NICE National Institute for Health and Care Excellence

NICE Pathways

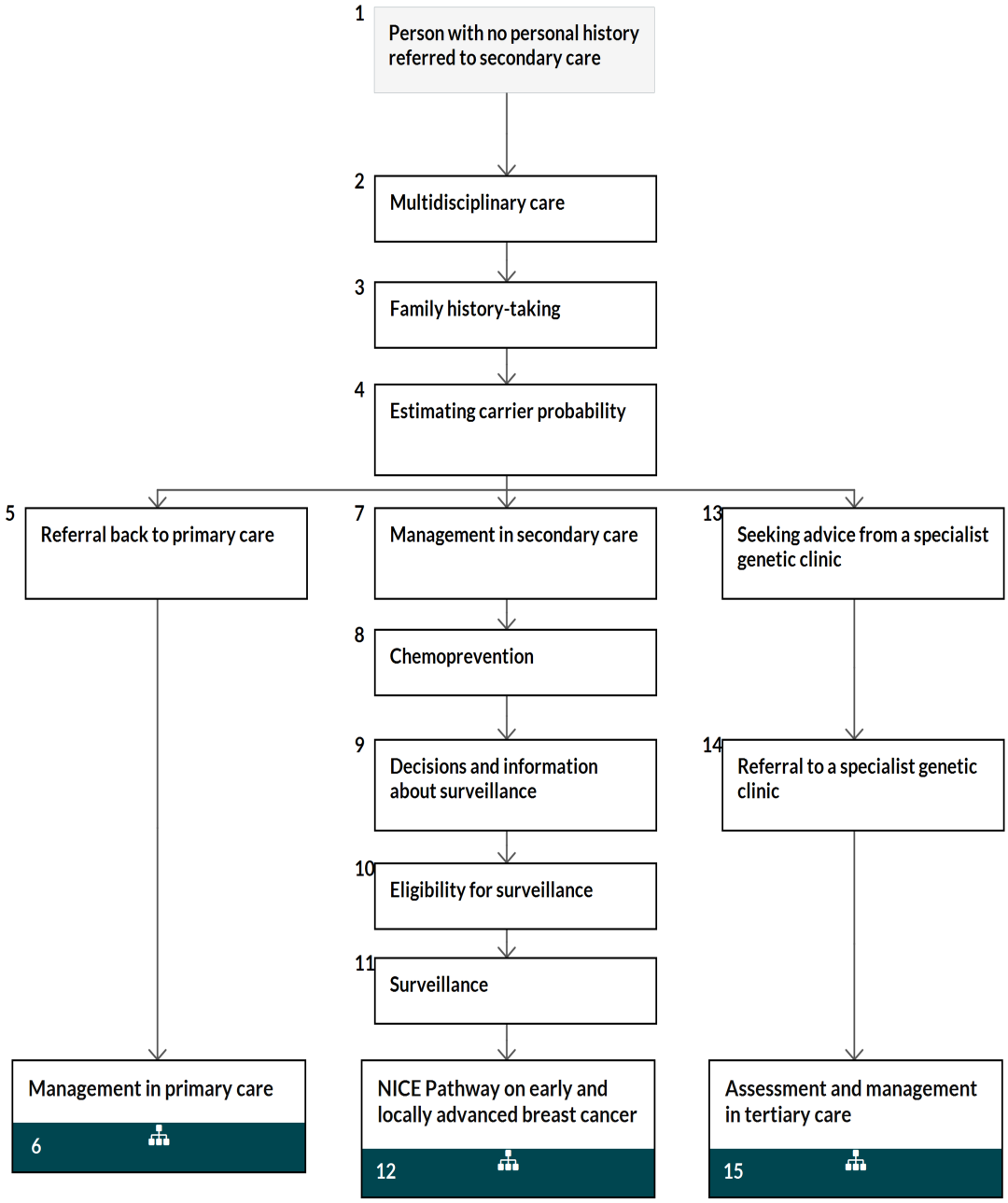
Person with no personal history of breast cancer: assessment and management in secondary care

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/familial-breast-cancer
NICE Pathway last updated: 25 May 2021

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Person with no personal history referred to secondary care

No additional information

2 Multidisciplinary care

Ensure that in secondary care (such as a breast care team, family history clinic or breast clinic) people are cared for by a multidisciplinary team. Care should include the following:

- written protocols for management
- central, standardised resources
- mammographic surveillance available to standard of the national breast screening programmes (England – NHS Breast Screening Programme; Wales – Breast Test Wales; Northern Ireland – NI Breast Screening Programme
- access to surveillance (see the recommendations on surveillance [See page 10])
- access to a team offering risk-reducing surgery
- standardised written information
- designated/lead clinicians
- a designated contact for primary care
- a designated contact in a specialist genetic clinic
- audit
- clinical trials access
- access to psychological assessment and counselling
- information about support groups and voluntary organisations
- administrative support.

3 Family history-taking

Take a family history when a person presents with breast symptoms or has concerns about relatives with breast cancer.

Take a third-degree family history in secondary care where possible and appropriate.

Ensure that tools such as family history questionnaires and computer packages that can aid accurate collection of family history information and risk assessment are available.

Following initial consultation in secondary care, provide written information to reflect the outcomes of the consultation.

4 Estimating carrier probability

When available in secondary care, use a carrier probability calculation method with demonstrated acceptable performance (calibration and discrimination) as well as family history to determine who should be offered referral to a specialist genetic clinic. Examples of acceptable methods include BOADICEA and the Manchester scoring system.

5 Referral back to primary care

Refer people whose risk does not meet the criteria for referral to secondary care back to primary care with:

- standard information [See page 14]
- detailed information about why secondary care or a specialist genetics service are not needed
- advice to return to primary care to discuss any implications if there is a change in family history or breast symptoms develop, and
- support mechanisms (for example, risk counselling, psychological counselling and risk management advice) for people not eligible for referral and/or surveillance on the basis of age or risk level who have ongoing concerns.

6 Management in primary care

See Familial breast cancer / Person with no personal history of breast cancer: assessment and management in primary care / Management in primary care

7 Management in secondary care

Care for people who meet the following criteria in secondary care and do not refer to a specialist genetic clinic:

- one first-degree relative diagnosed with breast cancer at younger than age 40 years, **or**
- two first-degree or second-degree relatives diagnosed with breast cancer at an average

- age of older than 50 years, **or**
- three first-degree or second-degree relatives diagnosed with breast cancer at an average age of older than 60 years, **or**
- a formal risk assessment (usually carried out in a specialist genetic clinic) or a family history pattern is likely to give risks of greater than 3 to 8% risk in the next 10 years for women aged 40 years, or a lifetime risk of 17% or greater but less than 30% (a woman's age should be assumed to be 40 for a woman in her forties; a 10-year risk should be calculated for the age range 40 to 49)

provided that none of the following are present in the family history:

- bilateral breast cancer
- male breast cancer
- ovarian cancer
- Jewish ancestry
- sarcoma in a relative younger than 45 years of age
- glioma or childhood adrenal cortical carcinomas
- complicated patterns of multiple cancers at a young age
- very strong paternal history (four relatives diagnosed at younger than 60 years of age on the father's side of the family).

Offer management in secondary care to people at high risk if they do not want genetic testing or risk-reducing surgery and do not wish to be referred to a specialist genetics service.

Information for people cared for in secondary care

Give:

- standard information [See page 14]
- details of the risk assessment outcome, including why they are not being referred to a specialist genetics service
- details of surveillance options including risk and benefits.

8 Chemoprevention

Healthcare professionals within secondary care or specialist genetic clinics should discuss the absolute benefits and risks of options for chemoprevention with women at high risk or moderate risk of breast cancer. Discussion using a decision aid should include the following to promote

shared decision-making and informed preferences:

- the reduced risk of invasive breast cancer
- the lack of effect on mortality
- the side effects of the different options
- alternative approaches, such as surveillance alone and, for women at high risk, risk-reducing surgery.

Women should also be given information in an accessible format.

NICE has produced patient decision aids about chemoprevention for women at moderate or high risk of breast cancer.

Do not offer chemoprevention to women who were at high risk of breast cancer but have had bilateral risk-reducing mastectomy.

Premenopausal women

Offer tamoxifen for 5 years to premenopausal women at high risk of breast cancer unless they have a past history or may be at increased risk of thromboembolic disease or endometrial cancer.

Offer anastrozole for 5 years to postmenopausal women at high risk of breast cancer unless they have severe osteoporosis. In March 2017 this was an off-label use of anastrozole. See prescribing medicines at NICE website. Women with or at risk of osteoporosis should have their bone mineral density assessed when starting treatment and then at regular intervals. Treatment or prophylaxis for osteoporosis should be started when needed and carefully monitored.

For postmenopausal women at high risk of breast cancer who have severe osteoporosis or do not wish to take anastrozole:

- offer tamoxifen for 5 years if they have no history or increased risk of thromboembolic disease or endometrial cancer, **or**
- consider raloxifene for 5 years for women with a uterus if they have no history or increased risk of thromboembolic disease and do not wish to take tamoxifen.

In March 2017 this was an off-label use of raloxifene. See prescribing medicines at NICE website.

Consider tamoxifen for 5 years for premenopausal women at moderate risk of breast cancer,

unless they have a past history or may be at increased risk of thromboembolic disease or endometrial cancer.

Postmenopausal women

Consider anastrozole for 5 years for postmenopausal women at moderate risk of breast cancer unless they have severe osteoporosis. In March 2017 this was an off-label use of anastrozole. See prescribing medicines at NICE website. Women with or at risk of osteoporosis should have their bone mineral density assessed when starting treatment and then at regular intervals. Treatment or prophylaxis for osteoporosis should be started when needed and carefully monitored.

For postmenopausal women at moderate risk of breast cancer who have severe osteoporosis or do not wish to take anastrozole:

- consider tamoxifen for 5 years if they have no history or increased risk of thromboembolic disease or endometrial cancer, **or**
- consider raloxifene for 5 years for women with a uterus if they have no history or increased risk of thromboembolic disease and do not wish to take tamoxifen.

In March 2017 this was an off-label use of raloxifene. See prescribing medicines at NICE website.

Stopping treatment

Do not continue chemoprevention beyond 5 years in women with no personal history of breast cancer.

Inform women that they must stop tamoxifen at least:

- 2 months before trying to conceive
- 6 weeks before elective surgery.

9 Decisions and information about surveillance

Offer support (for example, risk counselling, psychological counselling and risk management advice) to women who have ongoing concerns but are not eligible for surveillance additional to that offered by the national breast screening programmes (England – NHS Breast Screening Programme; Wales – Breast Test Wales; Northern Ireland – NI Breast Screening Programme

Before decisions on surveillance are made, discuss and give written information on the benefits and risks of surveillance, including:

- the possibility that mammography might miss a cancer in women with dense breasts and the increased likelihood of further investigations
- possible over diagnosis
- the risk associated with exposure to radiation
- the possible psychological impact of a recall visit.

At the start of a surveillance programme and when there is a transition or change to the surveillance plan, give women:

- information about the surveillance programme, including details of the tests, how often they will have the tests and the duration of the programme
- information about the risks and benefits of surveillance
- details of sources of support and further information.

Ensure that women know and understand the reasons for any changes to the surveillance plan.

10 Eligibility for surveillance

Do not offer surveillance to women who have undergone a bilateral mastectomy.

The recommendations on surveillance for women with no personal history of breast cancer have been summarised in a table (see Summary of recommendations on surveillance for women with no personal history of breast cancer [See page 14]). The individual recommendations are also given below.

Mammographic surveillance

Offer annual mammographic surveillance to women:

- aged 40 to 49 years at moderate risk of breast cancer
- aged 40 to 59 years at high risk of breast cancer but with a 30% or lower probability of being a *BRCA* or *TP53* carrier
- aged 40 to 59 years who have not had genetic testing but have a greater than 30% probability of being a *BRCA* carrier
- aged 40 to 69 years with a known *BRCA1* or *BRCA2* mutation.

Offer mammographic surveillance as part of the population screening programme to women:

- aged 50 years and over who have not had genetic testing but have a greater than 30% probability of being a *TP53* carrier
- aged 60 years and over at high risk of breast cancer but with a 30% or lower probability of being a *BRCA* or *TP53* carrier
- aged 60 years and over at moderate risk of breast cancer
- aged 60 years and over who have not had genetic testing but have a greater than 30% probability of being a *BRCA* carrier
- aged 70 years and over with a known *BRCA1* or *BRCA2* mutation.

Consider annual mammographic surveillance for women:

- aged 30 to 39 years at high risk of breast cancer but with a 30% or lower probability of being a *BRCA* or *TP53* carrier
- aged 30 to 39 years who have not had genetic testing but have a greater than 30% probability of being a *BRCA* carrier
- aged 30 to 39 years with a known *BRCA1* or *BRCA2* mutation
- aged 50 to 59 years at moderate risk of breast cancer.

Discuss the benefits and risks of mammographic surveillance with the person before making a shared decision, as described in decisions and information about surveillance [See page 7].

Do not offer mammographic surveillance to women:

- aged 29 years and under
- aged 30 to 39 years at moderate risk of breast cancer
- aged 30 to 49 years who have not had genetic testing but have a greater than 30% probability of being a *TP53* carrier
- of any age with a known *TP53* mutation.

MRI surveillance

Offer annual MRI surveillance to women:

- aged 30 to 49 years who have not had genetic testing but have a greater than 30% probability of being a *BRCA* carrier
- aged 30 to 49 years with a known *BRCA1* or *BRCA2* mutation
- aged 20 to 49 years who have not had genetic testing but have a greater than 30% probability of being a *TP53* carrier

- aged 20 to 49 years with a known *TP53* mutation.

Consider annual MRI surveillance for women aged 50 to 69 years with a known *TP53* mutation.

Do not offer MRI to women:

- of any age at moderate risk of breast cancer
- of any age at high risk of breast cancer but with a 30% or lower probability of being a *BRCA* or *TP53* carrier
- aged 20 to 29 years who have not had genetic testing but have a greater than 30% probability of being a *BRCA* carrier
- aged 20 to 29 years with a known *BRCA1* or *BRCA2* mutation
- aged 50 to 69 years who have not had genetic testing but have a greater than 30% probability of being a *BRCA* or a *TP53* carrier, unless mammography has shown a dense breast pattern
- aged 50 to 69 years with a known *BRCA1* or *BRCA2* mutation, unless mammography has shown a dense breast pattern.

Ultrasound surveillance

Do not routinely offer ultrasound surveillance to women at moderate or high risk of breast cancer but consider it:

- when MRI surveillance would normally be offered but is not suitable (for example, because of claustrophobia)
- when results of mammography or MRI are difficult to interpret.

11 Surveillance

Ensure that individual strategies are developed for all women having mammographic surveillance and that surveillance is:

- to national breast screening programme standards
- audited
- only undertaken after written information is given about risks and benefits.

For women under 50 years who are having mammography, use digital mammography at centres providing digital mammography to national breast screening programme standards.

Ensure that MRI surveillance includes MRI of both breasts performed to national breast screening programme standards.

NICE has published a medtech innovation briefing on artificial intelligence in mammography.

12 NICE Pathway on early and locally advanced breast cancer

See Early and locally advanced breast cancer

13 Seeking advice from a specialist genetic clinic

Seek further advice from a specialist genetics service for families containing any of the following, in addition to breast cancers:

- triple negative breast cancer under the age of 40 years
- Jewish ancestry
- sarcoma in a relative younger than age 45 years
- glioma or childhood adrenal cortical carcinomas
- complicated patterns of multiple cancers at a young age
- very strong paternal history (four relatives diagnosed at younger than 60 years of age on the father's side of the family).

14 Referral to a specialist genetic clinic

Offer people who meet the following referral criteria a referral to a specialist genetic clinic.

At least the following female breast cancers only in the family

- two first-degree or second-degree relatives diagnosed with breast cancer at younger than an average age of 50 years (at least one must be a first-degree relative), **or**
- three first-degree or second-degree relatives diagnosed with breast cancer at younger than an average age of 60 years (at least one must be a first-degree relative), **or**
- four relatives diagnosed with breast cancer at any age (at least one must be a first-degree relative).

Families containing one relative with ovarian cancer at any age and, on the same side of the family

- one first-degree relative (including the relative with ovarian cancer) or second-degree relative diagnosed with breast cancer at younger than age 50 years, **or**
- two first-degree or second-degree relatives diagnosed with breast cancer at younger than an average age of 60 years, **or**
- another ovarian cancer at any age.

Families affected by bilateral cancer (each breast cancer has the same count value as one relative)

- one first-degree relative with cancer diagnosed in both breasts at younger than an average age 50 years, **or**
- one first-degree or second-degree relative diagnosed with bilateral cancer **and** one first- or second-degree relative diagnosed with breast cancer at younger than an average age 60 years.

Families containing male breast cancer at any age and, on the same side of the family, at least

- one first-degree or second-degree relative diagnosed with breast cancer at younger than age 50 years **or**
- two first-degree or second-degree relatives diagnosed with breast cancer at younger than an average age of 60 years.

A formal risk assessment has given risk estimates of

- a 10% or greater chance of a gene mutation being harboured in the family **or**
- a greater than 8% risk of developing breast cancer in the next 10 years **or**
- a 30% or greater lifetime risk of developing breast cancer.

Women not at high risk but seriously considering oophorectomy

Offer women not at high risk who raise the possibility of risk-reducing bilateral oophorectomy appropriate information and, if seriously considering this option, referral to the team that deals with women at high risk.

Information for people being referred to tertiary care

Give:

- standard information [See page 14]
- details of the risk assessment outcome, including why they are being referred to a specialist genetics service
- details of surveillance options, including risk and benefits
- details of what should be expected in a specialist genetics service, including counselling and genetic testing.

15 Assessment and management in tertiary care

See Familial breast cancer / Person with no personal history of breast cancer: assessment and management in tertiary care

Standard written information for all

Give the following standard written information to all:

- risk information about population level and family history level of risk, including a definition of family history
- the message that if their family history alters their risk may alter
- breast awareness information
- lifestyle advice regarding breast cancer risk, including information about:
    - HRT and oral contraceptives (women only)
    - lifestyle including diet, alcohol, etc
    - breastfeeding, family size and timing (women only)
- contact details of those providing support and information, including local and national support groups
- people should be informed prior to appointments that they can bring a family member/friend with them to appointments
- details of any trials or studies that may be appropriate.

Summary of recommendations on surveillance for women with no personal history of breast cancer

	Moderate risk	**High risk**				
Age	**Moderate risk of breast cancer**[1]	**High risk of breast cancer**[2] **(but with a 30% or lower probability of being a *BRCA* or *TP53* carrier)**	**Untested but greater than 30% *BRCA* carrier probability**[3]	**Known *BRCA1* or *BRCA2* mutation**	**Untested but greater than 30% *TP53* carrier probability**[4]	**Known *TP5* mutation**
20 to	Do not offer mammography	Do not offer mammography	Do not offer mammography	Do not offer mammography	Do not offer mammography	Do not offer mammograp

[1] Lifetime risk of developing breast cancer is at least 17% but less than 30%.

[2] Lifetime risk of developing breast cancer is at least 30%. High risk group includes rare conditions that carry an increased risk of breast cancer, such as Peutz-Jegher syndrome (*STK11*), Cowden (*PTEN*), familial diffuse gastric cancer (E-Cadherin).

[3] Surveillance recommendations for this group reflect the fact that women who at first assessment had a 30% or greater *BRCA* carrier probability and reach 60 years of age without developing breast or ovarian cancer will now have a lower than 30% carrier probability and should no longer be offered MRI surveillance.

[4] Surveillance recommendations for this group reflect the fact that women who at first assessment had a 30% or greater *TP53* carrier probability and reach 50 years of age without developing breast cancer or any other *TP53*-related malignancy will now have a lower than 30% carrier probability and should no longer be offered MRI surveillance.

29	Do not offer MRI	Do not offer MRI	Do not offer MRI	Do not offer MRI	Annual MRI	Annual MRI
30 to 39	Do not offer mammography	Consider annual mammography	Consider annual mammography	Consider annual mammography	Do not offer mammography	Do not offer mammograp
	Do not offer MRI	Do not offer MRI	Annual MRI	Annual MRI	Annual MRI	Annual MRI
40 to 49	Annual mammography	Annual mammography	Annual mammography	Annual mammography	Do not offer mammography	Do not offer mammograp
	Do not offer MRI	Do not offer MRI	Annual MRI	Annual MRI	Annual MRI	Annual MRI
50 to 59	Consider annual mammography	Annual mammography	Annual mammography	Annual mammography	Mammography as part of the population screening programme	Do not offer mammograp
	Do not offer MRI	Do not offer MRI	Do not offer MRI unless dense breast pattern	Do not offer MRI unless dense breast pattern	Do not offer MRI unless dense breast pattern	Consider annual MRI
60 to 69	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Annual mammography	Mammography as part of the population screening programme	Do not offer mammograp

	Do not offer MRI	Do not offer MRI	Do not offer MRI unless dense breast pattern	Do not offer MRI unless dense breast pattern	Do not offer MRI unless dense breast pattern	Consider annual MRI
70+	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Mammography as part of the population screening programme	Do not offer mammograp

Glossary

First-degree

(mother, father, daughter, son, sister, brother)

Second-degree

(grandparent, grandchild, aunt, uncle, niece, nephew, half-sister, half-brother)

Third-degree

(great grandparent, great grandchild, great aunt, great uncle, first cousin, grand nephew, grand niece)

High risk

(greater than 8% risk of breast cancer between age 40 and 50 years or lifetime risk of 30% or greater; this group also includes known *BRCA1*, *BRCA2* and *TP53* mutations and rare conditions that carry an increased risk of breast cancer, such as Peutz-Jegher syndrome (*STK11*), Cowden (*PTEN*) and familial diffuse gastric cancer (E-Cadherin))

Triple negative breast cancer

(oestrogen receptor, progesterone receptor, HER2 negative breast cancer)

Moderate risk

(between 3% and 8% risk of breast cancer between age 40 and 50 years or lifetime risk of 17% or greater but less than 30%)

Sources

Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer (2013 updated 2019) NICE guideline CG164

Your responsibility

Guidelines

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.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.