People and Family Experiences

Systems-related learning from our research

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SCOTTISH PARTNERSHIP FOR PALLIATIVE CARE CONFERENCE 2025

If somebody had explained to us, not necessarily what was going to happen, but what was available to us. ***You just felt... into the abyss...***

A caregiver for her husband with advanced lung cancer, Fife, 2015

I don’t know why but when I’m in a room people always ignore me

Photo by Wolfgang Hasselmann on Unsplash

Improving the Quality and Value of Care for People with Poor Prognosis Cancer (I-Qual PPC)

Illuminating the reality of pathways, experiences and outcomes for people with (potentially) poor prognosis cancers and their unpaid caregivers

Subjective realities – lived experiences explored through qualitative studies (Fife and Lothian)

Objective realities – pathway mapping using routine health data for thousands of people in South East Scotland (Cancer Informatics Team) and a prospective study of hospital admissions (Fife)

- Concurrent service developments – both in response to and informing our research work
- A 5 year programme of work funded by The Health Foundation, Fife and Lothian Health Charities

REALISTIC MEDICINE

CHANGE OUR STYLE TO **SHARED DECISION-MAKING?**

BUILD A **PERSONALISED** APPROACH TO CARE?

REDUCE HARM AND WASTE?

REDUCE **UNNECESSARY VARIATION** IN PRACTICE AND OUTCOMES?

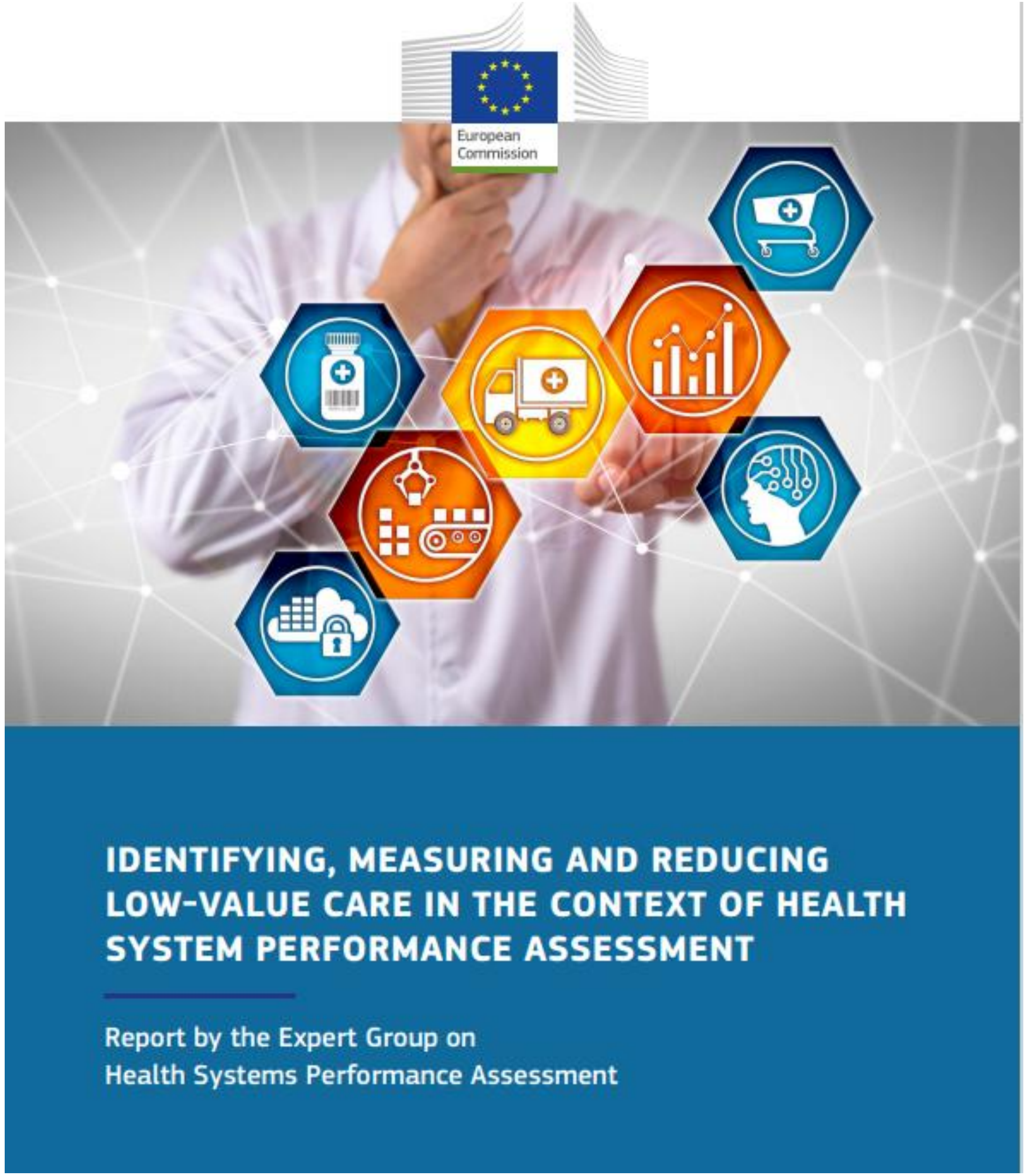
MANAGE RISK BETTER?

BECOME IMPROVERS AND INNOVATORS?

Value as making the best use of resources for individuals and for society

A framework for potentially low-value interventions

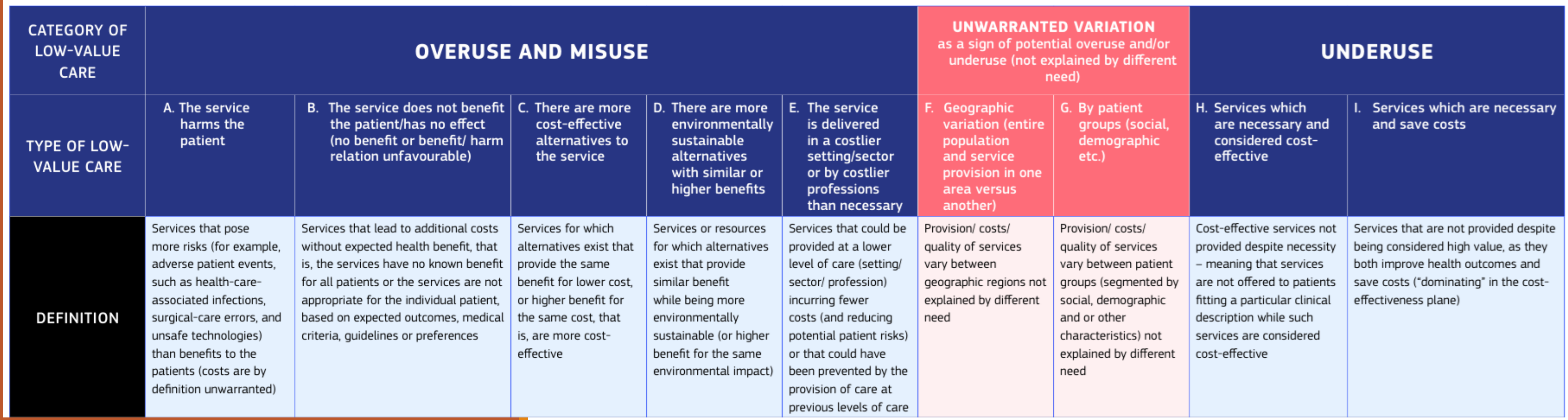
Bringing awareness to the costs that these carry for individuals and for society



European Commission

IDENTIFYING, MEASURING AND REDUCING LOW-VALUE CARE IN THE CONTEXT OF HEALTH SYSTEM PERFORMANCE ASSESSMENT

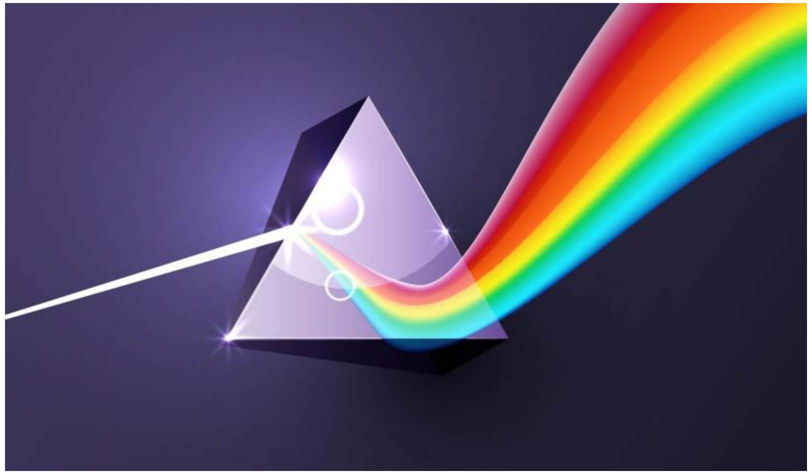
Report by the Expert Group on
Health Systems Performance Assessment



CATEGORY OF LOW-VALUE CARE	OVERUSE AND MISUSE					UNWARRANTED VARIATION as a sign of potential overuse and/or underuse (not explained by different need)		UNDERUSE	
TYPE OF LOW-VALUE CARE	A. The service harms the patient	B. The service does not benefit the patient/has no effect (no benefit or benefit/ harm relation unfavourable)	C. There are more cost-effective alternatives to the service	D. There are more environmentally sustainable alternatives with similar or higher benefits	E. The service is delivered in a costlier setting/sector or by costlier professions than necessary	F. Geographic variation (entire population and service provision in one area versus another)	G. By patient groups (social, demographic etc.)	H. Services which are necessary and considered cost-effective	I. Services which are necessary and save costs
DEFINITION	Services that pose more risks (for example, adverse patient events, such as health-care-associated infections, surgical-care errors, and unsafe technologies) than benefits to the patients (costs are by definition unwarranted)	Services that lead to additional costs without expected health benefit, that is, the services have no known benefit for all patients or the services are not appropriate for the individual patient, based on expected outcomes, medical criteria, guidelines or preferences	Services for which alternatives exist that provide the same benefit for lower cost, or higher benefit for the same cost, that is, are more cost-effective	Services or resources for which alternatives exist that provide similar benefit while being more environmentally sustainable (or higher benefit for the same environmental impact)	Services that could be provided at a lower level of care (setting/ sector/ profession) incurring fewer costs (and reducing potential patient risks) or that could have been prevented by the provision of care at previous levels of care	Provision/ costs/ quality of services vary between geographic regions not explained by different need	Provision/ costs/ quality of services vary between patient groups (segmented by social, demographic and or other characteristics) not explained by different need	Cost-effective services not provided despite necessity – meaning that services are not offered to patients fitting a particular clinical description while such services are considered cost-effective	Services that are not provided despite being considered high value, as they both improve health outcomes and save costs ("dominating" in the cost-effectiveness plane)

What Matters?

Illuminating
Some
Affirmatives



What Matters?

- **Dignity**

Everybody tells you as it is, but in a nice sort of way. They come and sit right close to you, and you feel they actually care… they’re not just telling you something, you feel they care about you.

What Matters?

- Dignity
- **Communication**

The more knowledge that we have the better - arming you with the knowledge of what’s happening now but also what might happen in the future... I think you're far more able to deal with things when they come up.

What Matters?

- Dignity
- Communication
- **Unpaid Caregivers**

If I didn’t have such strong family connections, I would be a bit goosed by now… it would be very terrifying.

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I had to phone my daughter, I said, I'm drowning here, I said, I'm absolutely drowning. I don't know what to do.

What Matters?

- Dignity
- Communication
- Unpaid Caregivers
- **Relational Care**

The continuity was an important thing… it’s speaking to a familiar face, or a familiar voice that knew the issue right from the start and all the way through it.

What Matters?

- Dignity
- Communication
- Unpaid Caregivers
- Relational Care
- **Time**

It was just very time-consuming. It’s just, your world became all about the cancer.

What Matters?

- Dignity
- Communication
- Unpaid Caregivers
- Relational Care
- Time

Moving Our Knowledge Forward

- **People don’t know what they don’t know**

Candidacy Framework (Dixon-Woods et al.)

★ **Recognising need for medical attention**

★ **Knowledge of available services**

★ **Ease of using services**

Turk et al. 2024 (adapted from Dixon-Woods et al. 2006)

If we had known that we had to do this and we had to do that and it was all lined up – but we had to try and get hold of somebody on the phone and then to turn round and say, well she's not been referred to us…well of course she's lying up the stairs like she is….We need help. We don't need somebody telling us she's not been referred to you…we don't need that. We need somebody to come now and help me. ***But we didn't know the procedure because we've never done it****.*

But the fact that you have to use contacts to get what you should be getting is wrong. Because not everybody's got a doctor in the family. ***I've never been in that situation, so you don't know what to ask, because I don't know what services there are available.***

Moving Our Knowledge Forward

- People don’t know what they don’t know

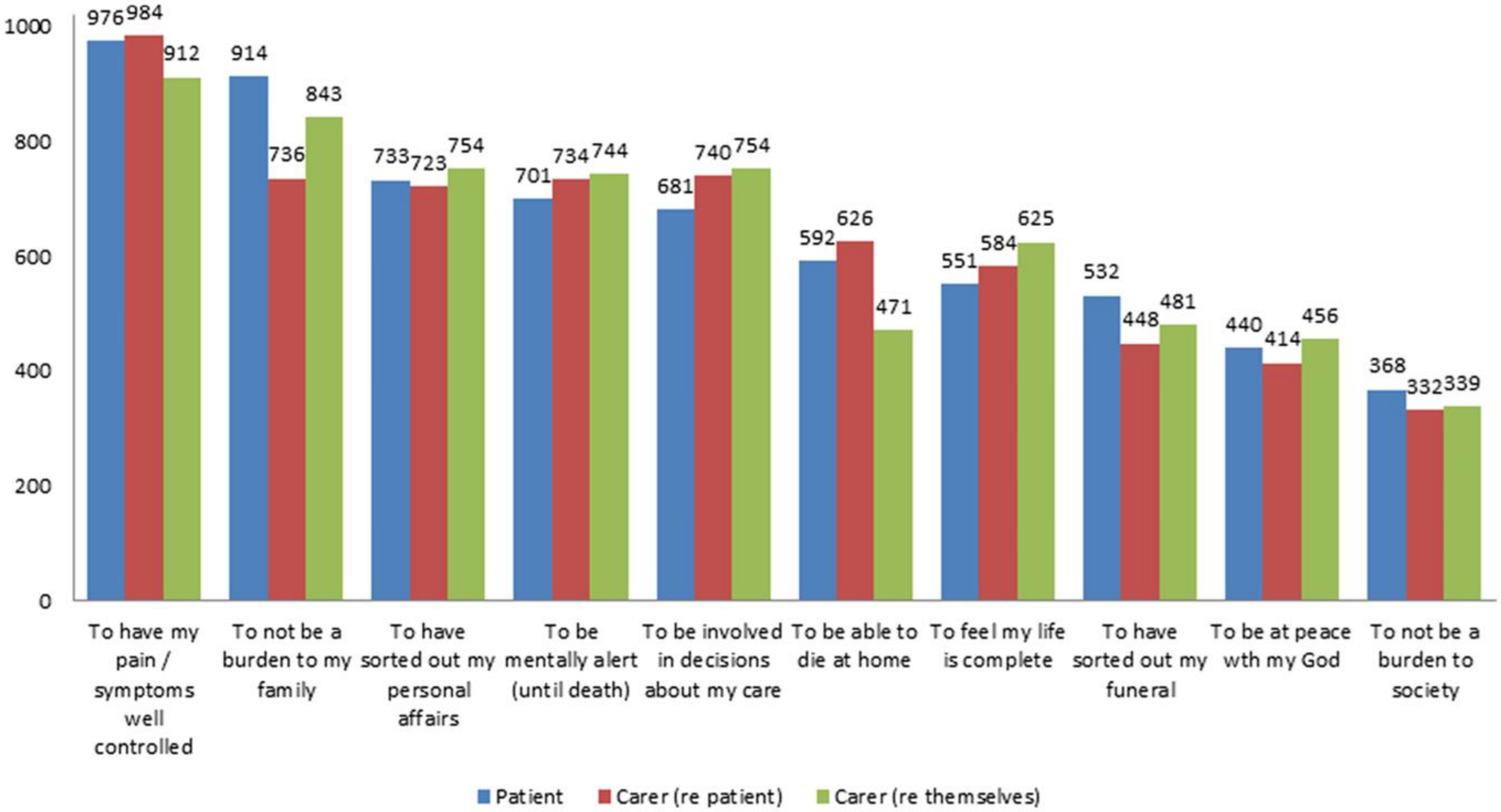
- **It is too simple to conclude that acute hospitalisation equals over-medicalisation**

I know I need the hospital, and you know, it was, it was great to come in. As I said, ***I was relieved****.*

For me, magic*. That’s the only words I can describe it.*

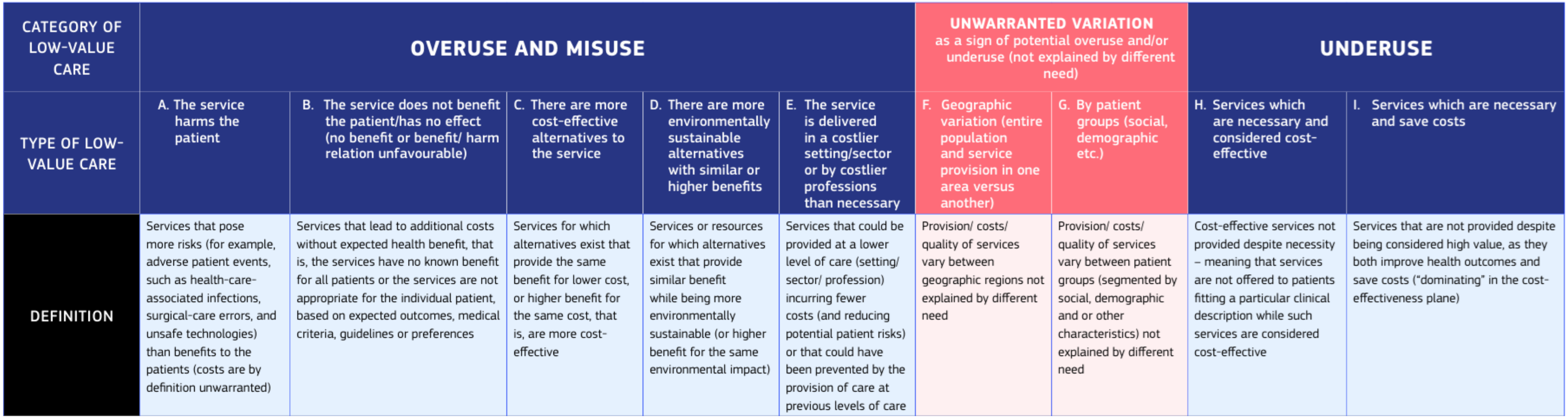
The sooner I felt that something was done about it, the better*, to get back to some kind of normality pain-wise, and just…life.*

Factors Important For a ‘Good Death’



Davies et al. 2019

Types of Low Value Care



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Fife Hospital Study Data (2024) - Unpublished

- **163 patients; 209 admissions**
- 34% admissions via Emergency Department
- 40% admissions due to disease-related factors, care needs or rapid decline at end of life
- 33% of those who died within 1 month had no markers of palliative care needs having been identified or acted upon

Moving Our Knowledge Forward

- People don't know what they don't know

- It is too simple to conclude that acute hospitalisation equals over-medicalisation

- **High value care is not necessarily achieved by high volume care**

She (the Palliative Care nurse) was here for two and a half hours. Which was a long time for him to cope with. ***That was too long. It tired me out.*** *And we also missed a whole meal.*

I don’t really need anything at the minute*. But it’s nice to have somebody in the background that I can go to or speak to when I need it…*

*But **it would be nice, even for thirty seconds, for somebody to phone** and say, you know, 'everything seems to be okay, are you feeling okay, anything else you need?'*

Moving Our Knowledge Forward

- People don’t know what they don’t know

- It is too simple to conclude that acute hospitalisation equals over-medicalisation

- High value care is not necessarily achieved by high volume care

- **Distress is inevitable but can be compounded by being made to feel invisible**

You normally have to phone up the doctor or send an email. It’s called Patient Access. And I’m not putting down about terminal cancer on a…on a phone call or an email.

I printed a big note. I didn’t want to shout out. ***I printed a big note, said I’ve got stage four cancer and a couple of months to live, that’s what I’ve been told, could I see the doctor.***

One nurse actually came along, eh, and said, er, ***you shouldn’t be lying on the floor [laughs] there’s germs, it’s not good for you****. And I was, like, ‘yeah, but he can’t stand or walk and you don’t have a bed for him’ [laughs]. I was just, like, what [laughs]…does he think he just chooses to lie on the floor?*

One nurse actually came along, eh, and said, er, you shouldn't be lying on the floor [laughs] there's germs, it's not good for you. And I was, like, 'yeah, but he can't stand or walk and you don't have a bed for him' [laughs]. I was just, like, what [laughs]…does he think he just chooses to lie on the floor?

She says, 'I haven't, I physically haven't got a bed for you so ***there's nothing I can do. I brought the discharge forms. Do you want to just discharge yourself?****' And I says, 'well we haven't actually checked in yet'. I said, erm, I says, 'well can we go home and will you give us a phone when the bed's ready so we can come back?'. 'No'. I says, 'well will he still get his MRI?' 'No'.*

She said, ‘I’ll just get it delivered to you, you know, you don’t need to come round and get it.’ Because, because I, I am, erm, quite agoraphobic. Walking along the street is not my…erm, favourite occupation, you know. So, she can understand that, too. Which made me feel a bit better. I mean, it’s nothing, I should just ignore it completely, ***but it’s…actually, for somebody just to see that, see you****’.*

Moving Our Knowledge Forward

- **People don’t know what they don’t know**
- **It is too simple to conclude that acute hospitalisation equals over-medicalisation**
- **High value care is not necessarily achieved by high volume care**
- **Distress is inevitable but can be compounded by being made to feel invisible**

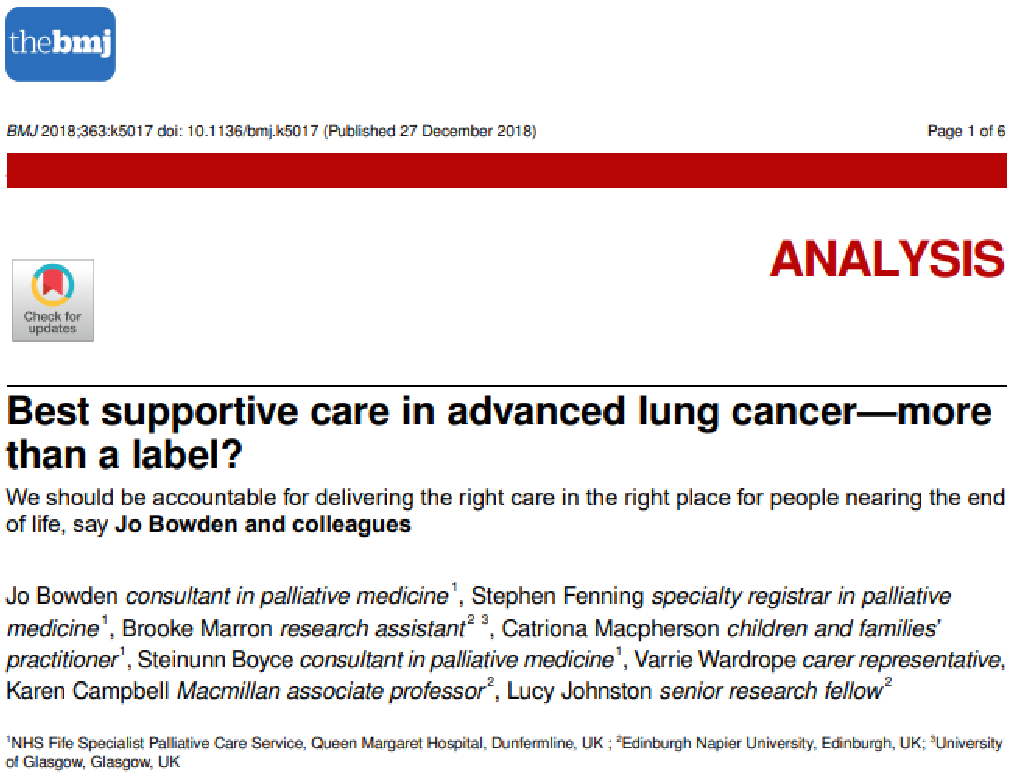
Unfortunate givens

1. There is no single palliative care system

2. Unwarranted variation is everywhere

3. There is no money

A systematic approach to individualised care



BMJ 2018;363:k5017 doi: 10.1136/bmj.k5017 (Published 27 December 2018) Page 1 of 6

ANALYSIS

Best supportive care in advanced lung cancer—more than a label?

We should be accountable for delivering the right care in the right place for people nearing the end of life, say **Jo Bowden and colleagues**

Jo Bowden *consultant in palliative medicine*[1], Stephen Fenning *specialty registrar in palliative medicine*[1], Brooke Marron *research assistant*[2,3], Catriona Macpherson *children and families' practitioner*[1], Steinunn Boyce *consultant in palliative medicine*[1], Varrie Wardrope *carer representative*, Karen Campbell *Macmillan associate professor*[2], Lucy Johnston *senior research fellow*[2]

[1]NHS Fife Specialist Palliative Care Service, Queen Margaret Hospital, Dunfermline, UK ; [2]Edinburgh Napier University, Edinburgh, UK; [3]University of Glasgow, Glasgow, UK

- Reliable identification
- Assessment and honest conversations
- Care coordination and follow-up

Levelling up around knowledge

It's normal to struggle... and for it to feel like too much. If that happens...

Many people find it helpful to...

But it's not always available...

A useful back-up can be...

We'd expect with time...

You'll probably notice...

If this happens...

A values-based approach

- going deeper than preferences and a plan

Questions from Atul Gawande's Being Mortal (2015)

What is your understanding of where you are and of your illness?

Your fears or worries for the future

Your goals and priorities

What outcomes are unacceptable to you?

What are you willing to sacrifice and not?

Are we too fixated on ticking 'Care Plan' boxes at the expense of good conversations that evolve with time?

Re-imagining care coordination

- A single point of palliative care coordination
- A net that reaches over and into all systems and teams (health, social care, third sector)
- A highly permeable net, available to all who need it, 24/7
- With no requirement for people who are struggling to know *what* they need, *how* to access it *or* to navigate themselves in

Improving the quality and value of care?

Facilitating more of the care that people need (correcting underuse of valuable interventions)

Ensuring that care is delivered where it needs to be and that it make most efficient use of society's limited resources (reducing overuse/misuse of low value interventions)

Ensuring that each person is able to access what they need, when they need it (reducing unwarranted variation)

Acknowledgements

- Qualitative research participants: 40 people with advanced cancer living in South East Scotland and many of their unpaid caregivers
- Study steering group members including:
  - Lived experience patient and family caregiver representatives: Peter Buckle, Susie Smith, Pam Mackay
  - Research leadership team: Professor Marie Fallon, Professor Peter Hall, Dr Debbie Cavers, Dr Karen Allum, Dr Piyumanga Karunaratne, Dr Giovanni Tramonti, Dr Maheva Vallet
- Funders: The Health Foundation, Fife Health Charity, Lothian Health Charity
- Governance: Cancer Informatics Team NHS Lothian, NHS Fife sponsorship for qualitative studies, NHS Research Ethics Approval

Questions to leave you with

- What can I do to reduce the variation in what people know/understand about what services can offer?
- How can I place a greater emphasis on a person’s values – in the discussions I have and in my approach to their care?
- How can I redirect my limited resources (time, energy, visibility, money) towards what we know adds most value?