



Welcome to the SIGN patient network update

Farewell Kara, welcome back Karen!

In the February edition of the patient network update I let you know that I was going on maternity leave for seven months and here I am back already! Where does the time go? Kara Clark has been covering my post and I'm sure everyone would agree that she has done a fantastic job.

I would personally like to thank Kara for contributing such a huge amount to patient involvement. She has been so enthusiastic and I was relieved to know that patient involvement was left in such good hands while I was away. Kara will be missed by all staff and lay members at SIGN! I would like to wish Kara all the best with her future!

SIGN's work with patients recognised by BUPA foundation

Every year the BUPA foundation awards are made to recognise excellence in medical research and healthcare in seven areas including:

- Care of the elderly
- Clinical excellence
- Communication
- Epidemiology
- Medical research
- Occupational health; and
- Patient safety.

I am delighted to tell you that SIGN's work with patients was shortlisted for a reward in recognition of improving communication between patients and healthcare professionals.

In September, my colleague Lorna Thompson presented SIGN's patient involvement project to a panel of judges at the BUPA foundation. To be shortlisted for an award was an exciting opportunity for us and it is encouraging that other organisations are recognising our work with patients.

Unfortunately, we weren't successful this time but being shortlisted allowed us to reflect on patient involvement developments over the years. It made us realise what significant developments we have made to patient involvement and how we have managed to incorporate it so well that it is now just a standard part of the guideline development process.

We no longer consider involving patients as being the huge challenge that it seemed when we first started. Patient involvement at SIGN is by no means perfect and we are continuing to develop it and now use our expertise to help other organisations engage with patients and the public at local, national and international levels.

We can use our achievement to look forward and develop patient involvement further by attempting to overcome some of the barriers we and many other organisations are currently facing.

You can see a PDF version of Lorna's presentation at www.sign.ac.uk/pdf/bupapresentation.pdf



Evaluation of patient guidelines

At the beginning of the year we commissioned researchers from the University of Glasgow to carry out an evaluation of the patient versions of our guidelines. The aims of the evaluation were to:

- assess the level of awareness about the patient versions;
- to collect views on their relevance and usefulness; and
- to look at the effectiveness of our dissemination strategies.

A sample of primary stakeholders including General Practitioners (GPs), community pharmacies, community health partnerships (CHPs), specialist units, voluntary organisations and the Royal Colleges were interviewed to collect feedback.

Some of the positive comments from the report included:

- ‘staff appreciated having a booklet on the topic to give to patients which was overall well received by patients’.
- ‘staff reported that they felt very positive about the patient versions, viewing them as well produced and supportive literature’.
- ‘really very good – nice and clear and not too daunting’
- ‘patients were taken with it, and especially their spouses, and they felt it armed them with the right things to be asking their GP’
- ‘they are treated like gold dust’

Although we received some negative feedback, we will learn from this to help improve our patient versions of guidelines and make them more useful to patients and carers. Concerning comments which SIGN needs to address included:

- ‘Concern over the SIGN logo – what does it mean to patients?’
- ‘Concern over what is a patient guideline – is it the same as a patient information leaflet?’
- ‘Concern that the information in the guidelines could create anxiety in the patient’
- ‘they have been thrown out or filed’



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The main conclusion from the report was that our patient booklets do not seem to be reaching people despite major efforts to disseminate them. We used two different approaches to dissemination and the report was inconclusive as to which approach worked best. The findings did suggest that sending the booklets via SIGN co-ordinators in clinical governance departments worked well as they usually have an established process for disseminating the clinical guidelines and sent the patient booklets to the same list of people.

We need to carry out further work in this area to make sure healthcare professionals, patients and carers are aware of our very much valued patient booklets. If you have any thoughts on how we could make sure that our patient guidelines are getting to patients, please let me know. You may know that we have now produced ten British Sign Language (BSL) DVDs of patient guidelines and three general information leaflets. We are now planning to consult with BSL users to collect feedback on these and to help us improve future DVDs. We are planning on working with users from organisations such as Deaf Connections and RNIB. If you know of anyone who has used our DVDs please encourage them to give us feedback. I will keep you posted!

Do you have some spare time to review our asthma draft guideline?

Do you or someone you know suffer from asthma? Interested in having your say on the latest update of the British Guideline on the management of asthma? The following areas are currently being updated:

- Inhaler devices; and
- Acute asthma in pregnancy.

This guideline is produced jointly by the British Thoracic Society and SIGN and we are currently looking for lay reviewers to comment on this guideline from a lay perspective. If you or someone you know might be interested, please let me know.

Management of sore throat and tonsillectomy

Our guideline on sore throat and tonsillectomy is being updated. Patients and carers have an opportunity to comment on the draft guideline to make sure it had addressed the issues that are important to them. If you would like to comment on the draft please let me know and I can send you a copy. You can send your comments in by post or e-mail or you can phone us.

What's on at SIGN?

Kick stroke into touch: the launch of a national package of stroke care

Tuesday 16th December, Murrayfield Stadium, Edinburgh

You are invited to the launch of the SIGN guideline on **The Management of Patients with Stroke or TIA: assessment, investigation, immediate management and secondary prevention**

A co-ordinated package of care for stroke patients in Scotland will be launched which includes:

- The SIGN guideline
- a patient version of the SIGN guideline translating the clinical recommendations into a user friendly booklet
- the updated clinical standards for care of the patient in the acute setting
- a budgetary impact assessment of the key recommendations
- a national key performance indicator in acute strokes
- showing patients and carers what care, support and information to expect immediately after a stroke.

We would like to see patient and carer representation at the launch. If you would like to book a place for yourself or members from your organisation please get in touch with me.



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SIGN helping to raise awareness of stroke

To promote stroke awareness week SIGN worked with the Patient Information Centre (PIC) at the Royal Infirmary of Edinburgh. SIGN was able to give staff and patients information on the upcoming guideline and patient guideline. This event received a lot of interest and was a positive experience for both SIGN and the PIC.

PICs are currently being set up in other hospitals throughout Lothian and SIGN plans to work with them to promote awareness of health issues.



Control of pain in patients with cancer

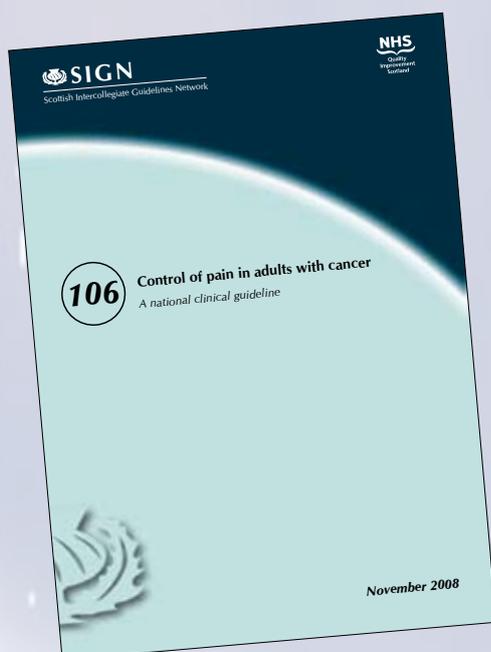
Our guideline on control of pain in patients with cancer has been published this month. The patient version is currently at the editorial stage of development. We already know that involving patients in the guideline development process really makes a difference but we feel this guideline in particular benefited significantly from having patient and carer representation.

At the beginning of the guideline development process, some of the 'key questions' which the guideline development group members aimed to answer were changed to incorporate more patient and carer issues.

By doing this, our guideline is more likely to meet the needs of patients with cancer pain. We are confident that the patient version of this guideline will be of benefit to cancer patients and their carers due to the huge contribution from our carer representatives on the guideline development group.

We are grateful to Adam Gillepsie and Gillian Wilson for their fantastic work!

If you would like to order copies of this patient version in advance, please let me know.



Events organised by other people

Health Awareness

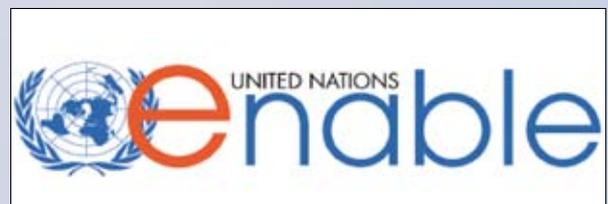
Anti-bullying week

17th-21st November 2008



Each year, the Anti-bullying Alliance sends out a clear message that bullying is neither acceptable nor inevitable in schools and communities. This year's Anti-Bullying Week is aiming to challenge this unacceptable behaviour through a campaign based on the slogan 'Being different, belonging together'.

If you were bullied as a child or your children have been bullied, you will know how crucial it is to prevent it and respond to it. Perhaps you are involved with children's and young people's groups and could display a poster in your meeting place? If you would like to find out more or would like an information pack please visit www.anti-bullyingalliance.org.uk



International day of disabled persons

Monday 8th December 2008

This annual day aims to raise awareness and understanding of disability issues. The 2008 theme of the International Day of Persons with Disabilities is "Convention on the Rights of Persons with Disabilities: Dignity and justice for all of us. If you would like to find out more about this please visit www.un.org/disabilities/



Looked after children and young people: we can and must do better than that

Tuesday 18th November
Crowne Plaza Hotel, Glasgow

This event will focus on what has been achieved locally and nationally to improve outcomes of looked after children, young people and care leavers. Discussions on health, education and after care will take place. For more information please visit www.cosla.gov.uk or 0131 474 9224.

Changing behaviour: improving society?

Thursday 27th November, Edinburgh

If your organisation is concerned with changing people's attitudes to help improve our society then this conference will give you the knowledge and tools to develop an effective campaign. Through a series of workshops delegates will learn about social marketing. For more information, please visit <http://holyrood.com> or phone 0131 272 2133.

Your experiences matter to the NHS!

It may be old news to some of you but for those of you haven't heard about it, Better Together: Scotland's Patient Experience Programme was launched in February of this year. This is a programme to gather patient experiences and they will be used to help improve NHS services in Scotland. The programme will support NHSScotland to improve care by:

- Listening to what patients and carers want;
- Comparing patients' service experiences with what patients want; and
- Acting on this information to improve services.

The programme will use an evidence-based approach, including surveys and focus groups to explore how patients experience their care. NHS Quality Improvement Scotland and the Scottish Health Council will use this information to ensure that health boards are making year-on-year improvements to services and patient experiences. It's important that everyone including you participate in Better Together.



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Visit the website to find out more and how this will be rolled out in your health board. www.bettertogetherscotland.com/bettertogetherscotland/CCC_FirstPage.jsp

Was it something I said?

During my time off I took my daughter Lyra to our local baby and toddler group. I would enjoy chatting to other mums until I was faced with the dreaded question 'where do you work?' When I replied that I worked for SIGN, the looks of curiosity changed to vague, confused faces and the conversation stopped.

I would explain that I was the Patient Involvement Officer but it was though I was speaking another language. If I had said I was a teacher or a nurse, I'm sure further conversation would have taken place. It made me realise that not only do people not know about SIGN but also that patient involvement is still a concept that some people are not familiar with.

This is a barrier that other health organisations as well as SIGN need to break through.

How do we educate the general public and encourage them to have a say in their NHS? How can SIGN become recognisable among the general public? It is extremely important that we continue to raise awareness of SIGN, highlight the importance of patient and public involvement and hopefully make our guidelines more patient-focused. If any network member has any good ideas or are willing to help us raise awareness of SIGN and patient involvement in general, please get in touch with me.

Perhaps we could host a stand at an event or we could visit your organisation and speak to your members.

This will be the last newsletter of 2008 and I would like to thank you for the contribution you have made to our work throughout the year. I look forward to working with you in 2009!

Best wishes