel more engaged in their treatment plan.</p>					

	Leadership Behaviour		Vocational 'Nudge' examples		Behavioural Standard for improving cancer care
<p>Acknowledge me if I'm in urgent need of support – "I'd like not to be ignored"</p>	<p>Leaders acknowledge where there might be pressure points in the system, and assist staff in prioritising the delivery of their care role in line with the Macmillan Values Based Standard.</p> <p>Leaders take notice of data and use it to create opportunities for service improvement.</p> <p>Leaders encourage staff to innovate in their quest for solutions to provide patient satisfaction.</p> <p>Leaders are prepared to recognise the need for system change, especially when indicated by staff at the frontline.</p>	<p>+</p>	<p>"You can trust me – I'll be honest with you and tell you when you have to be patient."</p> <p>"It will take some thinking about the practicalities, but I won't mislead patients or use routine statements to pacify patients in need."</p> <p>"I'll do my very best not to forget you, and update you on when I'm able to attend to your needs."</p>	<p>+</p>	<p>Staff ensure that they acknowledge patient need by letting patients know that they have recognised that they are in need of support.</p> <p>Patients may sometimes have to recognise that others have more urgent needs.</p> <p>Staff ensure that they indicate to patients when their needs may be met.</p>
<p>= Outcome:</p>					
<p>Patients' care needs are acknowledged, but they also understand that others might be in more urgent need of care, and that they might have to wait for staff support.</p>					

	Leadership Behaviour		Vocational /Staff 'Nudge'		Behavioural Standard for improving cancer care
<p>Control over personal space and environment – “I’d like to feel comfortable”</p>	<p>Leaders receive data on staff motivation and wellbeing, by service, team and consultant and actively monitor this data for trends, especially in relation to issues of grade, function or protected characteristics.</p> <p>Leaders appraise information on patient welfare and hygiene issues recognising where the service has been able to act upon patient concerns, and offering explanation if patient concerns have not been met.</p> <p>Leaders provide staff with flexibility and opportunities to influence policies and use of resources in order to encourage innovation and improved patient experience.</p>	<p>+</p>	<p>“If you’re happy then I’m happy – I’ll make it my business to check up on your immediate environment.”</p> <p>“I won’t mind or get defensive if you point out where there are problems – I’ll try not to take it personally.”</p> <p>“I will be the problem-solver whenever a patient’s comfort is compromised, and I’ll let the patient know if I can’t improve the situation.”</p> <p>“I’ll be an agent for change – noting when the system is at odds with legitimate needs”</p>	<p>+</p>	<p>Staff ensure that they ask patients about their comfort and respond to these needs where possible.</p> <p>Patients inform staff if they are uncomfortable and explain why.</p> <p>Staff explain if particular needs cannot be met, and if appropriate highlight these requirements to others in the system who may be able to resource this in the future.</p> <p>Staff ensure that the patient environment is clean, and attend to their own hygiene needs before supporting patients.</p>
<p style="text-align: center;">= Outcome:</p> <p style="text-align: center;">Patients are able to express their comfort needs, have these needs met, and be cared for in a clean environment</p>					

	Leadership Behaviour		Vocational 'Nudge' examples		Behavioural Standard for improving cancer care
<p>Managing on my own – “I don't want to feel alone in this”</p>	<p>Leaders actively support vocational excellence and recognise and encourage staff in this endeavour.</p> <p>Leaders enable staff to have valuable reflection time, which in turn supports the implementation of their role.</p> <p>Leaders reward staff who have acted on patient interests.</p> <p>Leaders develop strong partnerships with other support services to ensure patient needs are met.</p>	<p>+</p>	<p>“I will support you in making the transition from ward care to home care.”</p> <p>“I want to know what's best for you – the who, where, and how in your health care journey.”</p> <p>“I want to do what's best for you and will liaise with other professionals to ensure that your support needs can be met.”</p>	<p>+</p>	<p>Staff ensure that they have understood how patients wish to receive information on their onward care.</p> <p>Patients disclose any anxieties they may have regarding their ability to self-care.</p> <p>Staff ensure that future care, including the managing of planned and unplanned events are discussed.</p> <p>Staff ensure that lifestyle changes are discussed and that patients are appropriately supported and signposted to further help.</p> <p>Staff assess the impact of information on patients and ensure that they understand what to do next and where to go to for support.</p>
	<p style="text-align: center;">= Outcome:</p> <p>Patients are enabled to manage their own care and recognise the 'normal' tolerances of their condition. Patients feel better able to control and manage their condition and to maintain their independence, whilst also understanding when and who to refer to should they be in need of support.</p>				

	Leadership Behaviour		Vocational 'Nudge' examples		Behavioural Standard for improving cancer care
<p>Getting care right – “My concerns can be acted upon”</p>	<p>Leaders promote and implement 'real time' feedback across their services, and encourage criticism as part of the improvement process.</p> <p>Leaders recognise that middle managers and staff can be 'squeezed' within the change process and actively manage decision-making at appropriate levels of the organisation.</p> <p>Leaders 'role model' the acceptance of criticism and 'walk the floor' to understand more about patient and staff experiences.</p> <p>Leaders take notice of patterns of care – who is most likely to make complaints, what they are most likely to complain about, and use this information to make positive change.</p>	<p>+</p>	<p>“I want to get it right for you and will ask you what can be done better.”</p> <p>“I won't take it personally, and will try to get it right for you when you are in my care.”</p> <p>“I am rewarded by your satisfaction with our care.”</p> <p>“I will raise concerns about other professionals or systems which I think have worked against your care.”</p>	<p>+</p>	<p>Staff actively request feedback from patients on the quality of patient care.</p> <p>Patients co-operate by providing real-time feedback.</p> <p>Staff act upon feedback to ensure that adequate support can be offered in 'real time'.</p> <p>Staff ensure that they respond positively to patient feedback, especially if it is negative.</p>
<p style="text-align: center;">= Outcome: Patients feel enabled to make complaints in an environment where complaints are welcome and their experiences of care are enhanced as a result</p>					