

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. How to talk to those close to you. What to do about work. How you'll cope with the extra costs.

At Macmillan, we know how a cancer diagnosis can affect everything. So when you need someone to turn to, we're here, because no one should face cancer alone. We can help you find answers to questions about your treatment and its effects. We can advise on work and benefits, and we're always here for emotional support when things get tough.

Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support to help you feel more in control of your life.

We are millions of supporters, professionals, volunteers, campaigners and people affected by cancer. Together we make sure there's always someone here for you, to give you the support, energy and inspiration you need to help you feel more like you. We are all Macmillan.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

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**MACMILLAN
VALUES
BASED
STANDARD[®]**

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**Transforming the experiences
of patients and professionals**

CONTENTS

1. How can it help improve the experience of patients and professionals?	2
2. The eight behaviours	3
3. The framework	4
4. How to apply the framework to improve patients' and professionals' experiences	6
5. Tools and support	8
6. Detailed descriptions of the behaviours	10

The **Macmillan Values Based Standard**[®] was developed through an 18-month engagement process with more than 300 patients and their carers, along with healthcare professionals. The idea was to develop a standard for cancer care services based upon human rights principles. It builds on the views and aspirations of patients, carers and professionals to provide a framework for improving patients' and professionals' experience of healthcare. It identifies specific behaviours – practical things that you can do on a day-to-day basis to ensure that people's rights, including dignity and respect, are protected. It focuses on the 'moments that matter' to people and their carers. It builds increased trust and improved relationships between professionals, patients and carers, leading to more opportunities to identify problems earlier for higher patient satisfaction.

*Please note that in referring to professionals we are including all roles within your healthcare organisation that have a relationship or come into contact with patients and carers.

'The Macmillan Values Based Standard works. It isn't just about cancer, it's about people, it's about human connection, it's about what makes a good experience for everybody involved.'

CEO, John Taylor Hospice


1. How can it help improve the experience of patients and professionals?

The Macmillan Values Based Standard focuses on behaviours that will improve patient experience. The behaviours represent the areas that matter the most to people affected by cancer and were also developed to resonate with what matters to you in your role as a health professional.

In this way, the Macmillan Values Based Standard is more accurately described as person-centred as it is about professionals 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 stays¹.

Implementing the Macmillan Values Based Standard is not a one-off project: it is a way of working. It's about how you and your organisation can adapt it to the workplace. Each implementation is unique to the site or ward, and rarely mirrors another. However, the approach and methodology is always the same, and recognisably part of the framework of the Macmillan Values Based Standard. It is how this framework is implemented that engages professionals and includes patients. Although the Macmillan Values Based Standard was originally developed for cancer care, organisations across health and social care are using it to improve the experience of all patients.

This booklet sets out what these behaviours are and the framework you can use them in to implement change. It also shows how you begin to practically apply this to make changes; and what tools and support are available to you as you begin to implement the Macmillan Values Based Standard.



'I think over the years, you know, we get very busy and we're very good at saying we're busy. But actually we did all come into these roles because we care about people and patients. And I think the standards just make you rethink the way we talk to patients, the way we care for patients.'

Head of Nursing, Cancer, Kings College

2. The eight behaviours

The Macmillan Values Based Standard is structured around eight behaviours. These are designed to effect positive change in professionals' and patients' relationships, drive up performance – especially in patient experience, satisfaction and outcomes – and protect care rights². The eight behaviours and what these mean to patients are described as:

Naming

You're the expert on you and the information you give professionals will help them understand you. 'I am the expert on me.'

Private communication

You're entitled to privacy – you decide if information can be shared and who with. 'My business is my business.'

Communicating with more sensitivity

Expect to be communicated with in a sensitive way, be offered support and share any concerns about what you're told. 'I'm more than my condition.'

Clinical treatment and decision making

Be involved in decisions. You should be informed of the treatment options and why recommendations have been made. This includes how the treatment will make you feel and any longer-term effects. 'I'd like to understand what will happen to me.'

For more detailed descriptions of each behaviour, vocational examples of their use and their positive outcomes, please refer to section 6 of this booklet.

The Macmillan Values Based Standard provides a credible method for understanding and measuring patient experience. And it does this by focusing on standards of behaviour chosen for their potential to improve professionals and patient relationships and the care experience. It makes an explicit link between delivering care outcomes and the patient's entitlement to be treated with dignity, respect and equity by those who deliver their care.

Acknowledge me if I'm in urgent need

You can expect professionals to understand your needs and say when these will be met. However, there may be times when others are in more urgent need of care. 'I'd like to not be ignored.'

Control over personal space and environment

Expect to be cared for in a clean and comfortable setting and say what you need for this to happen. 'I'd like to feel comfortable.'

Managing on my own

You should be supported to manage your own care but also know where to go if you're worried or need support. 'I don't want to feel alone.'

Getting care right

Your feedback is always welcome and your concerns are acted on, as part of a process to improve your experience of care. 'My concerns can be acted upon.'

'It doesn't feel like another top-down initiative – it feels like a conversation professionals can become part of and influence.'

CEO, John Taylor Hospice

3. The framework

The model below sets out the eight behaviours that make up the standard but also the foundations that need to be in place to really make a difference. This is not a project – it is an organisational focus on continuous improvement with professionals and patients working together to design and implement improvement.

Rather than performance benchmarks ‘imposed’ from above, the framework of the Macmillan Values Based Standard emphasises co-productive behaviours between professionals and patients. Applying this to your organisation can be a process of change to improve the experiences of those who receive and give care.

Implementing the Macmillan Values Based Standard Framework

FOUNDATIONS

Care is person-centred

Patients are equal partners in the planning, development and assessment of their care, making sure it is most appropriate for their needs

Co-design principles are being applied

Professionals and patients work together to design improvements

Measurement and feedback processes are in place

It is important to use a number of ‘measures’ to help see whether patients’ and professionals’ experiences are improving

There is a culture of enabling leadership

People are given permission to act as leaders no matter where they sit in the organisation. This kind of distributed leadership supports professionals to make improvements

Professionals are practising reflective learning

Professionals are encouraged to look back at their own practice and consider what and how they have achieved, and also what they might also change

Robust facilitation is available

This will support multiple stakeholders to work together when implementing the framework

‘Bottom up’ and permission based approaches are in place

Front-line professionals are best placed to lead the improvement of the patient’s experience of care and all professionals are empowered to respond to patients’ needs

There is an evidence base demonstrating need and impact

Evidence is used to demonstrate why relational care is needed, and to track the impact of improvements made

BEHAVIOURS

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 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”

OUTCOMES

Improving patients’ and professionals’ experiences

Culture change

4. How to apply the framework to improve patients' and professionals' experiences

When implementing the Macmillan Values Based Standard in your organisation, we encourage a three-phase approach. In summary this concentrates on:

Discover

What is really going on here?

- Use survey data, annual and real time
- Work with professionals – identify system failures
- Interview patients, run focus groups
- Observation
- Identify front line improvement teams/leads

This is all about building up a really good picture of the current experience of patients and professionals. This will generate the evidence you need to decide on improvements.

- The first step is to consider what data (qualitative and quantitative) you may already have – what is it telling you?
- Set up a steering group or project group to help support the work
- Run a staff workshop in the area you want to start in
- Interview professionals and/or run an anonymous survey
- Interview patients and/or run a focus group – talk to some relatives
- Use observation as a tool to understand more
- Establish a base line that you can re-visit in future

Innovate

What interventions might help?

- Professionals and patients co-design interventions
- Agree measurement systems
- Small tests of change, evaluate and refine
- Diffused leadership and permissions to respond to individual need
- Workplace reflection, learning and support

This stage is about involving a wider group of people and gaining agreement about what interventions you are going to focus on.

- Run a way forward event where you present your evidence from the discovery phase
- At the event agree the broad areas you want to concentrate on – do not decide at this stage on specific interventions
- Decide who will lead the work areas – professionals? Former patients? Get the relevant permissions
- Decide how you will involve patients in helping shape and implement the interventions
- Use the model for improvement and small tests of change
- Set up systems for review and personal reflection

Improve

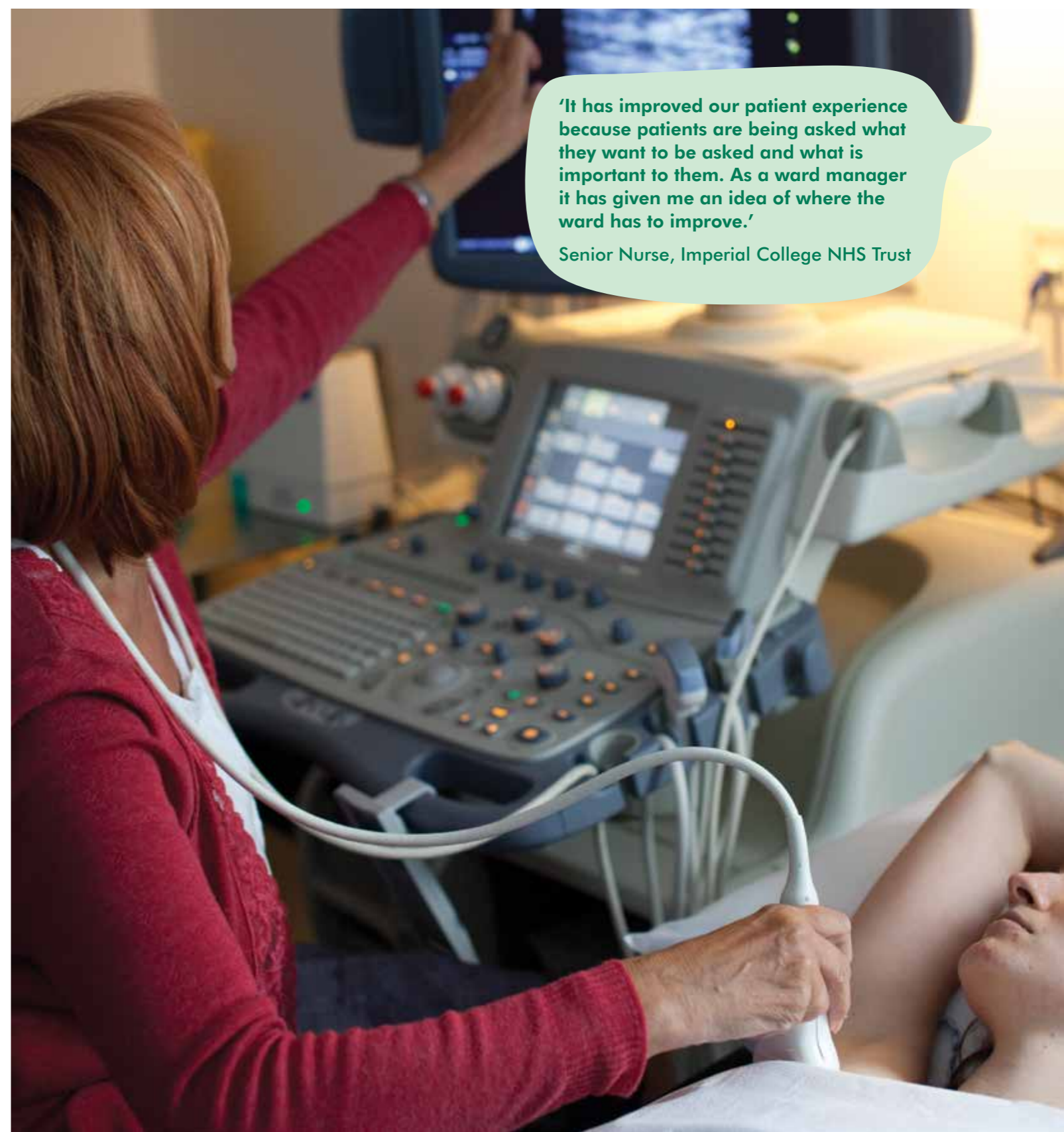
Measure, sustain and spread improvement

- Develop measurement systems that ensure on-going improvement
- Continually involve patients and professionals in understanding 'how we are doing'
- Embed workplace reflection
- Develop a plan for spreading good practice, including corporate processes such as , recruitment, induction and appraisal
- Feedback results – Ward to Board

This stage is all about sustaining the gains you have made and implementing your strategy for spread across the organisation.

- Consider who is best placed to ensure the work continues
- How will this be measured and where will it report to?
- Consider way sin which professionals can remain involved
- How are decisions being made about where to implement the values next
- Ensure your corporate practices are mirroring the values
- What role is leadership playing?
- Celebrate success and make feedback public

As with all change programmes, commitment from senior leaders is vital. This will ensure that you're encouraged to make positive changes and recognised for this work. Senior support is also necessary to ensure the spread of the work throughout the organisation. This should happen through linking this work to other change programmes, as well as other corporate practices such as recruitment and appraisal.



'It has improved our patient experience because patients are being asked what they want to be asked and what is important to them. As a ward manager it has given me an idea of where the ward has to improve.'
Senior Nurse, Imperial College NHS Trust

5. Tools and support

Macmillan Cancer Support is here to guide and support you through your implementation process with a number of methods.

1. Expert guidance

Macmillan Cancer Support has been helping sites implement the Macmillan Values Based Standard since 2012. We're here to provide guidance and support about how to get started, how to get buy-in, and how to overcome obstacles that arise. Implementation will be a programme for you and your site but we don't expect you to go it alone. We will ensure that you get all the support you need as you undergo the process.

2. Collaborative events

We run collaborative events for all sites implementing the Macmillan Values Based Standard. The events bring new and existing organisations together to share best practice and learning in implementing the approach across organisations and regions. It is mandatory that representatives from organisations implementing the Macmillan Values Based Standard attend. This is a great opportunity for people leading the work at the frontline to meet others like themselves at various stages of implementation. For more information please contact your Macmillan Development Manager, or email: Patientexperience@macmillan.org.uk

3. Learnzone.org.uk

We also have an extensive range of online resources for you to look through and use. On Learnzone, you'll find:

- videos about the experience of implementing the Macmillan Values Based Standard
- tips for engaging professionals
- guides to getting started
- case studies to support implementation
- useful tools and resources to support your implementation
- *Your cancer care* leaflet, an information resource for patients and carers
- presentations and visual resources

6. Detailed descriptions of the behaviours

NAMING:

'I AM THE EXPERT ON ME.'

Leadership behaviour

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.

Leaders 'role model' behaviours that emphasise the importance of relationship-building because they want to encourage professionals to develop better relationships with all patients.

Vocational 'nudge' examples

'I want to know who patients really are.'

'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.'

Behavioural standard for improving cancer care

Professionals ensure that patients are asked how they want to be addressed in every new professional/patient interaction and act on this information.

Professionals ensure that this initial introduction supports the gathering of essential information such as language, support requirements, disability issues, and religious and dietary needs.

Patients help professionals understand what is factual and what is presumed and take greater responsibility for the information they provide.

Professionals are open to correcting incorrect patient information.

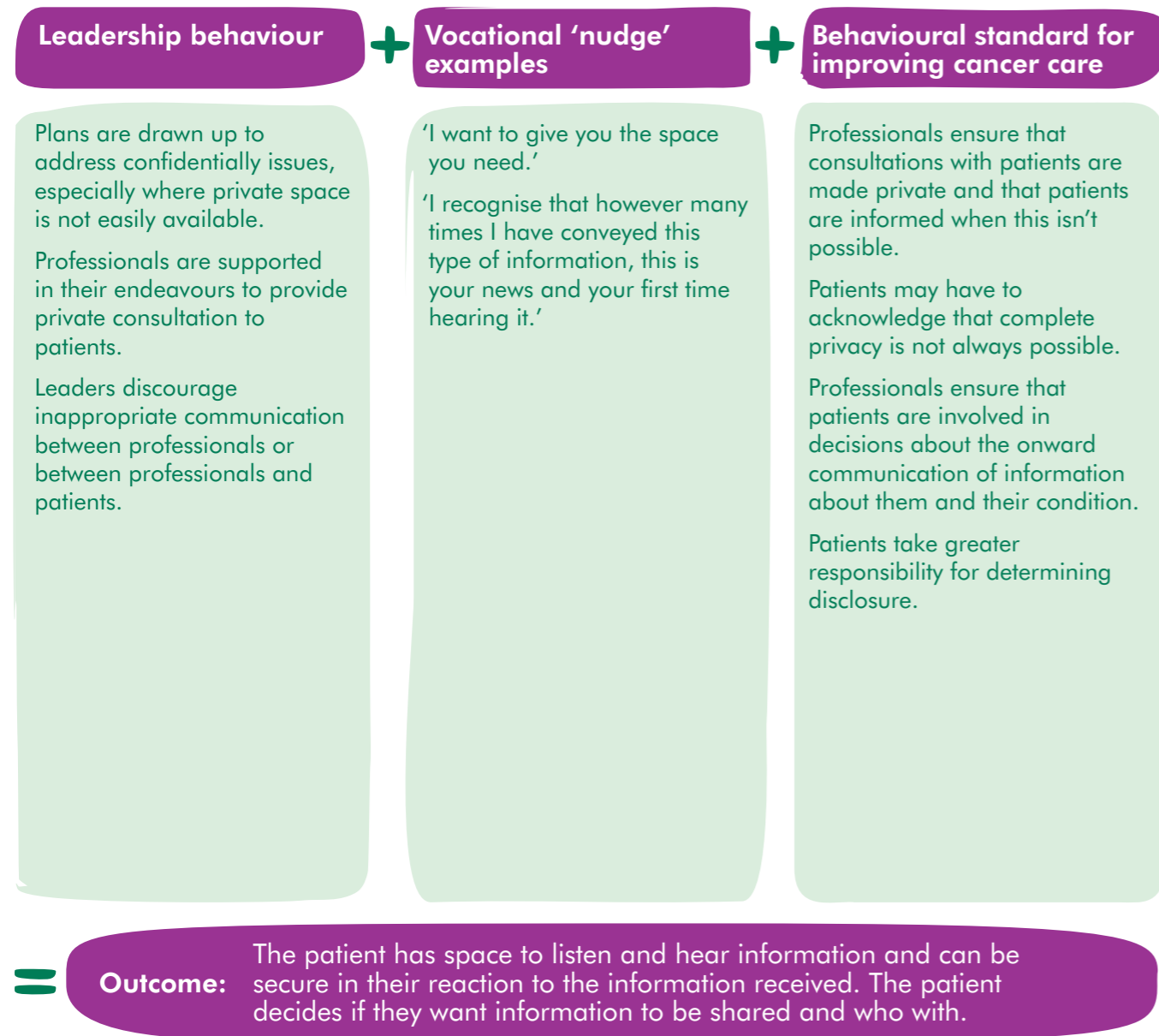


Outcome: Patients can disclose information which will help professionals to understand them and act on their needs.

→ Naming

- Private communication
- Communicating with more sensitivity
- Clinical treatment and decision making
- Acknowledge me if I'm in urgent need of support
- Control over personal space and environment
- Managing on my own
- Getting care right

PRIVATE COMMUNICATION: 'MY BUSINESS IS MY BUSINESS.'

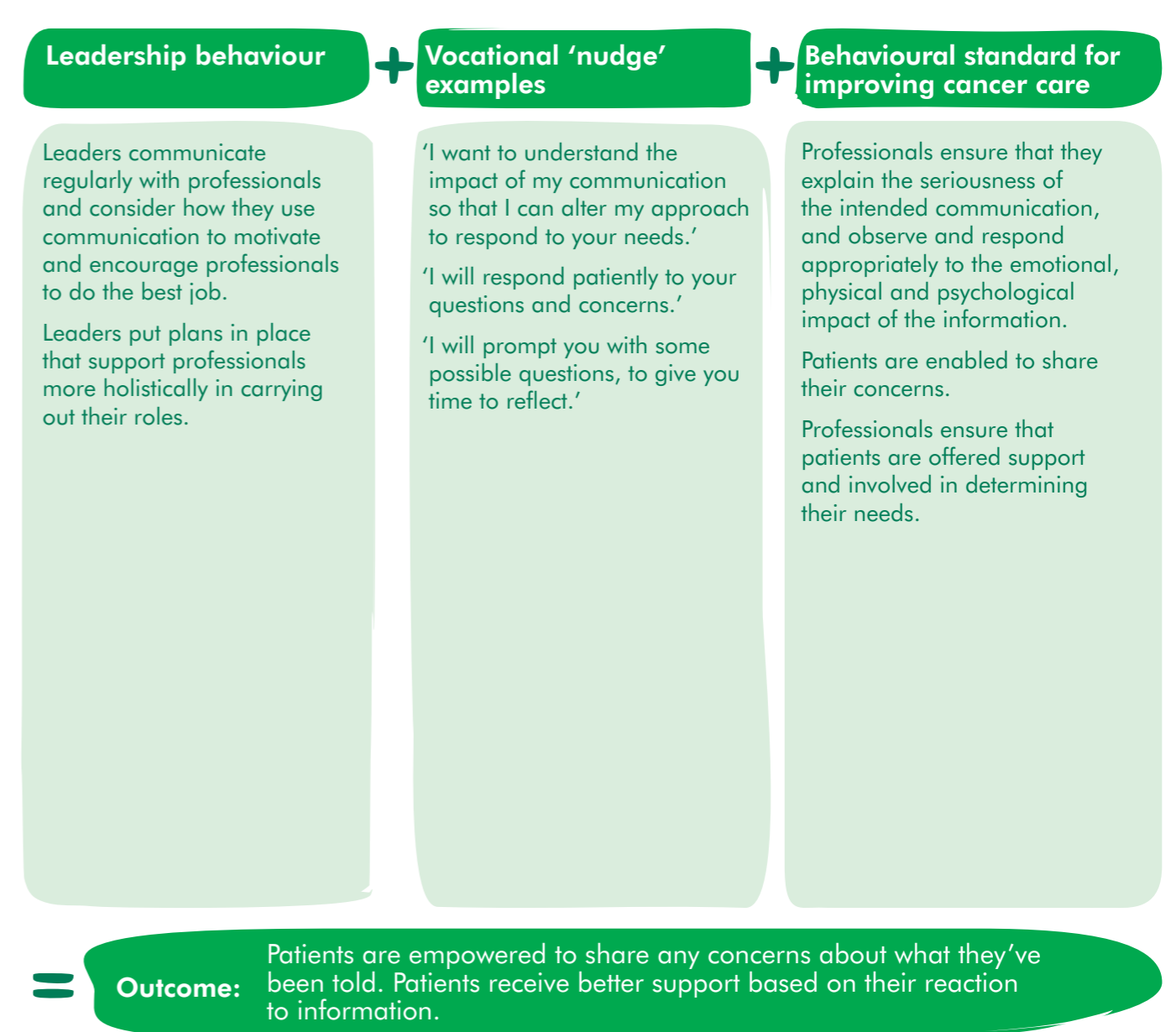


Naming

Private communication ←

- Communicating with more sensitivity
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COMMUNICATING WITH MORE SENSITIVITY: 'I'M MORE THAN MY CONDITION.'



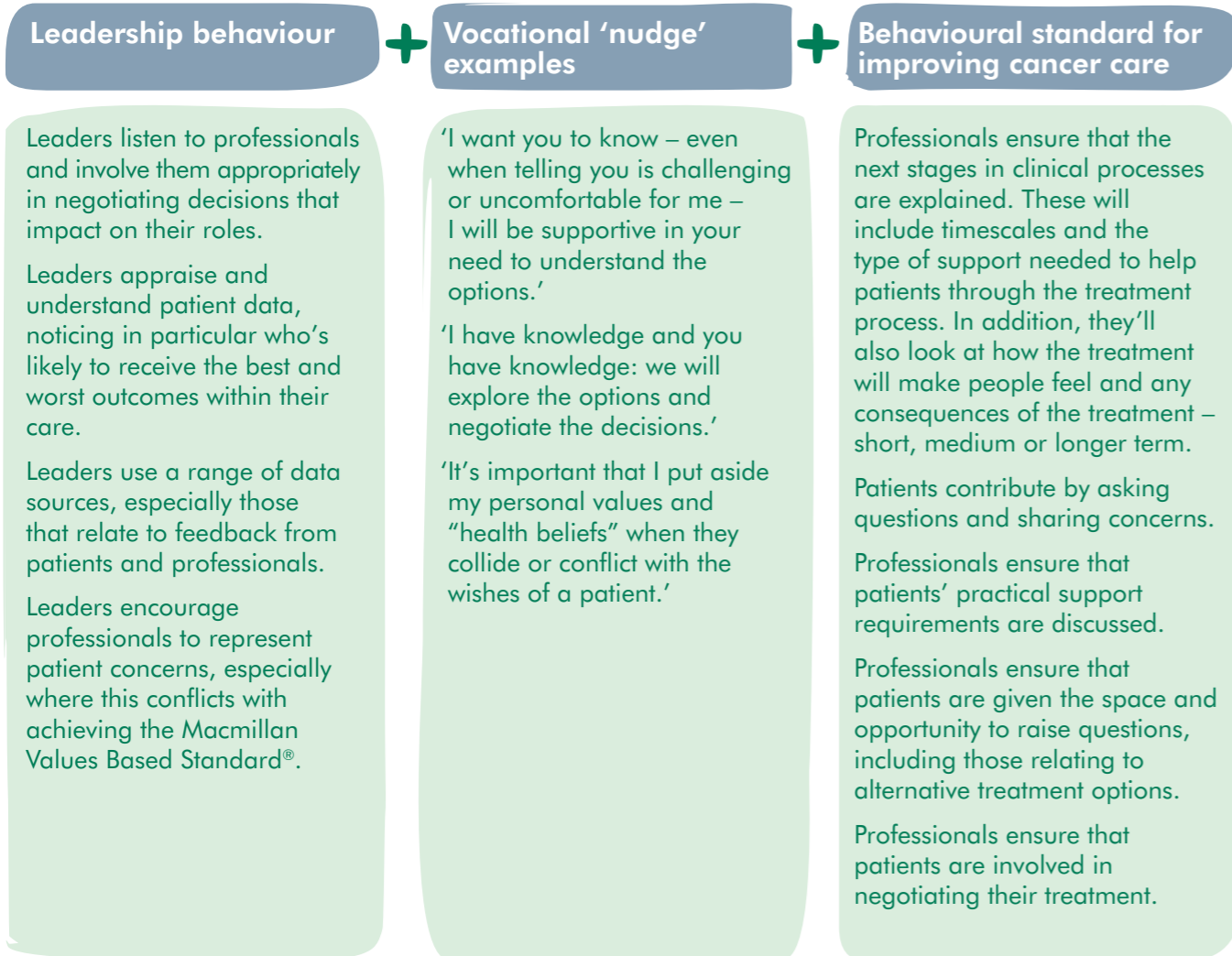
Naming

Private communication

→ Communicating with more sensitivity

- Clinical treatment and decision making
- Acknowledge me if I'm in urgent need of support
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CLINICAL TREATMENT AND DECISION MAKING: ‘I’D LIKE TO UNDERSTAND WHAT WILL HAPPEN TO ME.’



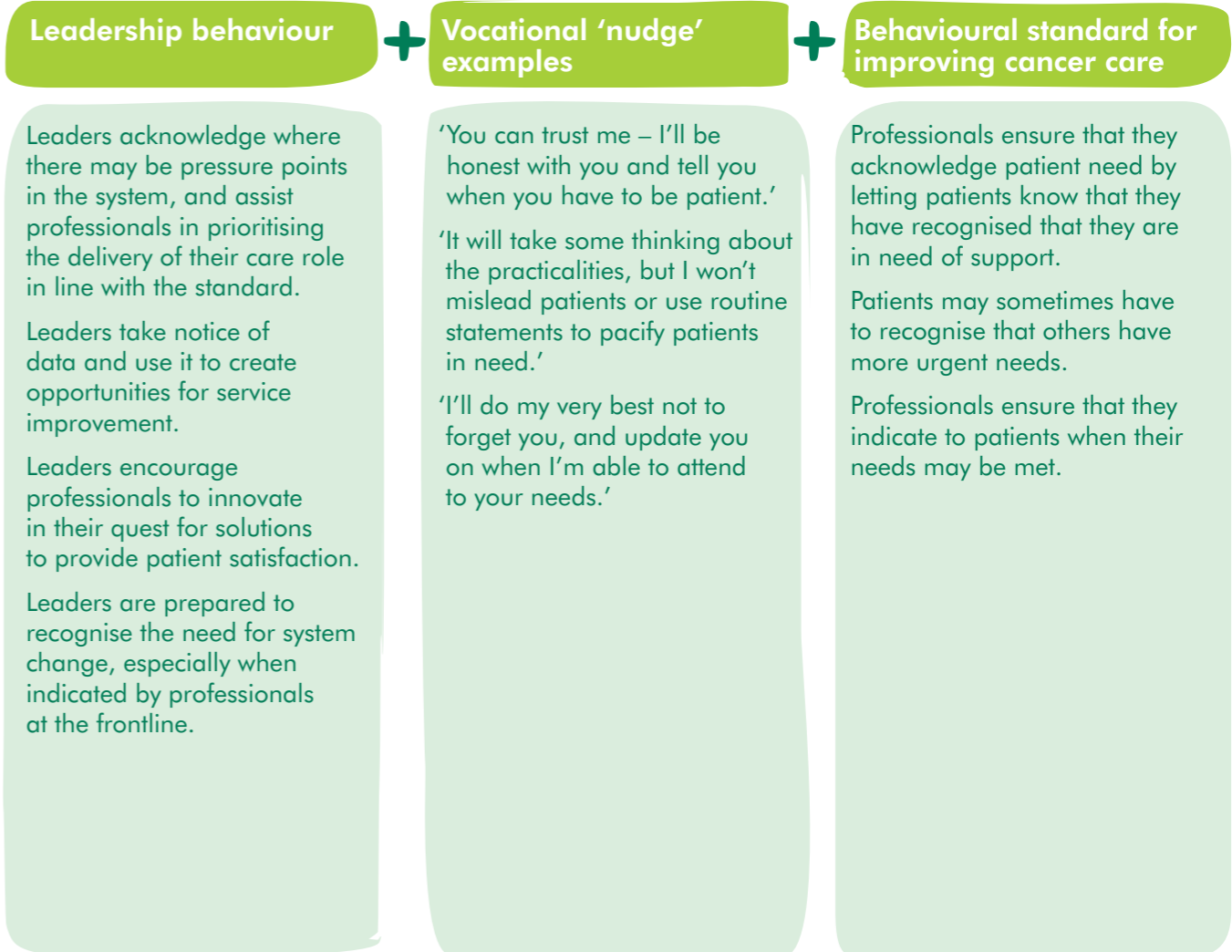
Outcome: Patients understand which options have been considered and why recommendations for a particular course of treatment have been made. They know how to prepare for the treatment and have a better understanding of the associated short, medium and longer-term treatment consequences. Patients feel more engaged in their treatment plan.

Naming
Private communication
Communicating with more sensitivity

Clinical treatment and decision making ←

Acknowledge me if I'm in urgent need of support
Control over personal space and environment
Managing on my own
Getting care right

ACKNOWLEDGE ME IF I'M IN URGENT NEED OF SUPPORT: ‘I’D LIKE NOT TO BE IGNORED.’



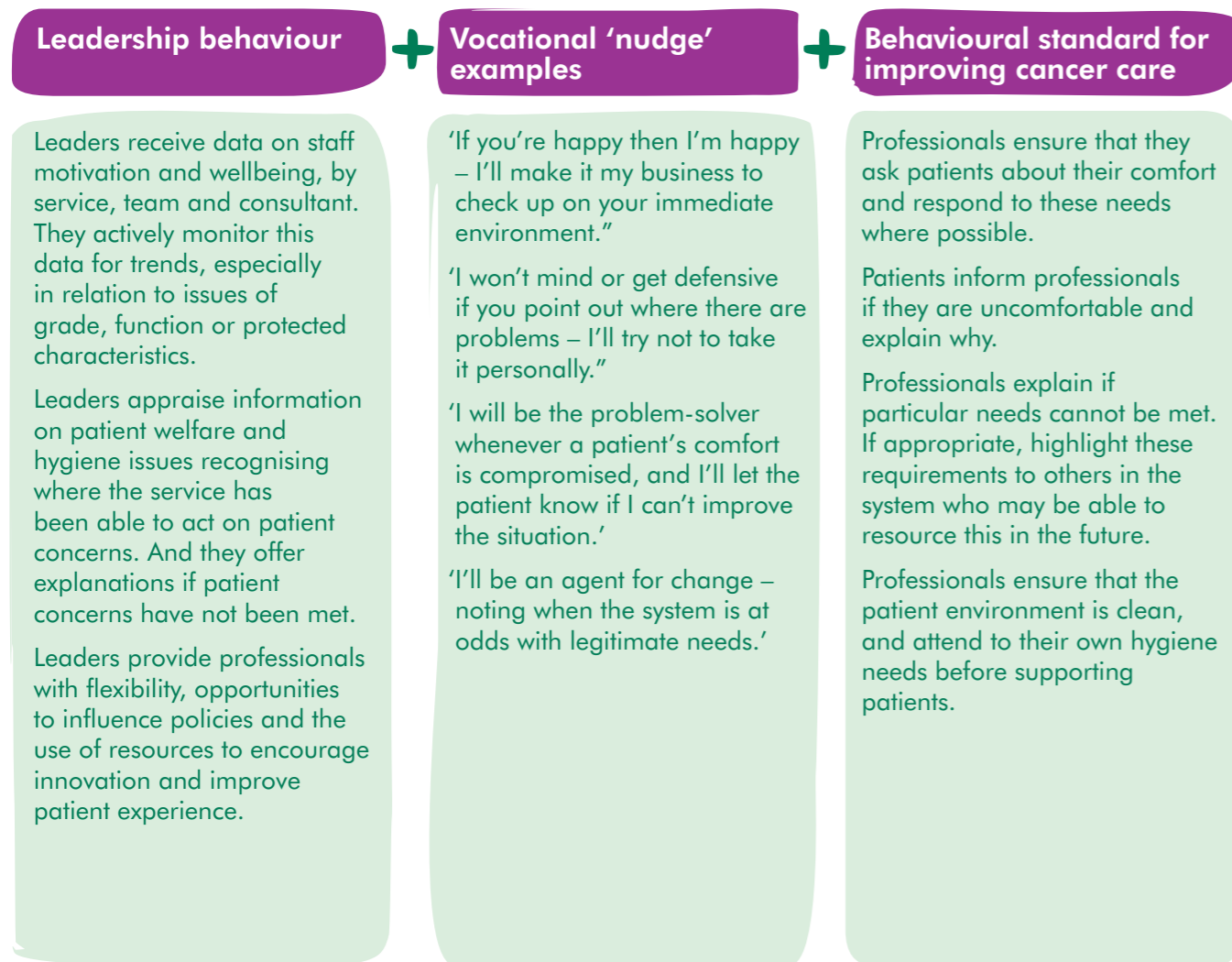
Outcome: Patients' care needs are acknowledged, but they also understand that others may be in more urgent need of care, and that they may have to wait for support from professionals.

Naming
Private communication
Communicating with more sensitivity
Clinical treatment and decision making

→ **Acknowledge me if I'm in urgent need of support**

Control over personal space and environment
Managing on my own
Getting care right

CONTROL OVER PERSONAL SPACE AND ENVIRONMENT: 'I'D LIKE TO FEEL COMFORTABLE.'



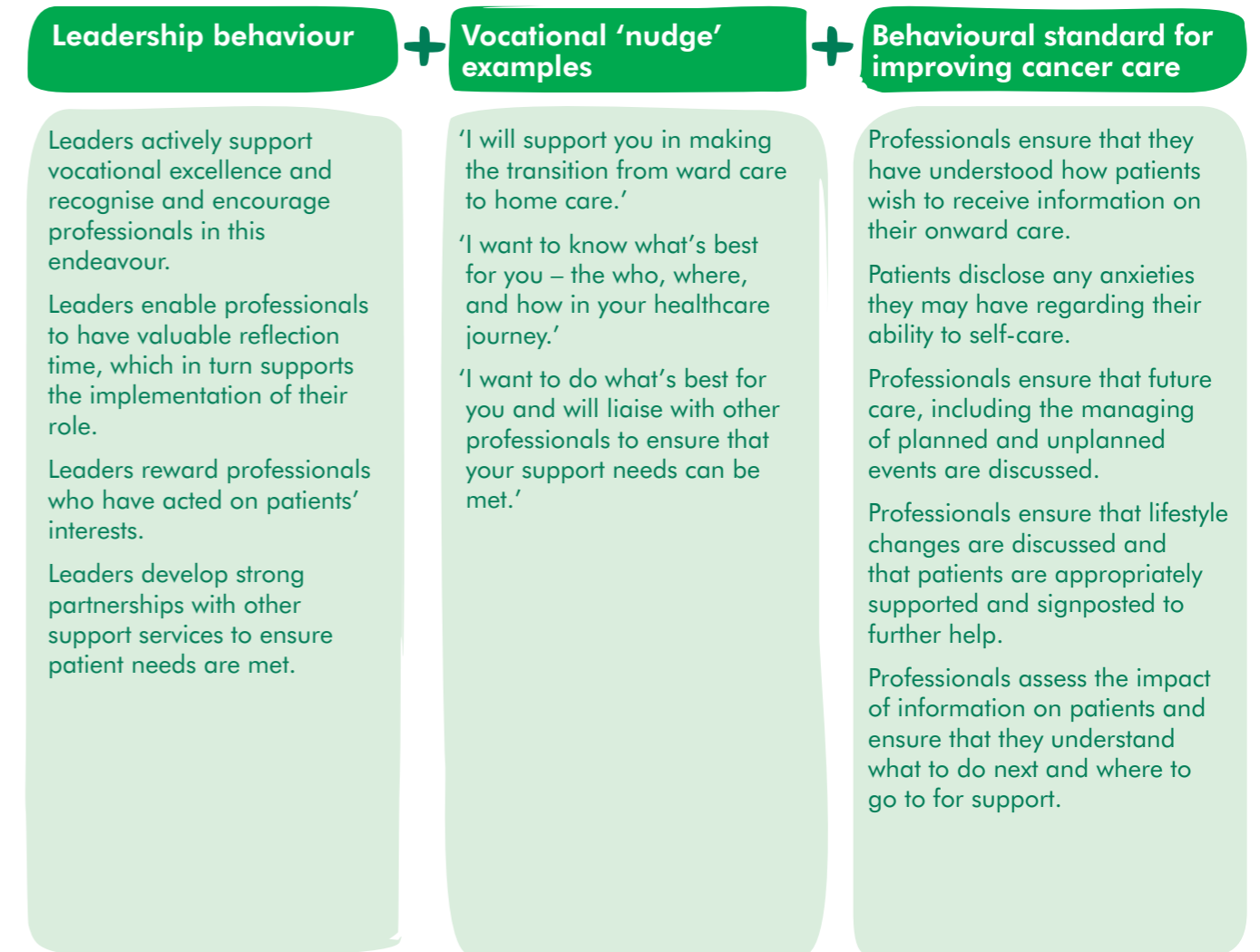
Outcome: Patients are able to express their comfort needs, have these needs met, and be cared for in a clean environment.

Naming
Private communication
Communicating with more sensitivity
Clinical treatment and decision making
Acknowledge me if I'm in urgent need of support

Control over personal space and environment ←

Managing on my own
Getting care right

MANAGING ON MY OWN: 'I DON'T WANT TO FEEL ALONE IN THIS.'



Outcome: 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, while also understanding when and who to refer to should they be in need of support.

Naming
Private communication
Communicating with more sensitivity
Clinical treatment and decision making
Acknowledge me if I'm in urgent need of support
Control over personal space and environment

→ **Managing on my own**

Getting care right

GETTING CARE RIGHT: 'MY CONCERNS CAN BE ACTED UPON.'

Leadership behaviour

Leaders promote and implement 'real time' feedback across their services, and encourage criticism as part of the improvement process.

Leaders recognise that middle managers and professionals can be 'squeezed' within the change process. Therefore, they actively manage decision-making at appropriate levels of the organisation.

Leaders 'role model' the acceptance of criticism and 'walk the floor' to understand more about patients' and professionals' experiences.

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.

Vocational 'nudge' examples

'I want to get it right for you and will ask you what can be done better.'

'I won't take it personally, and will try to get it right for you when you are in my care.'

'I am rewarded by your satisfaction with our care.'

'I will raise concerns about other professionals or systems which I think have worked against your care.'

Behavioural standard for improving cancer care

Professionals actively request feedback from patients on the quality of patient care.

Patients cooperate by providing real-time feedback.

Professionals act upon feedback to ensure that adequate support can be offered in 'real time'.

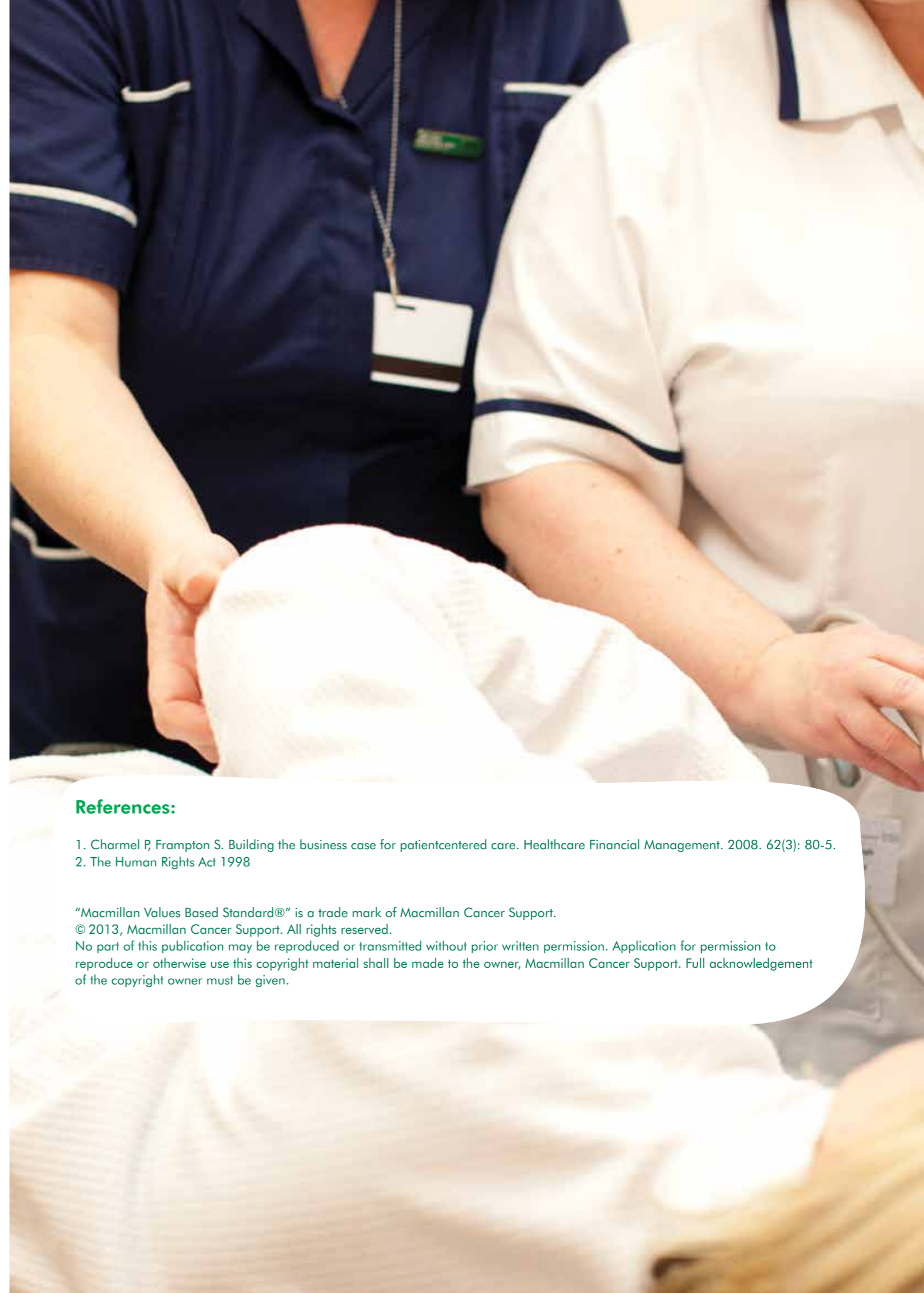
Professionals ensure that they respond positively to patient feedback, especially if it is negative.

Outcome:

Patients feel enabled to make complaints in an environment where complaints are welcome and their experiences of care are enhanced as a result.

Naming
Private communication
Communicating with more sensitivity
Clinical treatment and decision making
Acknowledge me if I'm in urgent need of support
Control over personal space and environment
Managing on my own

Getting care right ←



References:

1. Charmel P, Frampton S. Building the business case for patientcentered care. *Healthcare Financial Management*. 2008. 62(3): 80-5.
2. The Human Rights Act 1998

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