‘From populations to people’ – the dilemma of NICE guidance

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What is NICE's job?

- NICE uses the best available evidence to recommend clinically and cost-effective care for people using the healthcare system in England (and Wales when wanted)
- Also support the idea that the care and treatment people are offered should reflect their individual preferences and values
- Inherent tension between
  - population-level recommendations within guidelines and
  - person-centred approach to decision-making for individuals

Two different paradigms?

- NICE has explored how to reconcile these two concepts and enable people to make informed decisions about their care.

- We aim to help people make decisions that:
  - reflect their values
  - reflect their preferences, and the
  - address the outcomes that matter to them

BUT

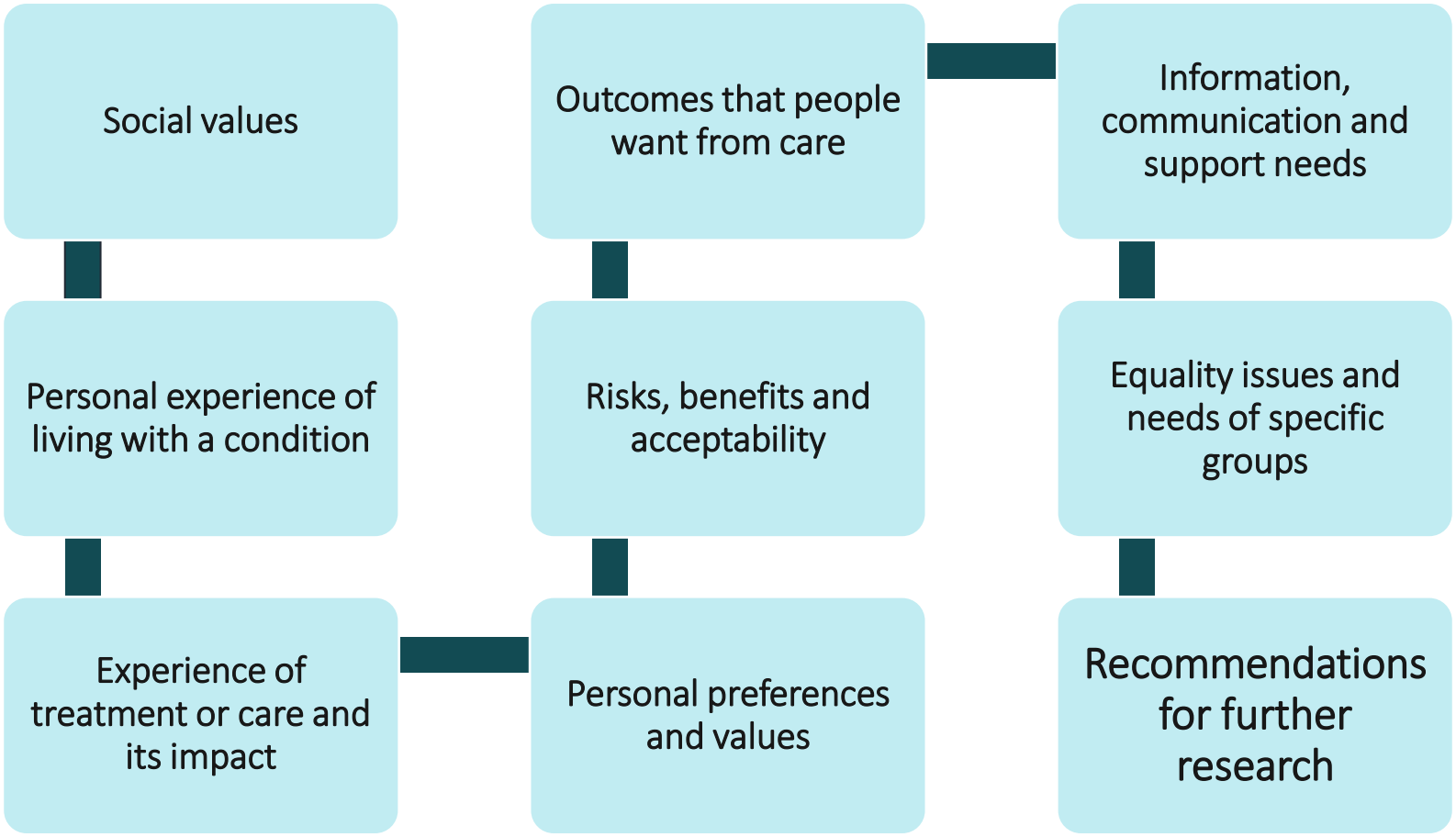
- from a range of clinical and cost-effective options.

Involvement as core business

'The expertise, insight and input of these lay members is essential to the development of all NICE guidance and advice, and helps us to make sure that our work reflects the needs and priorities of those who will be affected by them.'

NICE Charter

What do we get from patients and the public?



What our guidance is like - diabetes

VibraTip for testing vibration perception to detect diabetic peripheral neuropathy

Medical technologies guidance [MTG22] Published date: December 2014 Last updated: March 2015

Do not do

Do not do information

FreeStyle Libre for glucose monitoring

Medtech innovation briefing [MIB110] Published date: July 2017

nagliflozin, dapagliflozin and empagliflozin as notherapies for treating type 2 diabetes

ogy appraisal guidance [TA390] Published date: 25 May 2016

Diabetes

The proportion of adults with a diagnosis of diabetes who have a recording of MI, stroke and/or end stage kidney disease

View indicator details NICE id code: CCG12 CCG

The proportion of adults with diabetes who have received all nine basic care processes.

View indicator details NICE id code: CCG13 CCG

List

Statement 2 Adults with type 2 diabetes are offered a structured education programme at diagnosis. **[2011, updated 2016]**

Statement 3 Adults with type 1 diabetes are offered a structured education programme 6–12 months after diagnosis. **[2011, updated 2016]**

Statement 4 Adults with type 2 diabetes whose HbA1c level is 58 mmol/mol (7.5%) or above after 6 months with single-drug treatment are offered dual therapy. **[new 2016]**

Statement 5 Adults at moderate or high risk of developing a diabetic foot problem are referred to the foot protection service. **[2011, updated 2016]**

Statement 6 Adults with a limb-threatening or life-threatening diabetic foot problem are re for specialist assessment and treatment. **[2011, updated 2016]**

Statement 7 Adults with type 1 diabetes in hospital receive advice from a multidisciplinary t diabetes. **[2011, updated 2016]**

Your target blood glucose (HbA1c) level: weighing it up

Make a mark on the lines to show how you feel about these statements. The more you agree with the statement on the left, the further to the left you should put the mark. The more you agree with the statement on the right, the further to the right you should put the mark. You and your healthcare professional can use this to help decide the best target HbA1c level for you.

Thinking about things like driving, having severe hypos would not be a problem for me* — Thinking about things like driving, having severe hypos would be a big problem for me*

I'm not bothered about the possibility of getting other side effects — Getting other side effects would be a big problem for me

I'm happy to take more medicines if I need to — I don't want to take any more medicines

I don't have any health problems apart from my diabetes — I have lots of health problems

Thinking about my age and health overall, I'm hoping to — longer-term benefits — more important to me

Favours a lower tar — et HbA1c level

Physical activity

Improve levels of physical activity and increase positive health and non-health benefits.

Key interventions:

- counselling and advice
- activity programmes
- community and environmental
- workplace.

Find out more

Community engagement: improving health and wellbeing and reducing health inequalities

es: prevention in people at high risk

Published date: July 2012 Uptake of this guidance

ent

Uptake

Public Health England

NICE National Institute for Health and Care Excellence

A Guide to Delivering and

Algorithm for blood glucose lowering therapy in adults with type 2 diabetes

TYPE-2 DIABETES WEBKIT

This page brings together all the PrescQIPP diabetes resources and showcase good practice examples of focusing on medicines optimisation in diabetes. Each set of resources contains tools that can be for local use before implementation.

menting QIPP Projects in Diabetes SWOT Analysis

tes Webkit Webinar

ising Medicines for Adults with Type 2 Diabetes E-learning Course

Preventing excess weight gain

NICE guideline [NG7] Published date: March 2015 Uptake of this guidance

es mellitus: medicines optimisation priorities

Published date: January 2015 Last updated: January 2017

Local Government Association

Royal College of Physicians

NICE National Institute for Health and Care Excellence

What is shared decision making?

"[shared decision making] is a

collaborative process that allows patients and their providers to make health care **decisions together**, taking into account the best scientific **evidence** available, as well as the **patient's values and preferences" ***

*Angela Coulter and Alf Collins, The King's Fund, 2011

Patient decision aids

Stacey D, Legare F, Lewis K, et al (2017) Cochrane database CD001431

- 105 studies involving 31,043 participants
- Decision aids increased
  - Participants' knowledge
  - Accuracy of risk perceptions
  - Congruency between informed values and care choices
- Decision aids decreased
  - Decisional conflict related to feeling uninformed
  - Indecision about personal values
  - The proportion of people who were passive in decision-making

The SDM Collaborative

- In 2015 NICE brought together experts in shared decision making.
- The Shared Decision-Making Collaborative, includes people who use healthcare services, academics, policy makers, practitioners, and professional and patient organisations.
- Over 3 meetings the Collaborative has developed a consensus statement and an action plan across 7 domains with specific short-term intentions and long-term ambitions to support the uptake of shared decision making in practice.
- In the summer of 2017, at a 4th meeting, further actions were identified for measurable improvement, particularly in musculoskeletal health, to make shared decision-making a standard expectation for people using healthcare services.

7 domains to support shared decision-making

- Leadership and culture change
- Local leadership
- Education and training
- Shared decision making tools
- Guidance development and evidence reviews
- Measurements of successful shared decision-making
- Research

NICE's response

- NICE has responded to the Collaborative's work by:
  - enhancing and building on our existing collection of decision support tools
  - setting up a committee to develop a clinical guideline on best practice in shared decision-making
  - proposing an approach for quality-assuring decision support tools
  - advocating for funding for shared decision-making research
  - considering how to record shared decision-making in clinical encounters

Your care (NICE website)

Making decisions about your care - Involving you

It is your right to be involved in making choices about your care. People often find they are happier with their care, and more likely to stick with any treatments or care plans, when they make decisions jointly with their health or care professional. To make a decision, you need to know what your options are and what might happen if you don't want any treatment or care. Your health or care professionals should explain what might work for you – some options may not be suitable.

You need to have information about the pros and cons of the options. This must be easy for you to understand. Your health and care professionals need to know what matters to you – no two people are the same and they should listen carefully to your views and concerns.

You and your health or care professionals need time to talk through what you want to get out of any treatments or care and any worries or questions you have.

Your responsibility – all NICE guidance

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service.

It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Developing support for shared decision making

- Commitment from Board and SMT for NICE to support the shared decision-making agenda – Centre for Guidelines Board report in Jan 2017
- Produce recommendations that supports people to make decisions rather than just informs them about their care

Supporting shared decision-making in NICE guidelines

- Updated our guidelines process and methods manuals, to better support shared decision making through evidence.
- Asking guideline developers to:
  - identify decision points - those where patients' values and preferences are likely to be the primary determinant of choice of treatment
  - publish a summary table of harms and benefits in the guideline to aid discussions about choice of treatments (clinician facing)
  - develop additional tools to support shared decision making (patient facing)
- NICE patient decision aids
- Guideline and quality standard on shared decision making to be developed

NICE patient decision aids

Patient decision aids

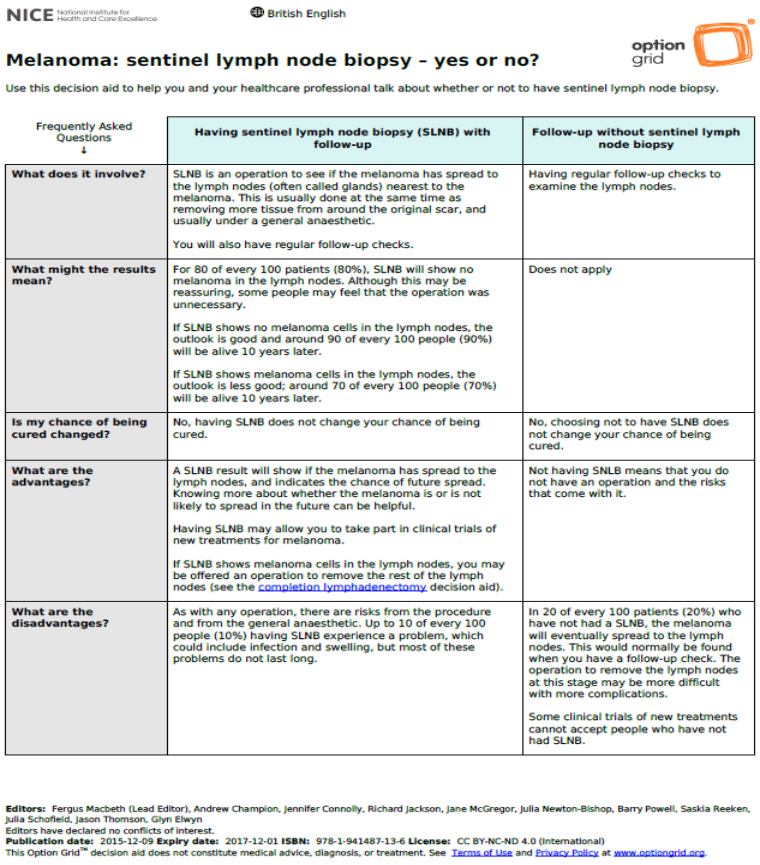
- Bisphosphonates for treating osteoporosis
- Atrial fibrillation: medicines to help reduce your risk of a stroke – what are the options?
- Taking a statin to reduce the risk of coronary heart disease and stroke.
- Type 2 diabetes in adults: controlling your blood glucose by taking a second medicine – what are your options?
- Taking a medicine to reduce the chance of developing breast cancer: postmenopausal women at high risk.
- Taking a medicine to reduce the chance of developing breast cancer: postmenopausal women at moderately increased risk.
- Taking tamoxifen to reduce the chance of developing breast cancer: premenopausal women at high risk.
- Taking tamoxifen to reduce the chance of developing breast cancer: premenopausal women at moderately increased risk.
- Hormone treatment for endometriosis symptoms – what are my options?

Brief decision aids (developed with OptionGrid)

- Treatment of long-term heart burn
- Melanoma: sentinel lymph node biopsy – yes or no?
- Melanoma: completion lymphadenectomy – yes or no?
- Melanoma: follow-up with regular CT scans – yes or no?

An example - melanoma

Possible advantages of sentinel lymph node biopsy	Possible disadvantages of sentinel lymph node biopsy
The operation helps to find out whether the cancer has spread to the lymph nodes. It is better than ultrasound scans at finding very small cancers in the lymph nodes.	The purpose of the operation is not to cure the cancer. There is no good evidence that people who have the operation live longer than people who do not have it.
The operation can help predict what might happen in the future. For example, in people with a primary melanoma that is between 1 and 4 mm thick: •around 1 out of 10 die within 10 years if the sentinel lymph node biopsy is negative •around 3 out of 10 die within 10 years if the sentinel lymph node biopsy is positive.	The result needs to be interpreted with caution. Of every 100 people who have a negative sentinel lymph node biopsy, around 3 will subsequently develop a recurrence in the same group of lymph nodes.
People who have had the operation may be able to take part in clinical trials of new treatments for melanoma. These trials often cannot accept people who haven't had this operation.	A general anaesthetic is needed for the operation.
	The operation results in complications in between 4 and 10 out of every 100 people who have it.



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British English

option grid

Melanoma: sentinel lymph node biopsy – yes or no?

Use this decision aid to help you and your healthcare professional talk about whether or not to have sentinel lymph node biopsy.

Frequently Asked Questions ↓	Having sentinel lymph node biopsy (SLNB) with follow-up	Follow-up without sentinel lymph node biopsy
What does it involve?	SLNB is an operation to see if the melanoma has spread to the lymph nodes (often called glands) nearest to the melanoma. This is usually done at the same time as removing more tissue from around the original scar, and usually under a general anaesthetic. You will also have regular follow-up checks.	Having regular follow-up checks to examine the lymph nodes.
What might the results mean?	For 80 of every 100 patients (80%), SLNB will show no melanoma in the lymph nodes. Although this may be reassuring, some people may feel that the operation was unnecessary. If SLNB shows no melanoma cells in the lymph nodes, the outlook is good and around 90 of every 100 people (90%) will be alive 10 years later. If SLNB shows melanoma cells in the lymph nodes, the outlook is less good; around 70 of every 100 people (70%) will be alive 10 years later.	Does not apply
Is my chance of being cured changed?	No, having SLNB does not change your chance of being cured.	No, choosing not to have SLNB does not change your chance of being cured.
What are the advantages?	A SLNB result will show if the melanoma has spread to the lymph nodes, and indicates the chance of future spread. Knowing more about whether the melanoma is or is not likely to spread in the future can be helpful. Having SLNB may allow you to take part in clinical trials of new treatments for melanoma. If SLNB shows melanoma cells in the lymph nodes, you may be offered an operation to remove the rest of the lymph nodes (see the completion lymphadenectomy decision aid).	Not having SNLB means that you do not have an operation and the risks that come with it.
What are the disadvantages?	As with any operation, there are risks from the procedure and from the general anaesthetic. Up to 10 of every 100 people (10%) having SLNB experience a problem, which could include infection and swelling, but most of these problems do not last long.	In 20 of every 100 patients (20%) who have not had a SLNB, the melanoma will eventually spread to the lymph nodes. This would normally be found when you have a follow-up check. The operation to remove the lymph nodes at this stage may be more difficult with more complications. Some clinical trials of new treatments cannot accept people who have not had SLNB.

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Future guideline developments

Exploring the use of structured content in authoring our guidelines, including working with the MAGIC team (http://magicproject.org) to consider how tools might support the surfacing of evidence to support shared decision-making.

Conclusions

- Collaboration promotes high-quality shared decision making, supporting the wider cultural change needed to make it a part of routine healthcare, and identifying practical actions to help make these changes.
- Led by NICE, the SDM Collaborative demonstrates the need for a collective approach to establishing shared decision making as the norm for healthcare.
- NICE has enhanced its own role in promoting evidence-based good practice, while embedding the principles of shared decision-making, to ensure that people receive care that meets their individual needs, values and preferences.

Links

- NICE. Shared Decision Making Collaborative Consensus Statement (2015) https://www.nice.org.uk/Media/Default/About/what-we-do/SDM-consensus-statement.pdf
- NICE. Shared Decision Making Collaborative Action Plan (2016) https://www.nice.org.uk/Media/Default/About/what-we-do/shared-decision-making-collaborative-action-plan.pdf
- NICE. Developing NICE guidelines: the manual (2014). https://www.nice.org.uk/process/pmg20/chapter/introduction-and-overview
- NICE. Shared decision making. https://www.nice.org.uk/SDM

Thank you - questions?