**Nancy Santesso**

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

I’m Nancy Santesso, I’m an Assistant Professor in the Department of Clinical Epidemiology and Biostatistics at McMaster University. I worked on work package 3 (WP3), which was all about disseminating information to patients and the public. We started from a point of not a lot of information, and so a lot of our challenges started from the beginning and focussed on whether we needed to do reviews or systematic reviews before we even started, so it was good experience to start from zero and build up within the project.

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

We were looking at patient versions of guidelines and we focussed on one part which was communicating recommendations. One of the most important findings was that there seemed to be this issue that people might not read the information because they thought it wouldn’t apply to them, and so what came out repeatedly was this need to personalise the information to them, otherwise they wouldn’t look at it at all. We haven’t necessarily figured out how to personalise the information or what the best method of doing so is, but we now know the need to personalise it is crucial so that people can identify that it may apply to their situation. This came out in the focus groups, the user testing and in the reviews of the literature that we did, and it seemed to be a prevalent theme across multiple patient groups. Even when we did create some different formats for patients we had to take that into consideration, and in some ways it was just saying explicitly at the very beginning ‘this information applies to patients who are...’, ‘if you are someone who is...’ then this information is for you.

This was interesting for me, a lot of the existing literature around communicating to patients and the public is around the effects and how to communicate the effects of an intervention, and you don’t often see information or literature covering how to personalise information.

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

I have a lot of people that I’m in contact with about disseminating and dissemination of guidelines, and that network of people has grown as a result of the DECIDE project. What’s great is having met all these different people, I’m now able to work with them. Now I’m much more involved in the Guidelines International Network and the people that are working on guidelines – that’s been an important outcome for me. These collaborations aren’t necessarily within formal research projects going forward, but what’s exciting is that there are so many new opportunities to discuss research work and what could be done in the future. It’s exciting to talk to people – there’s that issue of being stuck in your own office and not really in contact with a wide network, but learning from other people and talking about work is exciting for me. It keeps me motivated and ensures I enjoy the work I do as I have more people to bounce ideas off and work alongside.

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

In the patients group (WP3) the work that we did fed into a GIN Public toolkit, which is a toolkit for guideline developers to help involve patients and consumers and the public in guidelines development, and also how to communicate guidelines. The work from DECIDE went directly into the chapter on how to develop patient versions, so that’s something very practical that came out of the work that we did in DECIDE, we’re explaining exactly what we know about how to develop a patient version of a clinical guideline. To me, that’s very pragmatic and shows that we achieved our goal of coming up with practical tips and methods that mean the work we did doesn’t just stop when the DECIDE project ends.

**What do you think is the biggest strength of the DECIDE project?**

The DECIDE project involved so many different people from so many different organisations. Sometimes there’s a feeling in projects of ‘this is just the feelings of the group that’s doing the work, they’re not seeing what’s really going on with other groups’, but we had so many organisations and people with different perspectives involved that we were able to prevent that bias. We all worked together to come up with solutions that were then practical and able to be implemented by all these different organisations, ensuring that our work had a practical impact.

The diversity of languages and cultures was also a big advantage, and allowed us to translate tools into other languages and ensure the cultural implications of the work were taken into account.

**What is the biggest benefit of using GRADEProGDT?**

It’s covering the whole guideline process. GRADEProGDT starts at developing your scope and your team, it allows you to prioritise questions and outcomes, you then move on to putting together the evidence and putting it into tables and evidence summaries. Finally it allows you to put that evidence into a format that’s useful for everyone from patients to professionals and those making coverage decisions. It goes through the whole process of getting started through to disseminating information from guidelines, to me that’s the biggest pro.

**How do you think GRADEProGDT could be improved?**

We always would like to have other tools! At this point you do your systematic review of the literature outside of the GRADEProGDT software using another statistical software package, which is fine because there are other tools available to allow people to do the statistics, but it would be nice to have the GRADEProGDT tool integrate other tools. What we need to make sure we do is ensure that all the formats we come up with in DECIDE can be handled by the GRADEProGDT software package, we have a lot of formats but as we continue to develop new ones it’s important that we keep on top of putting those into GRADEProGDT as well.

**Is GRADEProGDT being developed further?**

Yes, it will continually develop. The tool existed before DECIDE and incorporated the findings from the DECIDE project. But it’s also being used by organisations such as Cochrane in their systematic reviews. Therefore it will continue to be developed and updated through the feedback that users provide, that won’t end.