



**PATIENT &
PUBLIC INVOLVEMENT
NEWSLETTER
AUTUMN 2017**

New publications

Guidelines



SIGN 149: Risk estimation and the prevention of cardiovascular disease

This guideline deals with the management of cardiovascular risk. It provides recommendations on how to estimate someone's risk of having a cardiovascular event whether or not they have established cardiovascular disease. It also recommends how to manage cardiovascular risk with medicines and through lifestyle changes.

SIGN 150: Cardiac rehabilitation

This guideline provides evidence-based recommendations and best practice guidance on the management of patients referred for cardiac rehabilitation. It provides recommendations on assessment, health behaviour-change techniques, lifestyle risk factor management, psychosocial health, vocational rehabilitation and medical risk management

Patient versions of guidelines

Managing asthma in adults: a booklet for patients, carers and families



Managing asthma in children: a booklet for patients, carers and families

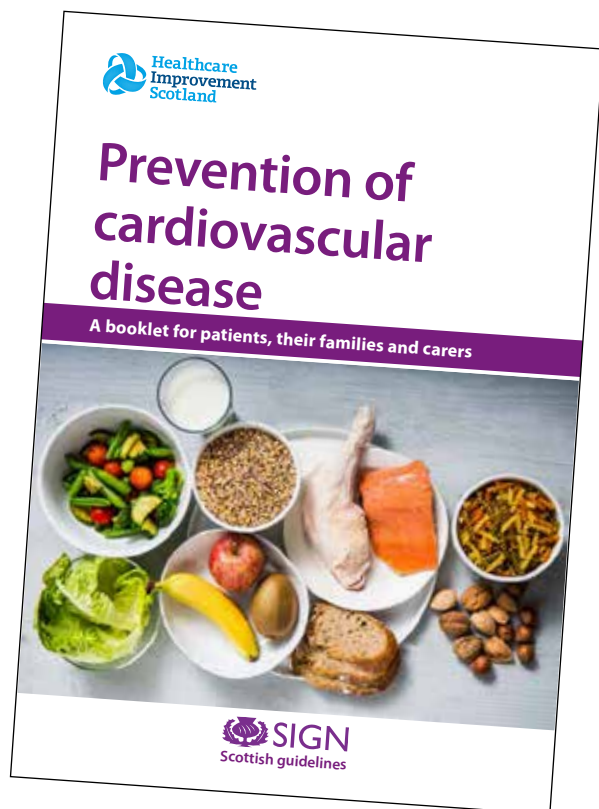
Asthma in pregnancy: a booklet for women, partners, friends, family members and carers



Cardiac rehab: a booklet for patients, their families and carers

Due for publication in 2017

Patient versions of guidelines



Prevention of cardiovascular disease

Mood disorders in pregnancy and after the birth of your baby

We are in the process of updating the presentation of information in this booklet to bring it in line with the style of our other patient versions of guidelines. We introduced a new way of presenting information in patient versions of guidelines in 2015 as a result of findings from an international research collaboration in which SIGN was a leading partner.

www.decide-collaboration.eu/

Opportunities to become involved with SIGN – can you help?

Guideline development groups

Epilepsy in children and young people

In October/November, we will begin to review our guideline on Epilepsy in children. We are in the process of recruiting patients, service users, parents and carers to this group.


Perioperative blood transfusion

In early 2018, we will start to produce a guideline on Perioperative blood transfusion for elective surgery. We will be looking for people who can offer a patient or carer perspective to this group.

Membership of a guideline development group provides an opportunity for service users', patients' and carers' voices to be heard so please help us to get people involved in the above guidelines. You can read more about joining a guideline group on our website.

www.sign.ac.uk/joining-a-group.html





If you don't have time to sit on a guideline group, we would still be interested in hearing what matters to you! Please get in touch with us karen.graham2@nhs.net

Cardiac arrhythmias – peer review

We are looking for people to review our draft guideline from a patient or carer perspective to make sure we have considered the issues that matter to them. You can read more about what's involved on our website. www.sign.ac.uk/consultations.html

Patient versions of guidelines

Angina and migraine

We are looking for a patient, service user or carer with experience of the above conditions to help us to develop the patient version of the SIGN guideline on Management of stable angina and Management of migraine. We would ask you to attend a planning meeting and contribute to or comment on drafts via email.


Prevention of cardiovascular disease

This patient version of this guideline is now out for consultation and can be downloaded from our [website](#). We are keen to gather your feedback to help us to improve our booklet and to make sure it is useful.

Helping patients, carers and the public to suggest guideline topics to SIGN

To encourage and support patients, carers and the public to submit topic proposals to SIGN, a public partner worked with us to produce user-friendly guidance to help with the process and to address expectations of proposers. A simplified proposal form detailing information requirements in simple language was also developed.

To ensure the proposal form and guidance was fit for purpose and understood by patients and the public, a pilot exercise was undertaken with the proposer for the guideline on Low carbohydrate/high fat diet as first-line management for people diagnosed with Type 2 diabetes. The proposer had a non-clinical background and completed the proposal form using the guidance. Feedback suggested that the guidance and the form explained the requirements well, it was written in user-friendly language and the tone was acceptable. This will help to ensure that SIGN's approach to topic selection is inclusive and that SIGN considers topics that are important to a range of stakeholders including patients, carers and the public. The guidance is available on our website. www.sign.ac.uk/patient-topic-proposal.html



Continuing to improve patient versions of guidelines – sharing our research findings

In previous newsletters, we updated you on the work of the DECIDE project www.decide-collaboration.eu/patients-and-public The project aimed to develop and test new ways of presenting research information in guidelines and tailoring these to the information needs of the public, patients and their carers, as well as clinicians and policymakers.

Improving the way information is presented helps to empower people to take an active role in shared decision making. To build on findings from the DECIDE project, we carried out research which aimed to engage with parents and carers of children and young people with autism spectrum disorder (ASD) to test a new and improved patient version of the guideline.


Using earlier findings from DECIDE on how patients and consumers prefer to see information from guidelines, a new design for a patient version of the SIGN guideline on ASD was created. We carried out formal 'think aloud walkthrough' user-testing interviews with parents and carers from across Scotland.

The booklet was valued by users, who expressed a desire to have had it when their child was being diagnosed. Clearly outlining key stages in the patient journey was useful, and made parents/carers feel empowered. The majority of users said they had heard of patient versions of guidelines, but were not aware that one existed for ASD, and how they could access it.

This user testing enabled us to develop a tailored and practical booklet for the target group. There is a fine balance between providing sufficient information and information overload. Patient versions of guidelines need to clearly state their intended purpose, and how a user can make use of them.

The findings have implications for presenting evidence-based information: overall. There was not a clear consensus on the usefulness of rating the strength of evidence underlying recommendations. Users appreciated evidence grading but some either did not fully understand this, or find it useful. It appears that evidence grading should be included in patient versions but kept as simple as possible.





We will share these findings this month at the Guidelines International Network (GIN) conference in Cape Town. We will also share the findings in October, at the International Society for Quality in Healthcare (ISQua) conference in London.

How your feedback helps to improve our information to patients and the public

We consulted on our patient version of the cardiac rehabilitation guideline in June.

We are very privileged at SIGN to have our patient and public involvement network who can act as a consultative body when we need input from patients, service users, carers and the public.

Here are a few areas of our cardiac rehabilitation booklet we have improved in light of your feedback.

Our booklet was well received and we received a wealth of positive comments. Thank you to all of you who took the time to comment and offer suggestions for improvement.

Would you like to hear from our Awareness Volunteers?

Are you hosting an event and would like to hear more about SIGN from our Awareness Volunteers?

Our Awareness Volunteers can come along and give a talk or they can exhibit. If you are interested please let us know karenking5@nhs.net





What you said	What we did
Layout	
The image on the cover was not representative and gave the impression that this was only aimed at older people.	Designed cover showing a diverse range of icons.
More images needed to break up text, particularly in relation to healthy eating.	More icons added next to recommendations.
More colour needed.	Black icons changed to coloured icons.
Content	
Booklet seems to be for people who have had a heart attack but people with other conditions such as angina also attend cardiac rehabilitation.	Referred to diagnosis instead of cardiac event which covers those who have not had a heart attack.
The patient story at the beginning of the booklet was unhelpful. People may not engage if their story is very different.	We replaced the story with a range of quotations from patients from various areas of Scotland to make this more meaningful.
Booklet focused too much on the exercise component of rehabilitation.	Linked more closely to recommendations from SIGN's cardiovascular disease prevention guideline to give people information on lifestyle changes such as diet.
Need for more information in lifestyle changes section to help people to self manage.	<p>Provided more information in the form of tips and quotes and linked to SIGN guideline on prevention of cardiovascular disease.</p> <p>Inclusion of Eat Well Guide to help people to eat a healthy balanced diet.</p>
Alcohol units need to be better explained.	Included information on government guidelines for alcohol.
Need for a reference to supporting people to return to work.	Added sentence in stating that people will be supported and their return to work will be planned.

