**Naomi Fearns**

**Can you briefly introduce yourself, and give some background on which part of DECIDE your work contributed to?**

My name is Naomi Fearns and I work as a Health Services Researcher at Healthcare Improvement Scotland, which is a special NHS health board; it works mainly on quality improvement projects across NHS Scotland. I worked on work package (WP3) of DECIDE which focusses on the communication of clinical guideline recommendations to patients, carers and members of the public. I came to the project later on after most of the data had been gathered by colleagues (Margaret Callaghan and co) earlier on in the process, so I was involved largely in the analysis of qualitative data from a series of focus groups that were carried out previously. I also analysed the data from the user testing of a patient version of a SIGN guideline that was designed based on the preliminary findings of the project so far.

**What are the most important findings from your work with DECIDE?**

I thought the most important findings centred mainly on the fact that awareness of clinical guidelines in the general public was often really quite low, and therefore that the accessing of patient versions of guidelines that are out there also seems quite low by the general public. It seemed like that was a real shame because the patients and members of the public that we spoke to really wanted information to help them choose between treatments, including information on harms. This information can come from patient guidelines and supports and empowers patients to make shared decisions with healthcare professionals.

Another key finding was that one size really didn’t seem to fit all in making patient versions. Some people seemed to want really detailed information and they were quite interested in numbers, graphical aids and the evidence itself, while others, maybe the majority of the people we spoke to, really just wanted patient versions of guidelines to be kept as simple as possible. When we were trying to balance out those needs it was key for us to keep the look and the layout of patient versions as simple and visually appealing as possible, I think that seemed to be really important, and essentially that came from looking for a really friendly look and feel by using a lot of colour and images, chunking up the text and keeping the language of the patient versions as informal as we could. Another aspect that seemed quite important was layering of information, where possible, because that’s very helpful in meeting the needs of all those different groups that make up the public.

**How has DECIDE changed the way you work?**

Healthcare Improvement Scotland is made up of various different groups or networks that have been brought together, one of them is the Scottish Intercollegiate Guideline Network which is known as SIGN. SIGN develops the evidence-based clinical practice guidelines for the National Health Service in Scotland, so part of the DECIDE project was the re-design of a template for patient versions of SIGN guidelines. So DECIDE has completely changed the way we produce patient versions of our guidelines, or at least it’s changed very much the way that they look and the way that they feel to the public when they’re accessing them. We also shared the learning from this about producing patient materials and communicating evidence based recommendations across the organisation. For example, we developed a patient version of a recent Health Technology Assessment report, and that used a similar design, look and feel of the DECIDE materials for SIGN. So I think it has impacted on the way myself, and my organisation, communicates about evidence with patients and the public quite substantially, and we really are trying to actively share our findings around the organisation.

**How might DECIDE’s work help other guidelines groups?**

The insights that we had from this work also contributed to the Guidelines International Network (GIN) Public Toolkit on patient and public involvement in guidelines. There are also 2 publications which should be coming out relatively shortly based around the qualitative work that we did with WP3, so that should make it accessible to other organisations. On top of that, SIGN’s new look patient versions are also available to download on our website (<http://www.healthcareimprovementscotland.org/>), and so is the patient guide to our Health Technology Assessment on anti-microbial wound dressings. I think we’ve made the outputs from DECIDE publically available, so that other organisation should be able to benefit. Probably the key way of communicating to other guideline makers is through the GIN update to their toolkit.

**How did you user test materials being developed for your audience?**

Initially the WP3 groups carried out 9 focus groups and other kinds of group activities provided us an opportunity to test the draft materials that had been developed. Following that we carried out user testing of the re-designed SIGN patient version which was of a glaucoma guideline. That user testing we based on a method of data collection and analysis which was developed by Rosenbaum and colleagues, and that uses a think aloud protocol and a semi-structured interview guide. The user testing takes place individually one on one and face to face, and we carried that out with about 13 people with glaucoma, one of which was actually a carer rather than a person with glaucoma. That uses an interviewer and an observer to take notes, and we were lucky in that one of our public partners agreed to be our observer.

**Were there any challenges and how did you overcome them?**

Some of the user testing early on in the process used workbooks and was carried out in pairs prior to us going on to this one to one interview method, that was before I was involved in the project and that user testing proved a bit less fruitful, or that the outcomes of it were more difficult to analyse. I think shifting to the think aloud protocol method was really helpful for us. Also we were covering a really diverse group when working with the public as a whole including patients and carers, inevitably those groups can have quite different views, so participants’ views may vary quite widely. The samples that you’re using and the methods you’re using for analysis need to be able to deal with that. In the end we came to realise that there’s no one single approach for communicating guideline recommendations that will work for all those groups, and that different groups such as older or younger people will require materials to be carefully tailored for them specifically. These differences were not so much a surprise, but they are a challenge. Things that seem clear to you when you are designing them may not be at all so to certain groups in the public. User-testing materials really helps you to get a handle on that.

**What were the most striking things you discovered?**

The more user testing we did the more we realised that some things in the materials, were actually being misinterpreted. For example we used a blue circle for a visualisation on risk and some people interpreted that as being a zero therefore meaning that they had no risk. That was the opposite of the intended message.

The overriding impression that I took away from the project was just how important good health information and access to useable patient versions of clinical guidelines are to patients and the public. When we talked to people with long term health conditions like diabetes and depression, when those patients realised that those patient guidelines are available to them, that they are on our website but they didn’t know anything about them, they were actually quite angry that the material is out there, but they weren’t aware or didn’t have access to it. I came away from the process thinking that increasing awareness and increasing access to well-designed patient versions of clinical guidelines is actually really important. Another thing linked to that is that a lot of organisations don’t produce paper copies of guidance anymore, it’s all online. For some groups that’s really tricky because if you don’t have access to the internet or a computer you’re left without access to these resources. Affected groups aren’t just older generations, the problem spans to younger generations too, people experiencing homelessness for example. There’s a challenge there for us in terms of getting resources out there to people.

**How will your organisation use DECIDE materials?**

The use of findings from WP3 is probably obvious from what I’ve said previously, but it’s important to say that the findings from other work packages and working groups may also be important to Healthcare Improvement Scotland in terms of communication of guidelines and Health Technology Assessment material to the clinical community and to decision makers. As more of the material from other work packages starts to come out, we’ll be interested in looking at that to allow us to refine our own evidence-based products going forward.

**What are the biggest advantages of these materials for your work, of that of your colleagues?**

Healthcare Improvement Scotland is focussed on improving activities across NHS Scotland, and we’re always looking to make improvements in our products, and then to share those improved products with NHS Scotland. GRADE and DECIDE now have helped us to produce the best evidence-based products that we can do; that’s a real advantage to us.