



Patient and Public Involvement Newsletter

Spring 2017

Welcome to the first edition of SIGN Patient and Public Involvement Network newsletter of 2017. Since summer 2016, we have been busy working with patients, carers and public partners (volunteers) to produce new patient versions of guidelines to accompany some clinical guidelines. To help Karen Graham develop these, Laura Walker was welcomed to the team, as Research Analyst, to produce the two patient versions of the guideline on management of asthma.



New publications

Guidelines

SIGN 146: Cutaneous melanoma

SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders (ASD)

SIGN 153: British guideline on the management of asthma

Patient versions of guidelines

Autism: a booklet for adults, partners, friends, family members and carers

Autism: a booklet for young people

Autism: a booklet for parents, carers and families of children and young people with autism



Leaflets

We have updated the following leaflets.

Peer reviewing a draft guideline: information for patients, carers and member of the public
www.sign.ac.uk/pdf/patient_peer_review_leaflet_2017.pdf

SIGN guidelines: information for patients, carers and members of the public
www.sign.ac.uk/patients/index.html

Due for publication in 2017

Guidelines

Cardiac rehabilitation

Risk estimation and the prevention of cardiovascular disease

Cardiac arrhythmias in coronary heart disease

Management of diabetes

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

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

Prevention of cardiovascular disease: a booklet for people at risk of cardiovascular disease, their families and carers

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

Ever wondered how we develop patient versions of guidelines?

To develop a SIGN guideline, we bring together a group of people from across Scotland including health and social care professionals, for example doctors, nurses, social workers, patients, carers and members of the public.

This group is known as the guideline development group (GDG). The GDG involves patients and carers so that their practical knowledge and experience of living with a condition complements that of the professionals on the group.



As part of the process, the GDG makes a decision on whether a patient version of the guideline is needed. If it is, once the clinical guideline reaches the editorial stage of the guideline development process, we start work on the development of the patient version(s). Members from the GDG (including professionals and patients) help with this process. Guidelines often have many recommendations but not all of these are required to go into patient versions. Patient versions should prioritise the recommendations that patients can influence or discuss with their clinician.

We work with patients, carers and Healthcare Improvement Scotland public partners (volunteers) to select recommendations for inclusion in the patient version. This helps to make sure that our patient versions are relevant. Once recommendations have been selected, we translate them into patient friendly language to allow them to be easily understood by patients and carers.

We ask a wider group of patients and the public for feedback on our patient versions of guidelines at the consultation stage of the development process. This helps to make sure that our information is useful and helps patients to make decisions about their care. It also helps to make sure that the way we have presented the information is helpful and that we have written it clearly.

All suggestions for change, or improvement, are considered by the group working on the patient version and the SIGN editorial team. A consultation report recording feedback and the guideline group's responses is published on the SIGN website alongside the final patient version.

On Patient Booklet publication day, Karen King, SIGN's Distribution Co-ordinator makes all the NHS Scotland health boards aware of the publication, with a brief summary of the information included and the hyperlink to the booklet.

All paper copies of patient versions are free to people living in Scotland and are free for anyone to download from the website. We are happy to provide booklets to display and promote at volunteer and health events across Scotland.

On request, SIGN booklets can be translated into any of the more common community languages. The process for doing this can take several weeks.

Please contact Karen Graham – karen.graham2@nhs.net, to become involved in SIGN's work or Karen King – kareking5@nhs.net, if you would like any of the publications or have details of any events that our awareness volunteers could attend to promote SIGN's work.



How SIGN worked with people with experience of autism to develop patient versions of guidelines

Autism: a booklet for adults, partners, friends, family members and carers.

This is the first time that a guideline development group has recognised the need for a patient version of the Autism Spectrum Disorder (ASD) guideline specifically for adults.

The patient version provides information for adults who may have autism or who have already been diagnosed with autism.

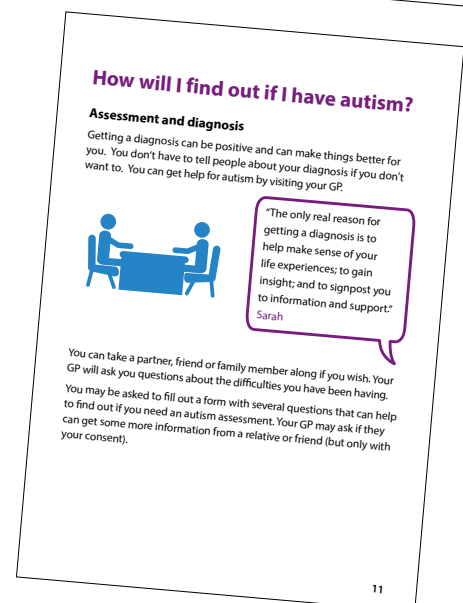
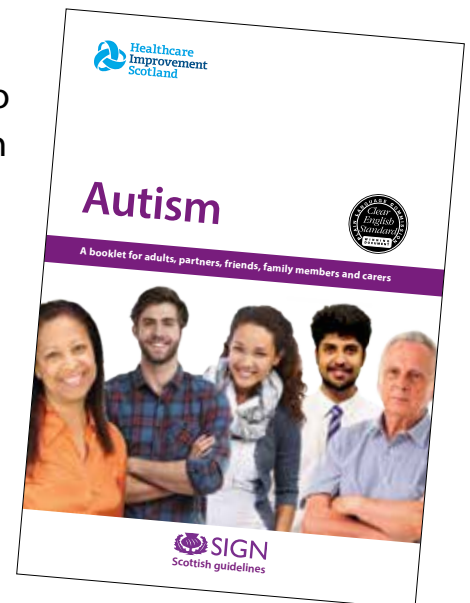
We worked with Autism Network Scotland who helped us to run a workshop with thirteen adults to decide and provide content for the booklet.

Some of the adults who attended the workshop continued to be involved in the development process to help us to make sure that our booklet would be accepted by other adults with autism.

The booklet covers the following:

- what is autism?
- initial concerns a person may have
- assessment and diagnosis
- what can help?
- the information and support someone with autism should receive, and
- details of organisations that provide further information.

The information provided may also be helpful for families and friends.





Autism: a booklet for young people.

As part of the development process for this patient version, we visited young people with autism in schools to hear about their experience of health services at diagnosis and during treatment and what information helped them to understand their condition.

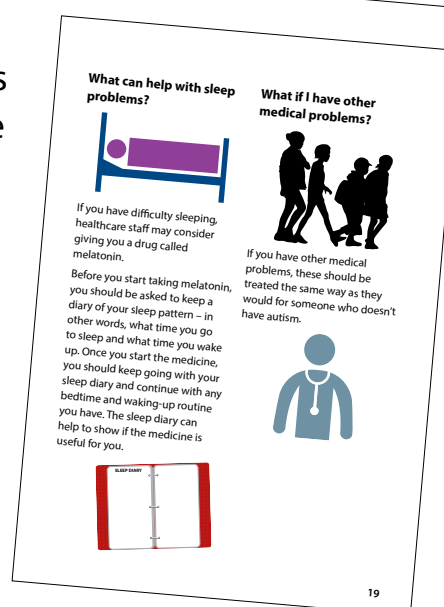
This booklet includes quotes from young people with autism about:

- what it was like for young people before and after they knew they had autism
- how young people were told they had autism
- what they found helpful; and
- what information people needed about autism

The booklet tells people what autism is, how autism is diagnosed, what can help and provides details of the services, information and support available.

Many young people with autism also took part in the consultation of the booklet and provided us with written feedback on what they found helpful and how we could improve our information.

The [consultation report is available on our website](#) alongside the booklet.





Autism: a booklet for parents and carers.

This booklet is an example of how the reviewers taking part in consultation can make a difference to the final draft.

We listened to what parents and carers said and felt that further work was needed to produce a booklet that better informed its readers in language and style that was acceptable to them.

The booklet was improved based on feedback from consultation and formal user testing of the booklet took place with fourteen parents/carers to formally test our improved booklet.

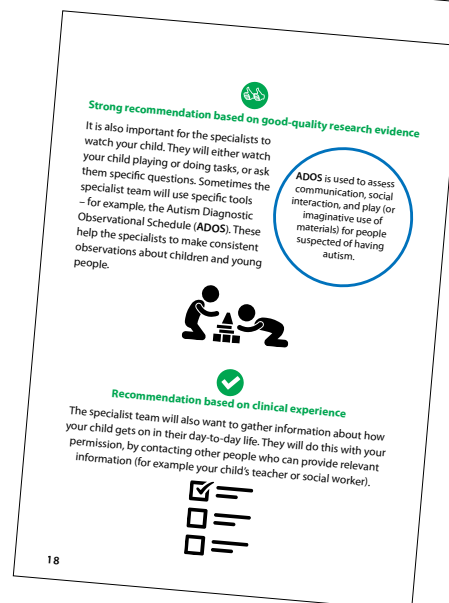
The booklet was improved further, taking into account feedback from user testing.

This booklet tells parents and carers:

- what autism is and the possible signs of autism in children.
- the processes professionals go through find out if a child has autism
- how to understand their child's profile, and
- what can help

These booklets are now available and are free to residents living in Scotland. They cost £2.00 per copy for people living outside Scotland, but anyone can download the booklets free of charge from the SIGN website www.sign.ac.uk.

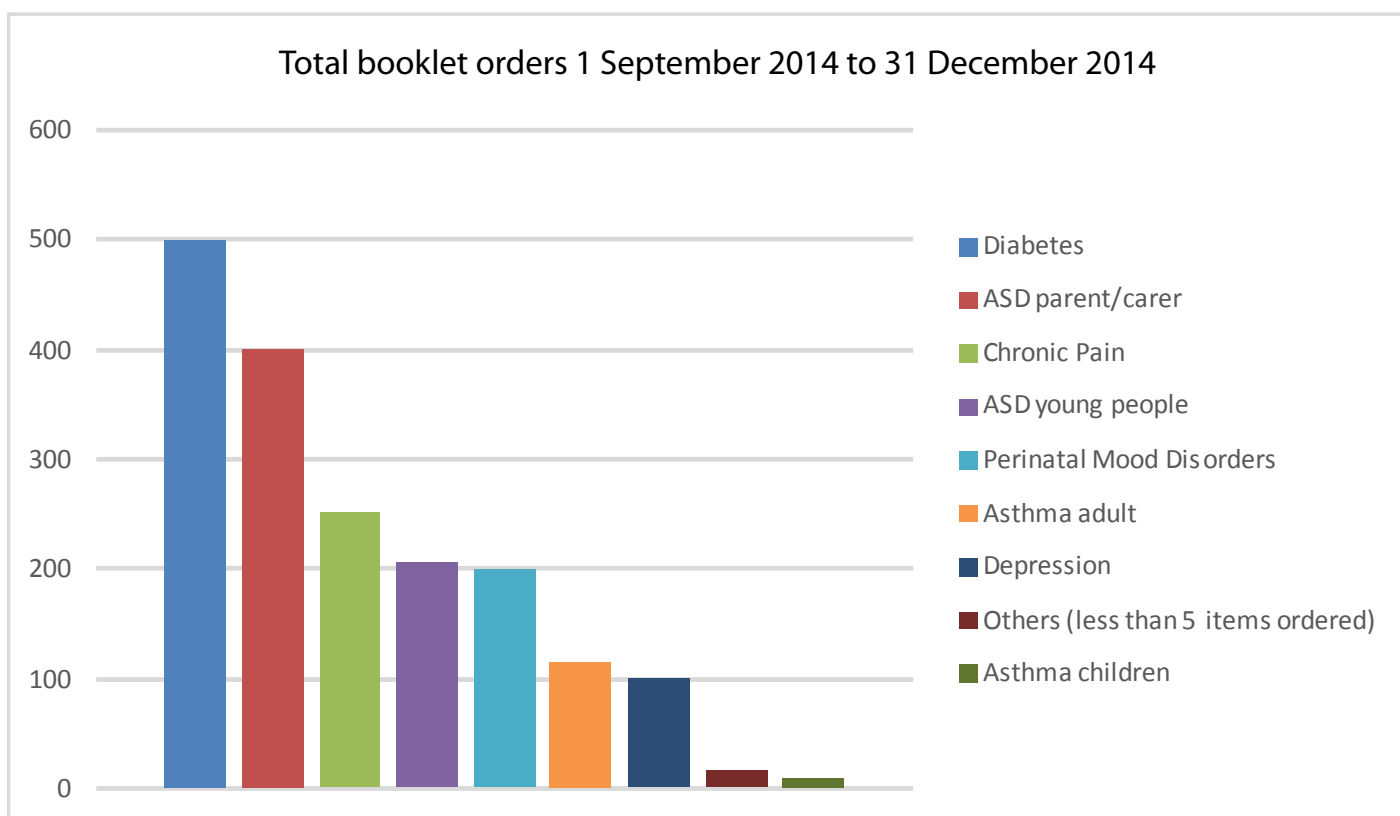
Orders for current patient booklets can be made to karenking5@nhs.net





Distribution of patient versions of guidelines

In September 2014, SIGN became more proactive in promoting patient booklets, monitoring the number of orders received and looking for new contacts that would be interested in the information the booklets provided.



During the period shown on this chart, SIGN only sent out booklets if a request for them was made. However, this still led to a total of 1,798 booklets being order in the three month period.

In February 2015, we saw that we were not connecting well enough with Primary Care - healthcare provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment. Contact was made with distribution co-ordinators in Primary Care (co-ordinators are usually someone with some involvement in clinical governance) and they are now always included when information about new patient booklets is sent out.

In 2015, Healthcare Improvement Scotland awarded a new printing contract. This was seen as a good opportunity to promote the quick reference guides (QRGs) and current patient versions, whilst also reducing costs. This resulted in a vast increase in orders, with 12,651 booklets being sent out and an increase in the number of repeat orders.



Other issues affecting the numbers of booklets ordered include:

- the ASD (autism) booklet and booklet for young people with ASD were both unavailable for a considerable part of the year, due to financial constraints
- the glaucoma QRG and patient version were both heavily promoted by NHS by NES, the education organisation, and by the International Glaucoma Association (IGA). Both these organisations handed out the guidelines and patient booklet at conferences and training events
- the diabetes booklet was also popular during the year and was unavailable for several months

During 2016, SIGN was due to publish guideline topics that had previously been some of its most popular – ASD, Asthma and the first few guidelines relating to heart disease. Again, this left periods where some of the booklets were not available, but advance orders were taken so the revised booklets could be sent out as soon as they were available.

The IGA continued its work in promoting the glaucoma booklet and the numbers ordered made it the third most popular.

On 12 December 2016, the new booklet Adults with autism was published and, as expected, the demand was high.



The booklet was well received by patients, healthcare professionals and other organisations working with adults with autism, for example, those helping to find career and educational opportunities. In early 2017, the demand for this booklet is still high with almost 3,000 booklets already sent out (mid-January 2017).



As can be seen from the chart, the booklets for the two heart disease topics have been very popular. Large numbers have been ordered by hospital departments, particularly in Glasgow and the surrounding areas. Although issued only three weeks before the end of the year the adult autism booklet is the fourth most popular.

A total of 15,646 booklets were ordered during 2016 – an increase of 23 percent on the 2015 total.

This year (2017) also looks like being a positive one. The combined number of advance orders for the upcoming booklets for heart disease and ASD is over 500 and the two patient versions for asthma will also be in high demand.



Training for patient representatives and public partners involved in the development of patient versions of guidelines

October saw the first training session for SIGN Guideline Development Group patient representatives and Healthcare Improvement Scotland (HIS) Public Partners (volunteers) who are involved in the production of patient versions. Their reasons for getting involved ranged from being a patient with a particular condition covered by a SIGN guideline topic to having worked previously as a healthcare professional.

The participants were asked why they felt it was important to communicate clinical guidelines to patients and members of the public. As you can see from the following responses, nearly all the thoughts of the group revolved around **communication**.





Group 1

This group were unsure who communicates this information to patients/public.

Working outside a medical environment the general public should be aware of the current recommendations.

It's good to have guidelines to adhere to.

Provides patients with an additional point of reference.

Communication equips the patient with the ability to have a dialogue with GPs and Doctors.

Group 2

Better informed and more able to discuss the condition with healthcare professionals.

It leads to discussions with family.

Breaks down barriers as there is less clinical jargon.

The good layout makes it easy to read and understand.

Patients can learn from other patients.

During the day, a number of group exercises took place to identify how to make the language used in a patient versions user friendly.

All SIGN patient versions are written in plain English. Participants carried out a practical task which looked at presenting information on treatment choices, shared decision making, areas of clinical uncertainty and indications for self care.

Participants also worked together to assess the quality of patient versions of guidelines to give them an understanding of the requirements for producing high quality health information.

New SIGN guideline on delirium – can you help?

The development process for a guideline on the diagnosis and management of delirium will begin in March 2017.

Perhaps you can help us to understand the key issues for patients, carers and families? If you are interested in joining the guideline development group or submitting patient and carer issues of concern, please get in touch with Karen Graham (karen.graham2@nhs.net).

We are also looking for feedback on draft key questions that will form the basis of the guideline. These are available on our website and it would be helpful to get your views on these. www.sign.ac.uk/consultation/index.html



Facebook

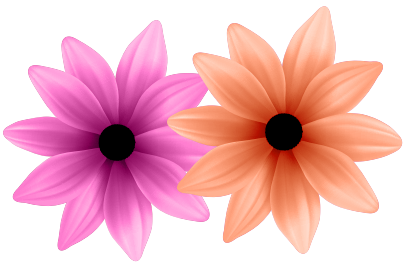
As some of you are aware, SIGN Patient and Public Involvement Network has a Facebook page, found using the following link:

www.facebook.com/SIGNPatientNetwork

What type of information would you like to see on our facebook page?
How could we use it better for patient and public involvement in our guidelines?



Best wishes



Karen Graham and Karen King