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PHB Training Course Part 3:
Shared Decision Making

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Learning Objectives

- What is Personalised Care
- System Drivers: Legislation and Policy
- Health Literacy
- Defining Shared Decision Making (SDM)
- Why is Shared Decision Making Important
- SDM in Practice – Goal-setting, preference elicitation and shared decision making
- Resources

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What does Shared Decision Making mean to you?

Defining Shared Decision Making

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Shared Decision Making (SDM) ensures that individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a person to reach a decision about their treatment.

The conversation brings together:

- The clinician's expertise, such as treatment options, evidence, risks and benefits.
- What the person knows best: their preferences, personal circumstances, goals, values and beliefs.

Shared decision making is a key component of universal personalised care.

NHSE – Personalised Care and Shared Decision Making

Shared Decision Making is where individuals and clinicians work together to understand and decide what tests, treatments, management or support packages are most suitable bearing in mind the persons individual circumstances. It brings together the individuals' expertise about themselves and what is important to them together with the clinician's knowledge about what is known about the benefits and risks of the available options. **In other words where lay expertise is given the same value as clinical expertise.**

NICE SDM Collaborative

Why is it Important?

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- It can create a new **RELATIONSHIP** between individuals and professionals based on partnership (Mulley et al, 2012)
- People want to be more **INVOLVED** than they currently are in making decisions about their own health and health care (Care Quality Commission inpatient survey, 2016; NHS England, GP survey. 2017)
- Both individuals and clinicians tend to consistently **OVERESTIMATE** the benefits of treatments and **UNDERESTIMATE** the harms (Hoffman, 2017)
- It has the potential to **ENHANCE** allocative efficiency and **REDUCE** unwarranted clinical variation (Mulley et al, 2012)
- It is intrinsic in **PROFESSIONAL CODES** of conduct/standards (General Medical Council, 2013; Nursing and Midwifery Council, 2018)
- It is a **LEGAL** requirement and health professionals now must take “reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant treatments”. (Health and Social Care Act 2012, Medical Protection Society, 2015)

Data about Shared Decision Making

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In 2017, 42% of patients said they were not involved as much as they wanted in decisions about their care and treatment *(Care Quality Commission Adult Inpatient Survey)*

There is still a significant perception gap between what patients want and what clinicians think patients want e.g. for breast cancer conditions 71% clinicians believe the top goal/concern is to keep the breast whereas this is only a priority for 7% of patients *(Sepucha et al. (2008). Pt Education and Counselling. 73:504-10)*

What skills do you need to deliver SDM?

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- Shared Decision Making (SDM) requires skill from health professionals and most importantly a willingness to involve people in decisions about their care.

- Health professionals also need to recognise that individuals, particularly those with lower levels of health literacy, may need support to take a more active role in partnership with their care professional.

To be successful, it relies on two sources of expertise:

- The health professional as an expert on the effectiveness, probable benefits and potential harms of treatment options.

- The person as an expert on themselves, their social circumstances, attitudes to illness and risk, values and preferences.

NHSE https://www.england.nhs.uk/personalisedcare/shared-decision-making/about/

Key skills needed to deliver SDM

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Ensure mandatory training is up to date:

- Active listening
- Listening to understand
- Observing and empathising (meeting people where they are)
- Cohesion and clarity
- Equality and diversity training
- Unconscious bias training, if available

The Montgomery Case: Law and Consent

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Clinicians now have to **take "reasonable care to ensure that the individual is aware of any material risks involved in any recommended treatment and of any reasonable alternative or variant treatments."** So, it's not just the treatment for which consent is being sought but all reasonable alternatives

The definition of what constitutes material risk has changed from the Bolam test of "responsible body of medical men," to "a reasonable person in the patient's position."

Material risk is subjective so Clinicians cannot determine it alone but must assess each case on an individual not generalised basis

For consent to be valid:

- It has to be freely given without coercion
- The person has to be "mentally capable" as defined by the Mental Capacity Act 2005
- The person has to understand all the relevant facts, risks and benefits of the treatment.

Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland) 1. [2015] UKSC 11.

System Drivers: Legislation and Policy

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- **Mental Capacity Act 2005, NHS Act 2006, Social Care Act 2012, NHS Mandate, 5YFV**
- **STPs / ICS' –** Greater individual involvement, enhance individual activation, support self-management for LTCs, greater personalization
- **"Realistic Medicine"** – a new relationship with individuals
- **NHS Long Term Plan –** drivers for improvements
- **Universal Personalised Care –** how to deliver personalised care
- **Rethinking Medicine –** prescribed the appropriate medicine – avoid over and under prescription
- **The Montgomery Judgement –** informed consent

❑ **MAKING SDM A REALITY –** No decision about me, without me
❑ **INDIVIDUALS' PREFERENCES MATTER –** Stop the silent misdiagnosis

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Health Literacy

Health Literacy - Definition

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"The personal characteristic and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health"

World Health Organisation 2015

Health Literacy - Data Findings

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- 43% - 61% of English working age population do not understand health information they are given (Institute of Health Equity/Public health England 2015)

- There is a strong social gradient in the population, with lower levels of health literacy much more common among the socially and economically disadvantaged ie it impacts on health inequalities.

Health Literacy - Techniques

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- **Plain, non-technical language**

- **'Chunk and check'.** Short sentences/paragraphs, pausing frequently, checking individual's body language that they are engaged. Precede with *'stop me if I am not explaining well'*

- **'Teach back'.** *'When you talk about what we discussed/our decision with your (husband/wife/daughter etc.) later, what will you tell them?*

- **Establishing baseline knowledge and activities:** *'what do you know about……?' 'what are you already doing to manage your…..?' 'what would you like to know more about….?'*

Health Literacy – In Practice

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- Getting it right
  - Establish and Check understanding
  - Clear correct information
  - Use appropriate language

- Getting it wrong
  - Disregard of the person's preferences
  - Reduced quality of life
  - Deciding informed preferences is difficult
  - Lack consent

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Shared Decision Making in Practice

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Goal-setting, preference elicitation and shared decision making

Slide decks provided with thanks from Professor Alf Collins

Preference Elicitation Definition

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What is Preference Elicitation and why do we need it?

“Preference elicitation is a requirement of decision support tools that assist clients faced with difficult decisions when in need of long-term care”

A preference elicitation tool

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This is used during the process of consideration

How to help people, carers and families with their decision?

- Act collaboratively
- Respect and autonomy
- Empathic approach

Five communicative steps are necessary

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- Constructive interpersonal engagement (Step 1 Introduction, framing, rapport building)
- Recognition of alternative actions (Step 2 Team Talk)
- Comparative learning (Step 3 Goal Talk)
- Preference construction and elicitation (Step 4 Option Talk)
- Preference integration (Step 5 Decision Talk)

Step 1. Introduction, framing, rapport building

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- *Hello, my name is…..'*
- **Exchange of pleasantries**: *'its good to meet you'* etc.
- *'I am'*….(job role)
- *'As I understand it, we are here to talk about…..and to decide…..'*
- *'Is that your understanding?'*

Step 2. Team talk: negotiated agenda setting

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- **Check if the person is prepared**: e.g. '*Have you had a chance to think about what you'd like us to focus on today?'*
- **Ensure they are confident and prepared: '***What would you like us to focus on today?'*
- **Await response then perhaps check back for clarification:** *'it sounds as though you want to know about all of the available options; is that right?'*
- **Compile a list***: what else/is there anything else/is there something else?*
- **Your agenda, if they haven't already covered it**: '*We are going to talk about ….and…… I wonder if we could also talk about….?' (*the clinician's agenda)

Watch SDM video on the next slide – Checking Shared Agenda

Watch Step 1. Introduction & Step 2. Team Talk

Checking Shared Agenda

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Summary of what we have learnt

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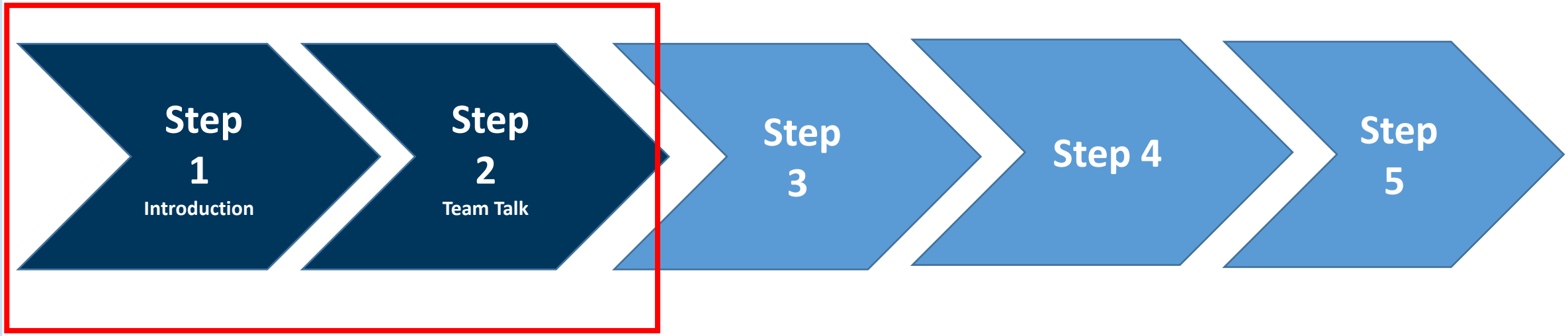

Step 3. Goal Talk

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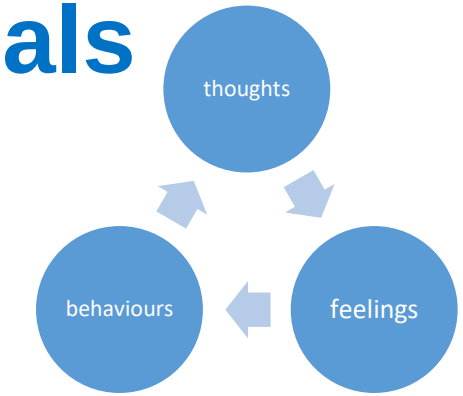
- **Check whether prepared**: *'have you had a chance to think about what you'd like to achieve as a result of treating your….?*

- **If confident that prepared**: *'what do you want to achieve/be able to do as a result of treating your…?*

- **Functional goal talk:** *'What are the activities that are most important to you/what matters most to you?* ***Tell me more*** *about what's important to you…" What are you missing out on?'*

- **Values goal talk:** *'**tell me more** about yourself and how you'd like life to be different'; '**tell me** about a normal day'; '**tell me** about a good day'; '**tell me** about how you'd like normal days to be different'.*

Step 3. The Importance of goals



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- Personal Agency
- Psychological flexibility
- Problem solving

- Purpose
- Meaning
- Connection
- Hope

I am the story I tell myself about myself

Watch the SDM video on the next slide – What's important to you

Step 3. Goal talk

What's important to you

Summary of what we have learnt

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Step 4. Option talk

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- **Reinforce partnership** and make it clear that there are choices to consider- including doing nothing: *'We have a number of options/choices to consider and we don't have to do anything'*
- **Introduce decision support tool if relevant and individual not prepared:** *'This is yours to keep. It tells you about your choices. Why don't we think it through together?'*
- **Minimise bias:** *'There is no 'right' choice from my perspective/ as far as I am concerned- only what's right for you'*
- **Link to goals:** (outcome preferences) but also to experience (treatment preferences): *'Hold in mind what's important to you as we think through the options together'*
- **Elicit prior preferences:** *'what do you already know about your options?'*
- **Invite preference construction**: '*why don't we look at the pros and cons of the options together?*
- **Elicit *conscious* preference construction**: *'tell me your thoughts as we think through the options together'*
- **Watch the SDM video on the next slide – Listing options & laying out a map Decision Support Tool**

Step 4. Option Talk

Listing options & laying out a map

Decision Support Tool

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Step 4. Preference elicitation and construction via option talk

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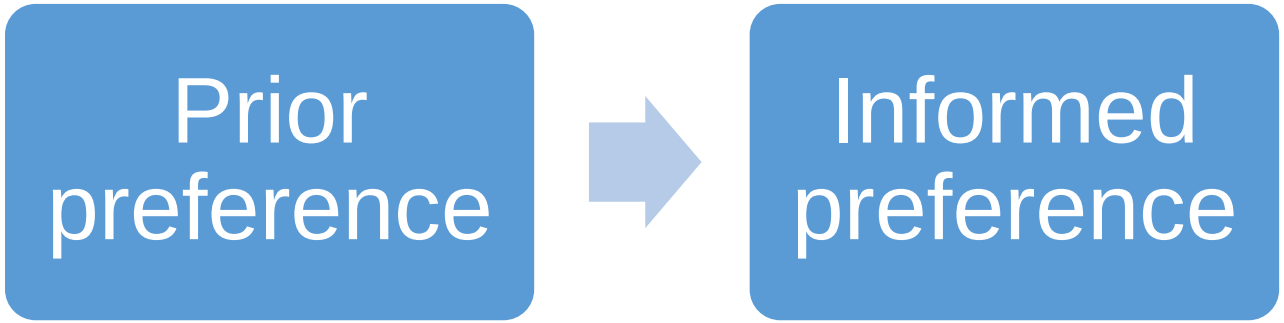
Preference construction via supported deliberation



Risk Language

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- Clear, up-to-date and accurate information based on the best available evidence concerning potential harms and benefits of treatment options.
- The option of doing nothing or not changing the current plan is shared with the person.

Patient conceptualisation of risk is likely multifactorial, involving not only numerical probability but also context, medical history and the perceived severity of health threats.

- Risk should be quantified as absolute (rather than relative) risk and presented as a natural frequency (rather than as a percentage).
- Colloquial descriptions of risk such as ‘common’ and ‘rare’ should be avoided
- Serious harms should be described, however unlikely.
- Patient understanding checked, eg with ‘chunk and check’ and ‘teach back’ methods.

Persons perception of risk

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- Think differently about presented risks and benefits.
- Likely multifactorial, involving not only numerical probability but also quality of life, medical history and the perceived severity of health threats.
- Perceptions of risk influence choices.
- Consider emotional impact as an aspect of risk communication alongside persons understanding.

Effective risk communication

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- Explain your reasons when making a recommendation and share information about reasonable alternatives all without putting pressure on the person to accept advice.
- It is important that the person does not feel pressured to accept the recommendation.
- Objectivity - must be aware of how your own preferences may influence the advice given and the choice of language used.
- This helps facilitate an honest and open approach, acting with integrity without unfair discrimination and maintaining trust.

Watch the SDM Film –

Using Good Risk Language

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Summary of what we have learnt

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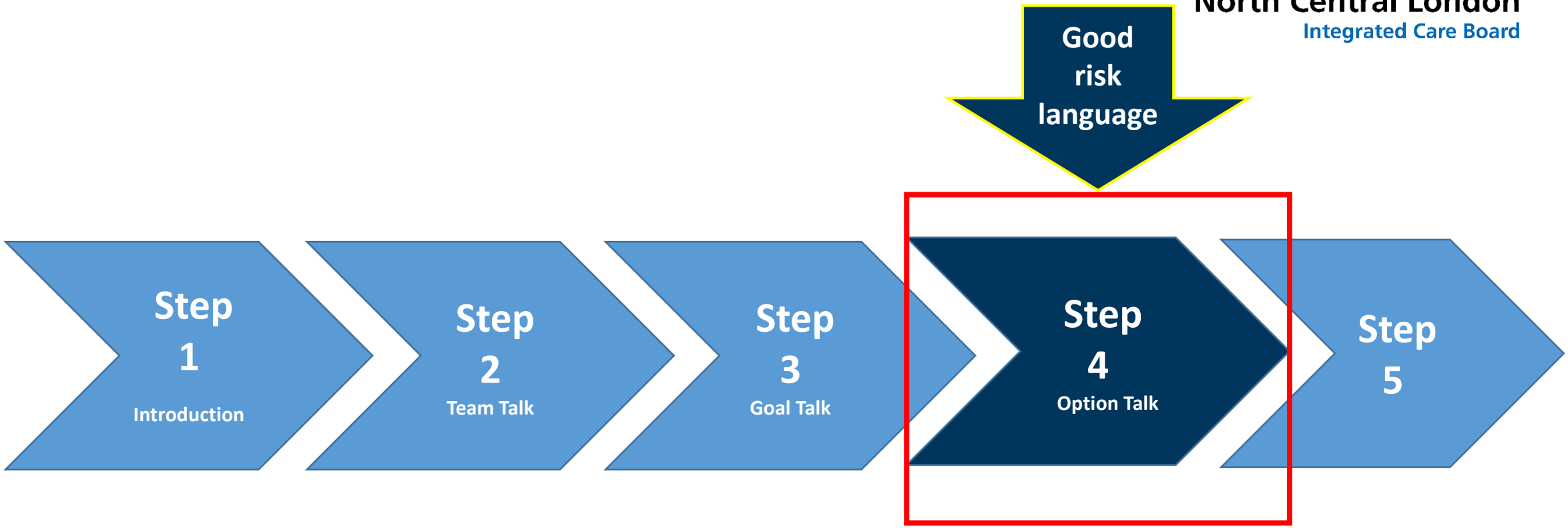

Break

Step 5. Decision talk

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- **Reflect informed preference(s):** *'it sounds as though you think surgery might well be the right option for you. Is that right?'*
- **If individual agrees:** *'That sounds like a plan. Before we agree next steps, could you tell me on a scale of 0-10 (define margins), how confident are you that this is the right choice for you?*
- **7 or more- proceed. 6 or less denotes ambivalence/uncertainty**
- **If ambivalent:** 'what led you to score (the number)?'
- **If ambivalent, make ambivalence explicit:** *'it sounds as though, on the one hand you think surgery could help you most and on the other hand you'd like the risks of the operation to be lower. Is that right?'*
- **If ambivalent, ensure each option has been considered**: *'would it help to think through the pros and cons of each of the options again?'*
- **If still ambivalent, (and clinically ok to do so) defer decision:** *'Many individuals want to spend more time thinking about their options. (If relevant) Why don't you take away the information we have shared, think it through perhaps with friends/relatives and we'll talk again soon?'*

Watch the SDM Film on the next slide - **Summarising and checking the preferred next steps**

Step 5 – Decision talk

Summarising and checking the preferred next steps

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Summary of what we have learnt

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Conversations about goals and preferences

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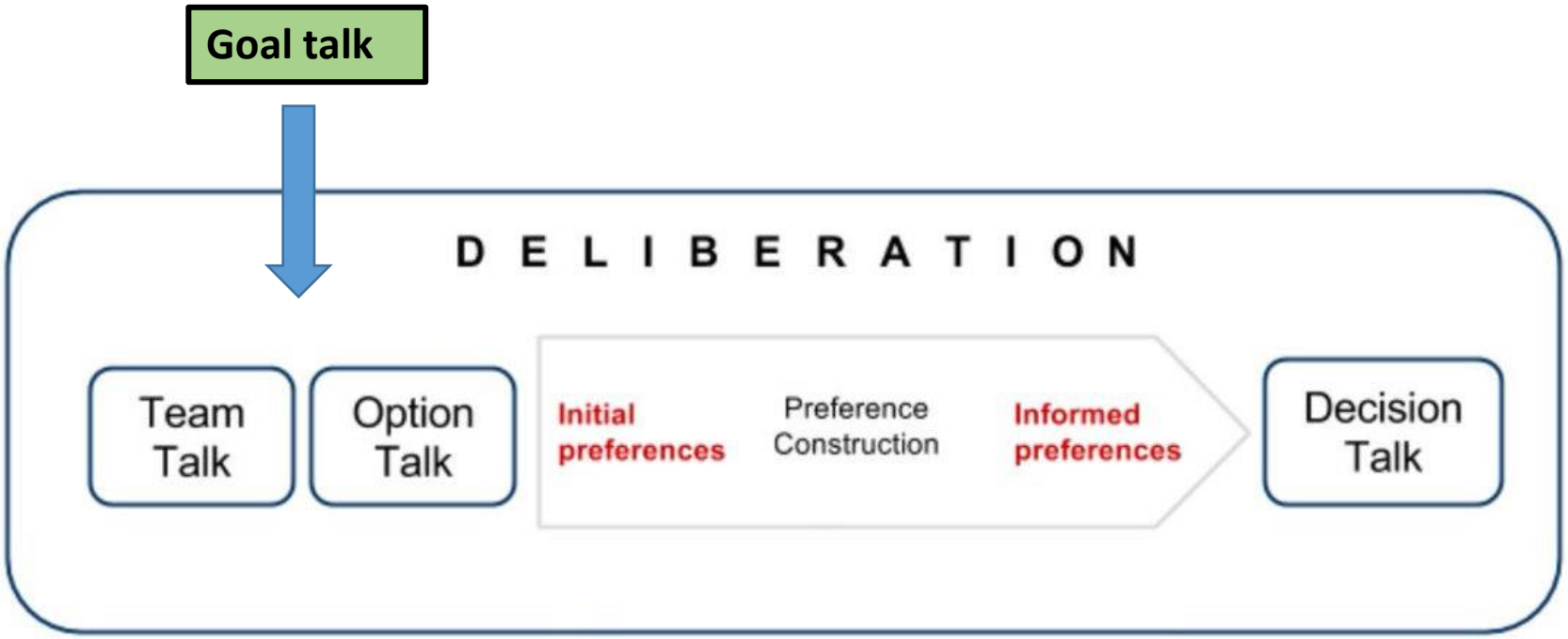

Team talk Explain the intention to collaborate and support deliberation

Option talk Compare alternatives

Decision talk Elicit preferences & integrate into subsequent actions

Three Talk Collaborative Deliberation Model ©
Glyn Elwyn 2015

Let's watch this Shared Decision Making Video

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Person requests to make changes to a drug regime (enhanced) - YouTube

A system to record preferences, decisions and actions

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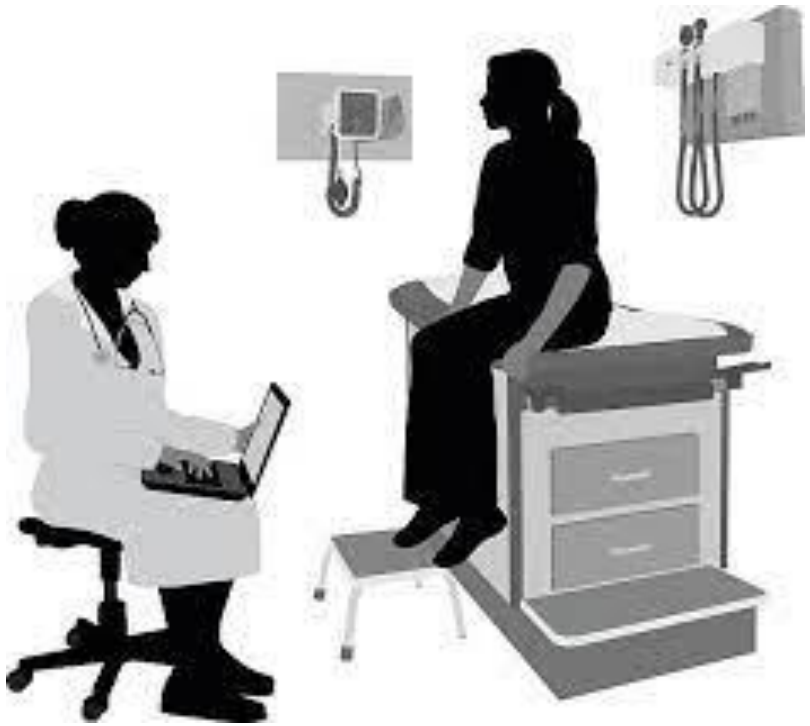

Quiz

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Quiz – Question 1

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In the three-talk collaboration model developed by Glyn Elwyn, which talk is not part of the model?

A) Team talk
B) Option talk
C) Preference talk
D) Decision talk

Quiz – Question 1 answer

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In the three-talk collaboration model developed by Glyn Elwyn, which talk is not part of the model?

A)Team talk
B) Option talk
~~C) Preference talk~~
D) Decision talk

Quiz – Question 2

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From the *The Montgomery Case: Law and Consent*, for consent to be valid, what factor is <u>not</u> considered:

A) It has to be freely given without coercion.
B) The person has to be “mentally capable” as defined by the Mental Capacity Act 2005.
C) The person has to understand all the relevant facts, risks and benefits of the treatment.
D) Coercion should be used to gain consent

Quiz – Question 2 answer

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From the *The Montgomery Case: Law and Consent*, for consent to be valid, what factor is <u>not</u> considered:

A) It has to be freely given without coercion.
B) The person has to be "mentally capable" as defined by the Mental Capacity Act 2005.
C) The person has to understand all the relevant facts, risks and benefits of the treatment.
~~D) Coercion should be used to gain consent~~

Quiz – Question 3

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Is this definition of Shared Decision Making true or false?

Shared Decision Making is where individuals and clinicians work together to understand and decide what tests, treatments, management or support packages are most suitable bearing in mind the persons individual circumstances. It brings together the individuals' expertise about themselves and what is important to them together with the clinician's knowledge about what is known about the benefits and risks of the available options.

Quiz – Question 3 answer

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Is this definition of Shared Decision Making true or false?

True **by** *NICE SDM Collaborative*

Shared Decision Making is where individuals and clinicians work together to understand and decide what tests, treatments, management or support packages are most suitable bearing in mind the persons individual circumstances. It brings together the individuals' expertise about themselves and what is important to them together with the clinician's knowledge about what is known about the benefits and risks of the available options.

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Further reading and support

Local Support

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NCL ICB PHB Team **do not hold a central budget for PHB delivery**, but can provide support with PHB development/implementation, advice and guidance. If support is required, please email: **nclicb.personalhealthbudgets@nhs.net**. The PHB Team also support with organising the:

- PHB Panel, held weekly, to review and approve Direct Payment/Third Party set ups and monitoring process by money management services (Chaired by the Caretrack and PHB Specialist).
- PHB Case Management Meetings (used to be known as the PHB Borough Meeting) to provide peer support with solving practical problems faced when delivering PHB (Chaired by the Caretrack and PHB Specialist). Meeting dates for this year will be published shortly.

In process of organising:

- PHB Champions for ICB service areas who support and deliver PHBs, so teams will have dedicated person(s) who support and champion PHB Direct Payment delivery.
- PHB page for the public on the ICB website.
- PHB page for staff on the ICB Intranet.
- PHB Support Services Directory (formerly PHB Procurement Framework), will resemble a service directory, and will contain a range of PHB support service providers to help people to complete complex personalised care and support planning and brokerage, money management support and other PHB support services (estimated delivery period is Q3 of 23/24)

Following documents are/will be available on the ICB intranet:

- NCL ICB PHB Policy
- NCL ICB Generic PHB Processes
- NHSE PHB Quality Framework Self-Assessment for the business, teams and Case Manager
- PHB tools and resources to help with Personalised Care and Support Planning
- NCL Training Hub - Internet: www.ncltraininghub.org

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SDM Resources

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SDM NHSE webpages

SDM MAGIC vignettes: Key Skills chunks, Pitfalls chunks, Full-length clips

Decision Support Framework

Health Literacy Toolkit

Contact: ENGLAND.shareddecisionmaking@nhs.net

Long Term Plan

Universal Personalised Care: Implementing the Personalised Care Model

Further information

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- NHS England website

- Personal Health Budgets Learning Network
  Personal Health Budgets - elearning for healthcare (e-lfh.org.uk)

- Personalised Health and Care Framework
  Personalised health and care 2020: a framework for action - GOV.UK (www.gov.uk)

- Personalised Care Institute
  (Contains e-learning courses on Core Skills, Shared Decision Making and Personalised Care and Support Planning)
  www.personalisedcareinstitute.org.uk

Further information

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- Personal Health Budgets
  https://www.nhs.uk/nhs-services/help-with-health-costs/what-is-a-personal-health-budget/

- Personalised Care Collaborative Network
  https://www.coalitionforpersonalisedcare.org.uk/

- Personalised Care
  https://www.england.nhs.uk/personalisedcare/

- Patient Stories
  NHS England » Personal health budgets in action

- NHSE/I Events
  https://www.events.england.nhs.uk/

Questions

Thank you for attending