

# Multiple sclerosis

Quality standard

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This standard is based on NG220.

This standard should be read in conjunction with QS89, QS54, QS53, QS45, QS43, QS24, QS13 and QS8.

## Quality statements

Statement 1 Adults with multiple sclerosis (MS) are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

Statement 2 Adults with MS are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

Statement 3 Adults with MS have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Statement 4 Adults with MS who have problems with mobility or fatigue are offered support to remain physically active.

Statement 5 Adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

Statement 6 Adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

# Quality statement 1: Support at diagnosis

## Quality statement

Adults with multiple sclerosis (MS) are given support at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

## Rationale

Receiving a diagnosis of a long-term condition like MS is life changing and stressful. It is important that consultant neurologists offer information, advice and support at the time of diagnosis so that the person with MS has a sense of control over their own life, is more able to make decisions about how their condition is managed, and is less anxious.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that adults with MS are supported at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications or service protocols.

## Process

Proportion of adults with MS who are given information about MS, its progression and the

ways it can be managed by the consultant neurologist at the time of diagnosis.

**Numerator** – the number in the denominator who are given information about the condition by the consultant neurologist at the time of diagnosis.

**Denominator** – the number of adults receiving a new diagnosis of MS from a consultant neurologist.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## Outcome

Patient satisfaction with the support provided at diagnosis.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient surveys.

## What the quality statement means for different audiences

**Service providers** (neurology services) ensure that systems are in place for adults with MS to be supported at the time of diagnosis to understand the condition, its progression and the ways it can be managed, by the consultant neurologist making the diagnosis.

**Healthcare professionals** (consultant neurologists) ensure that at the time of making the diagnosis, they support adults with MS to understand the condition, its progression and the ways it can be managed.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that they commission services that support adults with MS at the time of diagnosis to understand the condition, its progression and the ways it can be managed.

**Adults with MS** are given support by the consultant when first told that they have MS. This early support helps people with MS (and their families and carers) to begin to understand

what MS is, what treatments are available and how the symptoms can be managed.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendation 1.2.1

## Definitions of terms used in this quality statement

### Support

This should include oral and written information about:

- what MS is
- treatments, including disease-modifying therapies
- symptom management
- how support groups, local services, social services and national charities are organised and how to get in touch with them
- online resources
- legal requirements such as notifying the Driver and Vehicle Licensing Agency (DVLA; see the [DVLA webpage on multiple sclerosis and driving](#)), and legal rights including social care, employment rights and benefits.

[[NICE's guideline on multiple sclerosis in adults](#), recommendation 1.2.1]

## Equality and diversity considerations

Cognitive problems are a common symptom of MS. People can experience a wide range of difficulties, including problems with attention, memory and decision-making, and planning. All information should be accessible to people with cognitive problems. People receiving information about MS should have access to an interpreter or advocate if needed.

# Quality statement 2: Follow up after diagnosis

## Quality statement

Adults with multiple sclerosis (MS) are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

## Rationale

It can be difficult for people with MS to take in the information and advice they are given at the time of diagnosis. A follow-up appointment provides time for people with MS to adjust to their diagnosis. They can think about the information that they were given and any further information they want, and then can have any questions answered by a specialist. The appointment means that people with MS can meet healthcare professionals with expertise in MS, who may be involved in their future care, soon after diagnosis.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that adults with MS have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications and service protocols.



## Process

Proportion of adults with MS who have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Numerator – the number in the denominator who have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

Denominator – the number of adults receiving a new diagnosis of MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

## What the quality statement means for different audiences

**Service providers** (neurology services) ensure that systems are in place for adults with MS to have a face-to-face follow-up appointment with a healthcare professional with expertise in MS within 6 weeks of diagnosis.

**Healthcare professionals** (consultant neurologists) ensure that they offer adults with MS a face-to-face follow-up appointment with themselves or another healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that they commission services in which adults with MS are offered a face-to-face follow-up appointment with a healthcare professional with expertise in MS, to take place within 6 weeks of diagnosis.

**Adults with MS** are offered an appointment with a specialist to take place within 6 weeks of their diagnosis. This gives them time to read and think about the information they were given at the time of diagnosis and the opportunity to have any questions answered by a healthcare professional with experience in MS. They can also ask for more information and support if they need it. The appointment also gives them the opportunity to meet a healthcare professional who will be involved in their care and to find out how and when to

contact them in the future.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendation 1.2.3

## Definitions of terms used in this quality statement

### Healthcare professional with expertise in MS

The neurologist responsible for making the diagnosis of MS should ensure that a formal face-to-face follow-up within 6 weeks is provided by themselves or another healthcare professional with expertise in MS (such as an MS nurse), depending on the local service organisation. [Adapted from NICE's 2014 full guideline on multiple sclerosis in adults, section 6.6].

## Equality and diversity considerations

Cognitive problems are a common symptom of MS. People can experience a wide range of difficulties, including problems with attention, memory and decision-making, and planning. This might mean that people with MS forget that they have an appointment, so they should be reminded about the appointment and contacted if they do not attend.

# Quality statement 3: Coordinated care

## Quality statement

Adults with multiple sclerosis (MS) have a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

## Rationale

Adults with MS have different needs for information, advice and support, and this will change as their condition progresses. Support should be tailored to the individual person and responsive to changing needs, including relapses, acute deteriorating symptoms and progression. The single point of contact should have knowledge of MS services and will ensure that adults with MS can access care and support from health and social care practitioners, which is relevant to their specific needs.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

a) Evidence of local arrangements to provide adults with MS with a single point of contact with knowledge of MS services who coordinates access to care from a multidisciplinary team with expertise in MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service protocols or service specifications.

b) Evidence of local arrangements for a multidisciplinary team with expertise in MS to care for adults with MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from service specifications or local protocols.

## Process

Proportion of adults with MS with a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Numerator – the number in the denominator with a single point of contact who coordinates access to care from a multidisciplinary team with expertise in MS.

Denominator – the number of adults with MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

## Outcome

a) Patient satisfaction with a single point of contact for coordination of access to care.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient surveys.

b) Patient satisfaction with timeliness of access to care from the multidisciplinary team with expertise in MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient surveys.

## What the quality statement means for different audiences

**Service providers** (neurology services) ensure that adults with MS have a single point of

contact with knowledge of MS services who coordinates access to care from a multidisciplinary team with expertise in MS.

**Health and social care practitioners** (members of the multidisciplinary team) provide coordinated care for adults with MS through a single point of contact who has knowledge of MS services.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that, for adults with MS, they commission neurology services that have a single point of contact with knowledge of MS services who coordinates access to care from a multidisciplinary team with expertise in MS.

**Adults with MS** have someone they can contact to help them get the care they need from health and care services. They know when and how to contact this person. They can talk about any changes in their condition and any extra or different support they might need. Support should be available from a team with training and skills in managing MS.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendations 1.3.1 and 1.3.2

## Definitions of terms used in this quality statement

### Multidisciplinary team with expertise in MS

The team should involve professionals who have expertise in managing MS, including MS nurses, consultant neurologists, physiotherapists with expertise in MS and occupational therapists.

Other professionals should be involved, according to the needs of the individual adult with MS, such as consultants in rehabilitation medicine, speech and language therapists, psychologists, dietitians, specialist neuropharmacists or specialist MS pharmacists, primary healthcare team, social care and continence specialists. A multidisciplinary team approach should encompass all these perspectives as well as those of the person with MS and their family. [NICE's guideline on multiple sclerosis in adults, recommendation 1.3.2 and 2014 full guideline, section 7.6]

# Quality statement 4: Physical activity

## Quality statement

Adults with multiple sclerosis (MS) who have problems with mobility or fatigue are offered support to remain physically active.

## Rationale

Remaining physically active can improve mobility and fatigue, which are common problems experienced by adults with MS. It can also help to reduce the secondary complications of inactivity, such as pressure sores, and help adults with MS to regain or maintain their strength.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that adults with MS who have problems with mobility or fatigue are supported to remain physically active.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from service protocols.

## Process

Proportion of adults with MS who are offered support to remain physically active.

Numerator – the number in the denominator who are offered support to remain physically

active.

Denominator – the number of adults with MS who have problems with mobility or fatigue.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## Outcome

a) Adults with MS who have problems with mobility or fatigue feel supported by healthcare professionals to remain physically active.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from surveys.

b) Levels of physical activity among adults with MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from surveys.

## What the quality statement means for different audiences

**Service providers** (GPs, community health teams and neurology services) ensure that adults with MS who have problems with mobility or fatigue are offered support to remain physically active. It may be useful to compile information about local exercise classes, groups and facilities, so that people can be given information about any that are suitable.

**Healthcare professionals** (members of the multidisciplinary team) ensure that they offer adults with MS who have problems with mobility or fatigue support to remain physically active.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that they commission services in which adults with MS who have problems

with mobility or fatigue are offered support to remain physically active. The services commissioned should include provision of supervised exercise programmes for adults with MS who may benefit because of problems with mobility or fatigue.

**Adults with MS** who have problems with movement or fatigue are helped to do some exercise because this can improve these symptoms. Healthcare professionals should explain what types of exercise are suitable, what activities are available and ask which the person prefers.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendations 1.5.7, 1.5.9, 1.5.20, 1.5.21 and 1.5.23

## Definitions of terms used in this quality statement

### Support to remain physically active

Healthcare professionals should discuss the potential benefits of exercise with adults with MS who have problems with mobility or fatigue. Programmes or courses of exercise therapy should be supported by a competent professional, such as a physiotherapist with expertise in MS, who can suggest the most suitable exercises and monitor the effects.

Types of suitable physical activity may include the following:

- aerobic, resistive and balance exercises, including yoga and pilates
- a combination of a programme of supervised aerobic and moderate progressive resistance activity and cognitive behavioural techniques for people with MS with moderately impaired mobility (an EDSS [Expanded Disability Status Scale] score of greater than or equal to 4)
- supervised exercise programmes involving moderate progressive resistance training and aerobic exercise
- exercise referral schemes.

People with MS should also be encouraged to keep exercising after programmes end for longer term benefits. [Adapted from NICE's guideline on multiple sclerosis in adults,



recommendations 1.5.7, 1.5.9, 1.5.20, 1.5.21 and 1.5.23, 2014 full guideline, sections 10.3.6 and 10.4.6 and expert opinion]

# Quality statement 5: Managing relapses

## Quality statement

Adults with multiple sclerosis (MS) who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

## Rationale

Rapid treatment of relapse can improve recovery and long-term outcomes of people with MS and prevent unplanned hospital admissions. Local pathways for managing relapse can help to identify relapses early and improve response times. Recognition of relapses by the multidisciplinary team, based on effective assessment, is important because relapse frequency may influence which disease-modifying therapies are chosen and whether they need to be changed.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local pathways to ensure that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications, NHS trust directories of services and clinical commissioning group pathways.

## Process

a) Length of time between onset of symptoms of relapse and receiving treatment for adults with MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

b) Proportion of relapses in adults with MS that would benefit from treatment and are treated within 14 days of the onset of symptoms.

Numerator – the number in the denominator treated within 14 days of the onset of symptoms.

Denominator – the number of relapses in adults with MS that would benefit from treatment.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

## Outcome

Unplanned hospital admissions for MS.

**Data source:** NHS Digital Hospital Admitted Patient Care Activity, using ICD-10 code G35.

## What the quality statement means for different audiences

**Service providers** (GPs, community health teams, and neurology services) ensure that local pathways for managing relapse are in place so that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

**Health and social care practitioners** (those involved in the care of adults with MS) ensure

that they are aware of local pathways for managing relapse so that adults with MS who have a relapse that would benefit from treatment are offered treatment as soon as possible and within 14 days of the onset of symptoms.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that they commission services that have local pathways for managing relapse for adults with MS so that treatment is offered, for relapses that would benefit, as soon as possible and within 14 days of the onset of symptoms.

**Adults with MS** who have new symptoms or symptoms that suddenly get worse (a relapse) are offered treatment if this is likely to help. The treatment is offered as soon as possible and within 14 days of the symptoms starting. They can get the treatment through their single point of contact. Quicker treatment should help them get better sooner and may mean they don't have to go to hospital.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendation 1.7.5

## Definitions of terms used in this quality statement

### Relapse

A relapse should be diagnosed if the person develops new symptoms or their existing symptoms get worse and last for more than 24 hours in the absence of infection or any other cause after a stable period of at least 1 month. Relapses should be assessed and diagnosed by a healthcare professional with expertise in MS because not all relapses need treating with steroids. [NICE's guideline on multiple sclerosis in adults, recommendations 1.7.1 and 1.7.6]

### Treatment for relapse

Treatment should be offered for relapses of MS that affect the person's ability to perform their usual tasks. Adults with MS who have a relapse should be offered treatment with oral methylprednisolone 0.5 g daily for 5 days. Intravenous methylprednisolone should be considered if oral steroids have failed or are not tolerated or for people who need

admitting to hospital for a severe relapse or monitoring of medical or psychological conditions. People should not be given a supply of steroids to self-administer at home for future relapses. [NICE's [guideline on multiple sclerosis in adults](#), recommendations 1.7.5, 1.7.7, 1.7.8 and 1.7.10]

# Quality statement 6: Comprehensive review

## Quality statement

Adults with multiple sclerosis (MS) are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

## Rationale

A comprehensive review for people with MS ensures that they have the opportunity to hear from healthcare professionals about any new treatments, to be kept informed of their options, and for any issues or changes that might need referral to different services or other healthcare professionals to be identified. A planned review will also pick up people who have not been in contact with services, whose condition is not being monitored and who are not receiving support. These people may have more unmet needs than those in regular contact.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local arrangements to ensure that adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service specifications or audit of patient records.

## Process

Proportion of adults with MS who have a comprehensive review by healthcare professionals with expertise in MS within 12 months of the previous review or diagnosis.

Numerator – the number in the denominator who have a comprehensive review by healthcare professionals with expertise in MS within 12 months of the previous review or diagnosis.

Denominator – the number of adults with MS.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (GPs, community health teams and neurology services) ensure that adults with MS are offered a comprehensive review at least once a year by healthcare professionals with expertise in MS.

**Healthcare professionals** (members of the multidisciplinary team with expertise in MS) ensure that they offer adults with MS a comprehensive review at least once a year.

**Commissioners** (NHS England, integrated care systems and clinical commissioning groups) ensure that they commission services that offer adults with MS a comprehensive review at least once a year by healthcare professionals with expertise in MS.

**Adults with MS** are offered an appointment at least once a year to discuss their condition with healthcare professionals with experience in MS. At this appointment they are asked about their symptoms, their medicines, their overall health and wellbeing, and how their condition affects their day-to-day life (family life, work and other activities). They can raise any problems and mention any extra support they need. A planned yearly appointment will also pick up people who have not been in contact with services over the past year but need some support.

## Source guidance

Multiple sclerosis in adults: management. NICE guideline NG220 (2022), recommendations 1.6.1 and 1.6.2

## Definitions of terms used in this quality statement

### Comprehensive review

A comprehensive review involves reviewing all aspects of care for a person with MS. The review should be carried out by healthcare professionals with expertise in MS and its complications, be tailored to the needs of the person with MS, and assess the following:

- MS symptoms
- the course of the disease and number of relapses in the past year
- general health, including mental health
- social activity and participation
- care and carers
- palliative care, when needed.

Other health and social care practitioners with expertise in specific areas of the review should be involved if needed. It is likely that the emphasis in the review may change over time and that different healthcare professionals may carry out the review. Any issues identified during the comprehensive review should be referred to other members of the MS multidisciplinary team and to other appropriate teams so that they can be managed. People with MS should also be offered a medication review. [[NICE's guideline on multiple sclerosis in adults](#), recommendations 1.6.1 to 1.6.5, full guideline, section 11.6 and expert opinion]



# Update information

## Minor changes since publication

**June 2022:** Changes have been made to align this quality standard with the updated [NICE guideline on multiple sclerosis](#). Minor changes have been made to definitions, and data sources, links and source guidance references have been updated throughout.

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standard advisory committees](#) for details about our standing committees. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource

impact work for the source guidance. Organisations are encouraged to use the [resource impact statement for NICE's guideline on multiple sclerosis](#) to help estimate local costs.

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard 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 quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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## Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

## Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of General Practitioners \(RCGP\)](#)
- [Royal College of Nursing \(RCN\)](#)