Patient Newsletter Summer 2016

NEWLY PUBLISHED GUIDELINES

SIGN 147 Management of chronic heart failure

This guideline, the first of six to be issued by SIGN covering different topics of coronary heart disease, provides recommendations on the management of patients with chronic heart failure. It covers diagnosis, lifestyle modification to reduce risk and progression of heart failure, pharmacological and interventional therapies, organisational planning, palliative care and a checklist of information for patients.

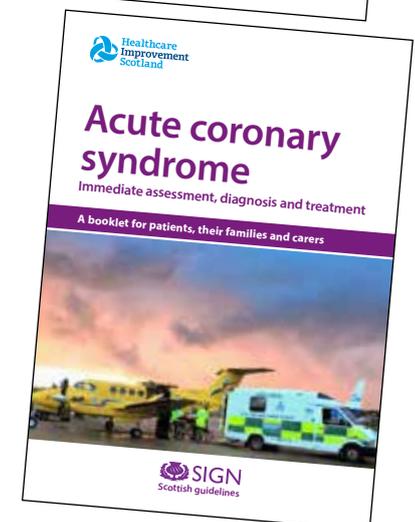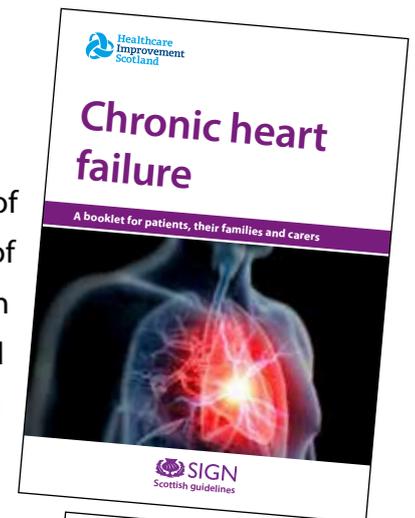There is a patient booklet that accompanies this, which explains:

- what chronic heart failure is
- what causes it
- what the symptoms are
- how it is diagnosed
- how it is treated; and
- what you can do to help yourself.

SIGN 148 Acute coronary syndrome

This is the second coronary heart disease guideline, and provides recommendations on the management of patients with acute coronary syndrome. It covers presentation, assessment and diagnosis, initial management, reperfusion therapy, risk stratification and non-invasive testing, invasive investigation and revascularisation, early pharmacological intervention and treatment of hypoxia and cardiogenic shock and includes a checklist of information for patients.

The accompanying patient booklet was issued in June 2016 and explains:

- assessment and investigation
- other treatments during the first 12 hours; and
- continuing investigation and treatment.

UPCOMING GUIDELINES

SIGN will start to develop the following guidelines this year.

Migraine

A new guideline on the use of devices and pharmacological management of patients with migraine is scheduled to start in summer 2016.

Fetal alcohol syndrome disorder

A new guideline on the early diagnosis and support of children with fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorder (FASD) is scheduled to start in summer 2016.

We have been working in partnership with patient organisations to identify people who have been affected by the above conditions and who can become members of the guideline development groups. Patient organisations have also been invited to make written submissions to SIGN highlighting patient needs and preferences for treatment to help us to ensure that our guidelines are patient centred.

Why not send in some patient and carer issues of concern you think the above guidelines should cover?

Consultation of patient versions of SIGN guideline on autism spectrum disorders

The following patient versions of the SIGN guideline on assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders are being updated to reflect the revisions to the clinical guideline.

- ⊙ Autism spectrum disorders: a booklet for young people
- ⊙ Autism spectrum disorders: a booklet for parents and carers

The revised guideline also covers adults and we have been a new patient version of the guideline specifically for adults in development. Parents, young people, and adults with autism spectrum disorders have been helping SIGN to develop the booklets to ensure they are useable and helpful.

We are now consulting on these booklets which can be found on our website **www.sign.ac.uk/consultation/index.html**. If this is a topic that you have experience of or are interested in, we would welcome your comments.
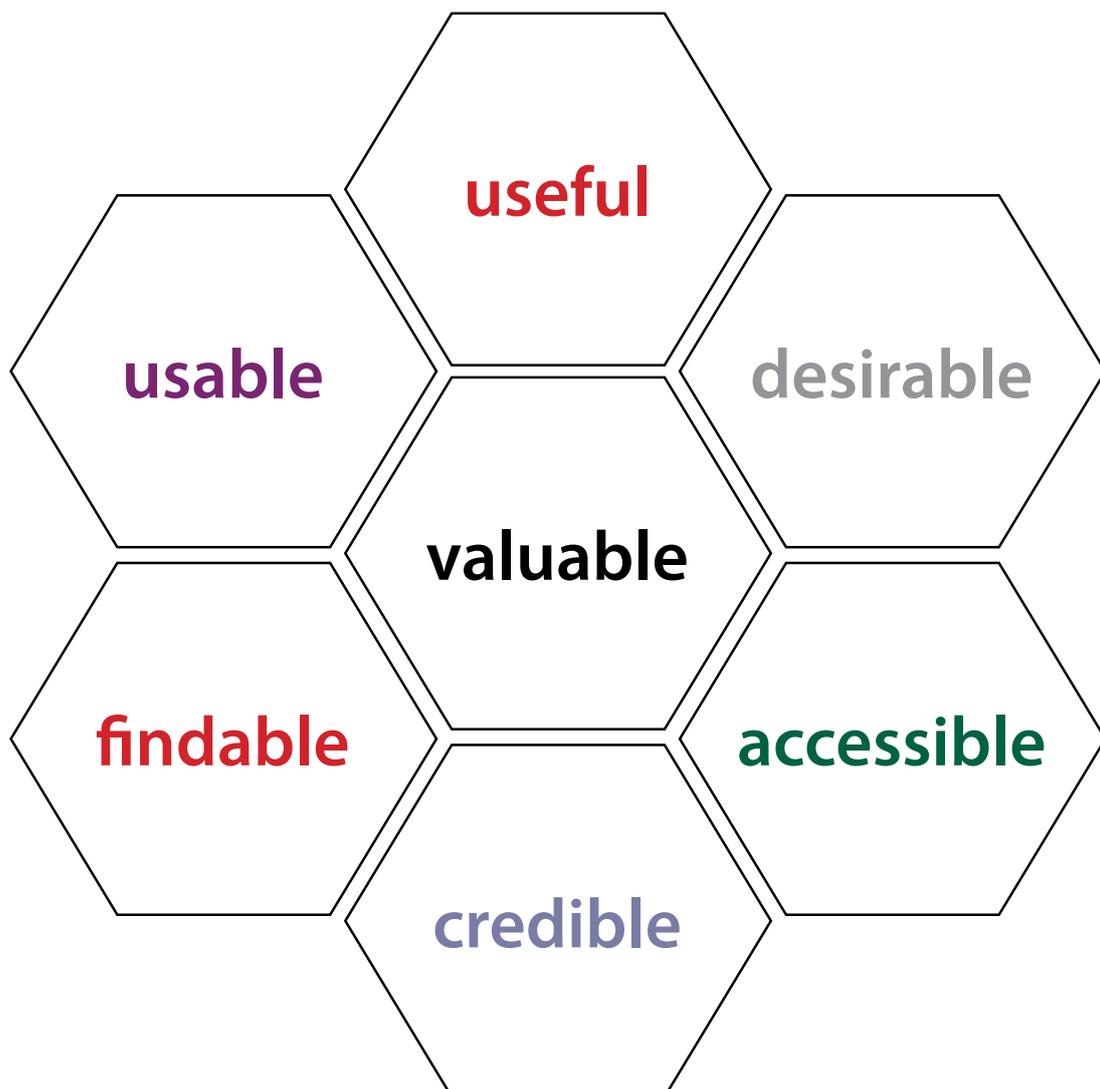
Please follow the SIGN Patient Network on Facebook for details of when patient versions are going to consultation or being published, and for information from groups and organisations that share common interests with the work done by Healthcare Improvement Scotland public partners. All details can also be found on the SIGN website – www.sign.ac.uk

UPDATE ON THE DECIDE PROJECT

In our last newsletter we updated you on user testing of the patient version of SIGN guideline 144 glaucoma referral and safe discharge. Karen Graham presented the results at the Guidelines International Network conference in October.

The work surrounding the development of this booklet, done with patients in spring 2015, led to publication of a paper in February 2016. Healthcare Improvement Scotland (HIS) staff members, including Karen Graham, were authors of the paper, *Improving the user experience of patient versions of clinical guidelines: user testing of a Scottish Intercollegiate Guideline Network (SIGN) patient version* **(http://bmchealthservres. biomedcentral.com/articles/10.1186/s12913-016-1287-8)**

We have summarised the findings from the user testing in the table overleaf. Findings were grouped using Morville's user experience honeycomb.
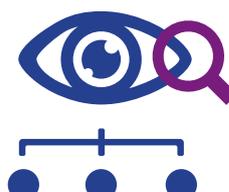
Usefulness

- Informs.
- Empowers to ask questions and request more information.
- Know what to expect when seeing a healthcare professional or having a procedure.
- Most useful around time of diagnosis – when lacking knowledge and may struggle to retain information.

Usability

- Levels of evidence/recommendation icons are generally clear, recognisable and useful.
- Front cover must communicate clearly what it is about and who it is for eg title(s) and image.
- Icons make the booklet clear, friendly, attractive and helps to 'chunk' the information.
- Patient quotes helped to personalise/humanise the information and helps to get the message across clearly.
- Some people want statistical information, some do not.
- Preference for bold, black and strong colours. Dislike for pale colours.

Family history

If you have a close relative, such as a parent, brother or sister, who has glaucoma, you may also have an increased chance of getting glaucoma yourself.

Credibility

- Patients/public do want reassurance that the information in the guideline is credible.
- Most guideline users placed an emphasis on the involvement of qualified professionals rather than evidence, or process of production.
- Status of guideline is key for some – are the standards and recommendations enforced?
- Information on guideline body and methodology preferred at back of the booklet.

How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.

1	2	3
Identify questions	Search for evidence	Look at the evidence
4	5	6

Desirability

- What made this patient guideline desirable?
- Quotes and use of icons gave a friendly and engaging look.
- Avoiding too many tables or too much text – keep it as simple as possible eg chunking of information.
- Colourful and glossy booklet.
- Avoid generic images or negative images.
- Avoid negative or 'bossy' tone.
- Cover the information people want to know.
- Clearly targeted at the intended audience.

"Following diagnosis I discovered that it was a hereditary disease and that all the family knew about our risk except me. My brother and my sister had been having regular tests for some time".
Roy, age 78

Findability	
• Informal and direct question style of contents was well received and clear. • Cover image must make it plain what the guideline topic is. • Dissemination is key. • Who is SIGN? • Online is not enough.	**Contents**
Accessibility	
• Internet is not enough – contact information and guideline itself. • Need for multiple versions? • Ensure useable and accessible for the intended audience. • Accessibility of interventions/services eg eye checks are free in Scotland.	**GLAUCOMA** Referral and safe discharge A booklet for patients, their families and carers

The glaucoma booklet is available on the SIGN website **www.sign.ac.uk/pdf/PAT144.pdf**

BRINGING A PUBLIC PERSPECTIVE TO PATIENT VERSIONS OF GUIDELINES

SIGN will now work with Healthcare Improvement Scotland public partners to develop patient versions of guidelines. Public partners will work with healthcare professionals and patients on the guideline development group to provide an objective user perspective to determine content of patient versions of guidelines, including appropriate images and diagrams. Developing patient versions with patients and public partners will ensure that these are relevant, accessible, user friendly and easy to understand.

ARE PATIENT BOOKLETS CRYSTAL CLEAR?

We are currently in the process of finding out the views of people on how important it is to have the crystal mark from the Plain English Campaign on SIGN's patient booklets. The previous style of the booklet meant that this was inside the booklet and not visible when the booklet is on a display stand. The recent redesign means that, if it made a difference to users, it would be possible to return this to the front cover. Please use the following link, which is also on the email issuing the newsletter, to answer six short questions to give us your opinion. www.smartsurvey.co.uk/s/3ZUN3/

AWARENESS VOLUNTEERS

Awareness Volunteers help to raise awareness of SIGN in several ways, including hosting exhibition stands. This year we had a stand at the Age Scotland National Conference in March.

If you have details of any events where SIGN Awareness Volunteers could exhibit, please contact Karen King (**karenking5@nhs.net**) several weeks before the event date.

Best wishes
Karen Graham and Karen King