



**How to develop a
patient-friendly
clinical audit report**

October 2012

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How this guide can work for you

While almost everyone connected with clinical audit agrees that **clearly informing patients is a good idea**, some concerns remain, and this short guide is designed to help address those with **practical examples, helpful contacts** and a simple chronological **planning tool** to help you develop your project.

Many national clinical audit projects are already experienced in producing **effective patient guides** including **MINAP** (Myocardial Ischaemia National Audit Project from the National Institute for Cardiovascular Outcomes Research), a number of projects from the **Royal College of Physicians, the National Joint Registry (NJR) and the Royal College of Paediatrics and Child Health**.

Pages four and five feature **case studies** from from the NJR and Diabetes UK outlining their **objectives, results, challenges, progress and goals**, while **page six** highlights some **effective design techniques** for communicating often complex findings in a straightforward manner.

Page seven plots a **simple timeline** from **deciding to create a patient guide** through to **evaluating its impact** and building on that process, page 8 acts as a **checklist guide** as you plan your guide and other patient-friendly publications.

This guide has been put together by Kim Rezel and James Thornton, with special thanks to Laura Fargher and Grant Price from Diabetes UK, and Mary Cowern from the National Joint Registry.

Further edits by Rebecca Beaumont and Helen Laing and the HQIP Patient Network.

Contents information

Contents information is essential so that readers can easily locate the information they require. When the final draft of the report is created go back and double check the contents order and numbering is correct as during the production of the report information may have moved position.



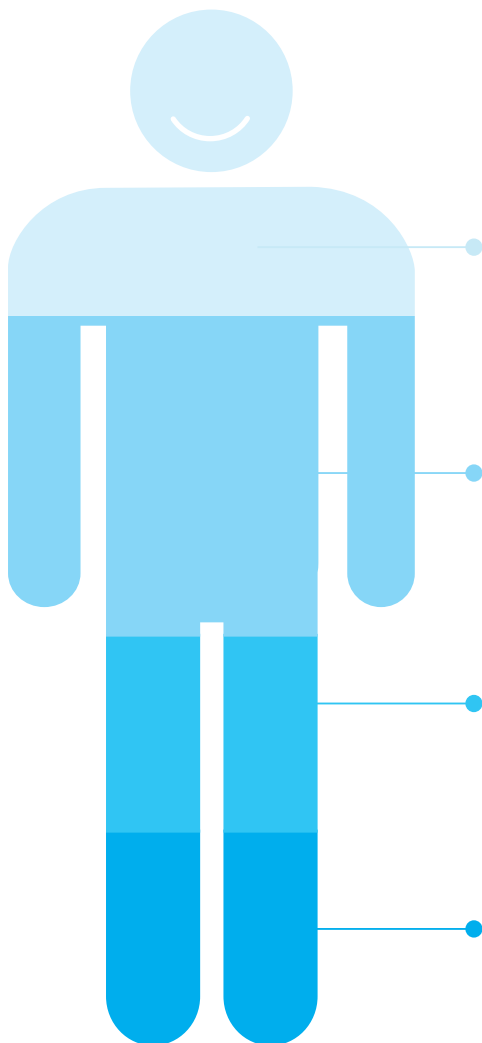
Executive Summary

A summary in the beginning of your report, highlighting key points can be useful. Include links and page numbers for ease of use.



Why is it important to clearly inform patients¹ about clinical audit projects?

One simple summary of clinical audit reads: ‘are we actually doing what we think we are doing for patients, and if not, what should we do about it?’. And while simple, it rings true: clinical audit is essentially about assessing and improving standards of healthcare, so:



There is a general duty to share results and recommendations with patients and their representatives in order to make informed choices and/or understand audits they have participated in



Good reporting should reassure patients as to the standards of care they should receive and on the likely outcomes for their specific condition



Good reporting should enable a positive cycle wherein more patients engage with the audit process, creating more reliable data and ultimately, better patient care



On a policy level, the Government has enshrined national clinical audit within its transparency agenda, with a clear motivation to make more data available to the public. It can only make sense to ensure that this data is accessible as well as available



Feedback

Ask the patients what they want from the report. To understand what results a patient wants to see, ask the patient.

¹ The use of the term “patients”, also refers to people who use services, carers and members of the public as appropriate.

CASE STUDY:

National Joint Registry (NJR)



The **National Joint Registry for England and Wales (NJR)** monitors hip, knee, ankle, elbow and shoulder joint replacements performance to improve clinical outcomes.

Established in 2002, the NJR is the largest registry of its kind in the world, collecting robust data on operations and anonymised patient information to support decision-making regarding patient safety and care quality.

What kind of PPI exists within NJR?

The NJR Steering Committee features **two patient representatives** (recruited formally via the Appointments Commission) sitting alongside surgeons, healthcare professionals, management and industry. Patient representatives also sit on two sub-committees monitoring implant and surgeon performance and **help lead patient initiatives**, alongside the management team at HQIP.

What stage is the NJR at in terms of producing patient-friendly reports?

The first was launched in 2011, following the 8th Annual Report and was well received. Improvements can always be made of course and a first **patient conference** and subsequent **establishment of NJR Patient Network** in 2012 are helping drive that.

What did these projects involve?

March 2012's 'Patient Focus Conference' was designed to engage patients and identify the best ways in which the NJR can **share information in a readable, accessible way**. The NJR then invited delegates to register for the patient network – offering a balance of virtual consultation and meetings, with an expenses policy to support participation. Its first meeting was a **full-day workshop focusing on this year's Public and Patient Guide**.

“**For our first Public and Patient Guide** we started with the original report (170 pages) and held a face-to-face focus group with patients to discuss what parts should be kept in, as most relevant for patients undergoing surgery. At that time, and without an established network, we actively sought patients to be involved through existing contacts, from an affiliated patient network and even a friend of a staff member affected by joint replacement. Virtually, I was able to involve the Arthritis Care readers' panel – it was one way we could ensure a diverse set of patients 'tested' the document we had put together. Over several months, their decisions were taken forward by the working group which included surgeons and NJR staff team members. The result was our first patient-friendly guide to the NJR 8th Annual Report.”

Mary Cowern NJR Steering Committee member and patient representative



Mary Cowern, NJR Steering Committee (SC) member and patient representative talks about her experience of patient involvement at the NJR.

Mary is a knee replacement patient who volunteered with Arthritis Care for 13 years before being appointed director for Wales in 2011 and became SC patient representative in 2006.

“Unfortunately, my first knee replacement in 1996 went wrong and took some time to put right. Thankfully my subsequent surgery and other knee replacement were more successful! The registry made me realise my experiences were avoidable and I'm passionate about making patients aware of the NJR and its vital work.”

Do you feel you are a valued part of the process? “My role is not tokenistic; the SC comprises different professions but we are all equal. We meet quarterly and I also present across England and Wales. It's great to see the NJR engaging patients in all its work.”

Have you encountered any challenges? “Until 2011 I was the only patient representative, so allocating time around full-time work was a challenge. Last year Sue Musson joined me and now share the workload – it's a real pleasure to work together and hear another patient voice at meetings. We can now work more actively on patient engagement projects and the NJR Patient Network.”

Are your views, and the wider patient perspective, taken on board? “Yes. Our meetings allow for open discussion. Launching our first Public and Patient Guide (2011) is testament to that.”

What next for the patient guide? “There is still plenty of work to be done. At our patient conference this year we received a lot of feedback on structuring it, and on content – enthusiastic discussion which continued at our first Patient Network meeting. Sharing NJR information in an accessible way is key to improving patient awareness and empowerment – both Sue and I want to help patients make informed healthcare decisions.”

CASE STUDY:

Diabetes UK case study

DIABETES UK
CARE. CONNECT. CAMPAIGN.

Diabetes UK is the leading UK charity that cares for, connects with and campaigns on behalf of all people affected by and at risk of diabetes, and has worked with the Health and Social Care Information Centre to support the delivery of the **National Diabetes Audit (NDA)** since 2011.

What kind of Patient and Public Involvement (PPI) exists within Diabetes UK?

Diabetes UK has more than 200,000 members, with **patient representatives on its Board**, along with a **Council for People with Diabetes**. Additionally, Diabetes UK works with **approximately 5,000 volunteers**—as Diabetes Voices, as fundraisers, as Community Champions, as well as through their 332 voluntary groups nationwide.

What kind of PPI exists within the NDA?

People with diabetes are represented across the governance structure of the NDA, including the **Partnership Board** and five **project steering groups**. Diabetes UK facilitates a meeting of all NDA patient representatives two or three times a year ahead of Partnership Board meetings. **Challenges** include ensuring patients can fully engage in meetings; most of the steering groups meet via teleconference, which is convenient, but the Chair needs to ensure that everyone's voice is heard. Solutions include maintaining at least one **face-to-face meeting** annually.

How did they find volunteers for development of the NDA?

Diabetes UK used a **formal recruitment process**, with a role description, application and telephone interview. Those not selected were offered other volunteering roles with Diabetes UK. Successful NDA volunteers were given a full-day **induction session** or **telephone briefing**.

What stage is Diabetes UK at in terms of producing patient friendly reports?

This year's NDA Core audit report has been published and Diabetes UK has now set its sights presenting this in a patient friendly format over the next few months. Once that process is complete, the template will have been created to produce patient-friendly reports for all audit streams.



Diabetes UK have found that one of the **most effective ways of communicating** to patients has been through **Facebook and Twitter**. Many new patient representatives have been discovered in this way and Diabetes UK have increasingly used social media for consultation purposes and in reporting news.



HQIP will be following Diabetes UK's progress in developing their patient friendly national clinical audit report via a blog on our website - <http://hqip.org.uk/patient-and-public-engagement-2/>

Grant Price got involved with Diabetes UK's PPI work by applying to join one of its local involvement networks and the national Diabetes Voices group. From there Grant joined the National Diabetes Audit (NDA) initiative and is now part of its steering group.

Do you feel you are a valued part of the process? "Very much so," he says. "We have regular teleconferences but also meet face-to-face. Diabetes UK are acutely aware of how to communicate to everyone, so copy is very well written, especially on the website and on products for its audience. So, yes I do feel valued. That is clear from the way meetings are handled – Diabetes UK make a determined effort to check in with people who have not spoken much so that their voices are heard."

Are your views acknowledged and taken on board? "It certainly feels like my voice is heard. For instance, at my first meeting people were keen to answer questions by sharing their experiences. This was not the precise agenda but our stories were listened to and discussed before the team carefully changed the focus."

What are the challenges? "The diabetic community is so diverse in terms of age, culture, and backgrounds, so accommodating everyone's input is hard and Diabetes UK do it well. When teleconferencing, it can sometimes be hard to understand what people are saying from their tone of voice."

What are the benefits? "People can feel isolated when first diagnosed and this provides a chance to meet others with common interests. Gaining understanding from medical and healthcare professionals about what they are supposed to be providing is great, and I always come out of meetings with new information about medical checks. I've also gained great understanding of what initiatives have been run in the past and the impact that they've had on diabetics."

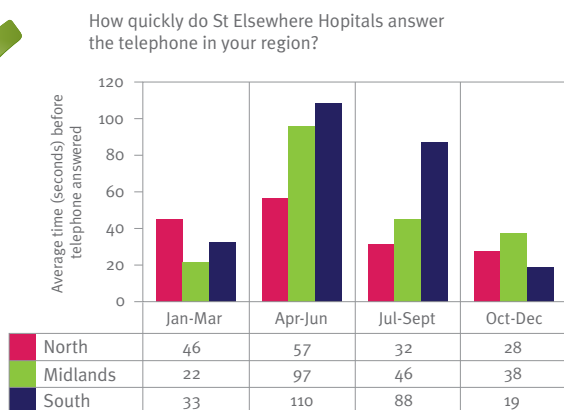
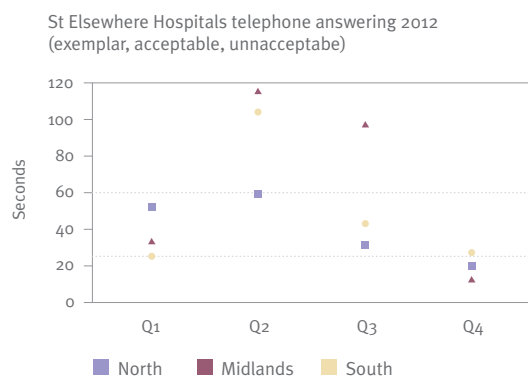
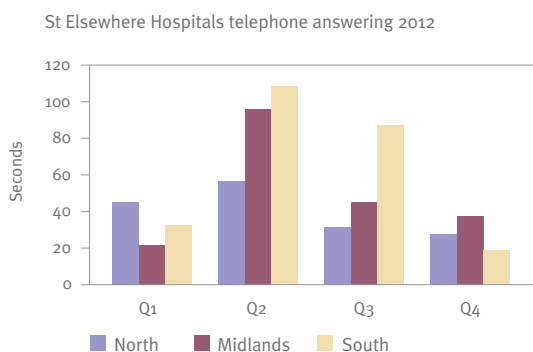
What would you like to see in a patient-friendly clinical audit report? "Having seen the core audit report I think we need to focus on making it clear to understand. To be made patient-friendly the language must be changed as some terminology wasn't always understood. And lots of assumptions are made in the report [about reader's knowledge] so more context is needed. I think we should consider things like how to personalise content for people, and whether the report might be specific to regions. Ideally we need information that is not just UK-wide, so we can see how one area compares to another and analyse how that makes a difference to us personally. I also feel we need involvement from patients outside of the NDA as they are not as familiar with the subject and they represent the majority of the audience. I'm aware the report can't please everyone and there are always opportunities for refinement, but I very much want to be involved in the patient-friendly report writing."

Good vs bad ways of representing your data

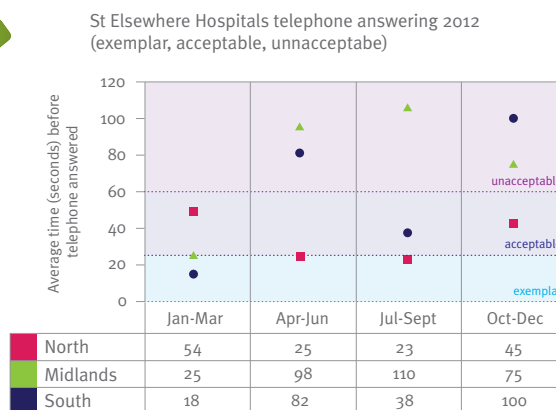
Done well, graphs, charts and tables are excellent devices with which to illustrate complex results. However, results are often difficult to understand. This can result from too much presumed knowledge from those working on reports, so it makes sense to get input from those not directly involved. Below are fictitious examples of bad and good statistical representation. We have begun with a simple bar chart (pie charts also work well of course) followed with a scatter graph.

Further examples from patient friendly reports can also be found here:

<http://www.hqip.org.uk/patient-and-public-engagement-2/#other>



Quarterly results by region for 2012



Quarterly results by region for 2012. Answering in 0-30 seconds = exemplar (or best practice), 31-60 = acceptable, 61+ = unacceptable

DONT's

- Don't use images below 300dpi (print quality resolution) as these will be blurred when in print
- Make sure your colour palette choices are complementary to each other but that give adequate contrast so it is obvious which data is which

DO's

- Give the text breathing space within the charts so text is easy to read and fonts are not used too small
- Include copyright symbols and source reference if you would like the viewer to know the origin of the data



Get the professionals in

A professionally designed report will mean that your content will be designed in the best way possible with clear graphs and diagrams. Publishing agencies experienced in reports will design your charts and graphs from your data and can supply you with a PDF on completion that you can make available online.

Report production timeline

1

Identify funding

- A budget will be required to cover not only the report costs (design, print, distribution) but also meeting costs; venue, travel expenses, catering. If you are recruiting patients for the first time, there may be additional costs in promoting the project; promotional posters, presenting at events; submitting to e-bulletins (email) and other social media (Facebook, Twitter, LinkedIn).

2

Put together a working group

- If there is already an established patient group for your project, you can choose to either consult with them throughout the development of the guide, or put together another working group. This group should also have a member of the Communications team and where possible, a representative from the original project team.
- If you are looking for patient representatives to join a working group or simply to be consulted during the development of the report, then consider holding a series of workshops. Here, you can gain ideas for the report and establish contacts who you can then seek out further feedback from.

3

Work from the original

- Using the original report, identify what it is the patient really needs from it; which bits are too detailed; where is it too text/diagram heavy; what is most useful?

4

Write a draft

- Develop a draft which you can send round to the working group for comment. This draft should include any graphs that you wish to use. However, it is worth bearing in mind that members from an already established patient group will have an insight into the project that your average patient may not, therefore it may be beneficial to extend the consultation process. Prepare a set of questions that will enable the patient to feedback more efficiently and easily, for example, are the diagrams clear and comprehensive?

5

Final consultation

- Consult with the group on the final draft; ensure all relevant words are defined in the glossary; all diagrams are understood; pictures are approved.

6

Dissemination

- Along with the working group, agree a list of groups and organisations who might be interested in receiving a copy of the report. Many organisations use e-bulletins and social media to promote their work, so you could add a link to many different bulletins, raising the reports profile. Print copies and make the report available in relevant waiting rooms, or you might want to consider holding a launch event and raising interest that way. It is important to reach the patients that the report has been developed for - be creative.

7

Evaluation

- Has the report reached the right people? Has it had the desired impact and outcome? Are people more aware as a result of the report? How can you improve on the next report? If possible survey a small number of patients and carers to find out how the report was received, or hold a small focus group to look at the report and find out which areas were most useful or areas that need improving. Continue to work with patients in developing future reports and finding a style, size and level of detail that suits the people the report is meant for.



Checklist

Some top tips for creating patient-friendly guides:

- **Keep the document relevant but short and engaging; considering how the original report might be presented. A leaflet or a poster can help in the initial stages – and can provide excellent extra materials to support the main and patient-focused reports**
- **Use everyday language wherever possible. Avoid jargon and unnecessary technical terms and check your copy with patients before finishing your guide**
- **Adding a glossary, definitions and explanations is vital**
- **Pictures – and certainly clearly designed graphs and other well-planned illustrations – can speak a thousand words**
- **Who is your primary audience? Might they have specific requirements in terms of the size of your text, colours used, format the guide is produced in (audio, video, print, online?) or the material it is made from?**
- **Who is your secondary audience? Good patient guides can double as powerful easy-access versions of main reports, providing simple access to key facts for management, the media, politicians, patient representative groups as well as clinicians**



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