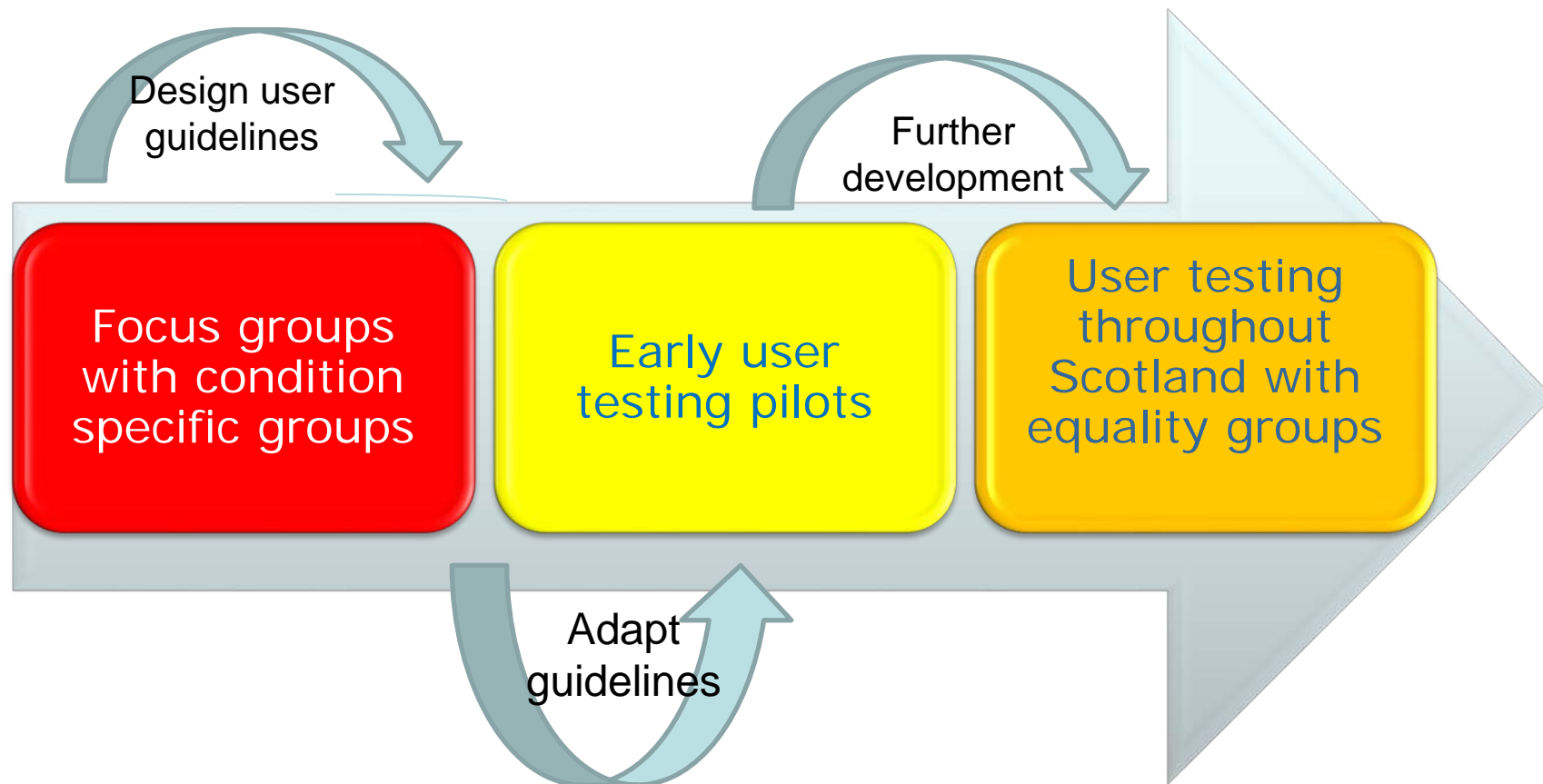


USER INVOLVEMENT IN GUIDELINE DEVELOPMENT

Dr Margaret Callaghan
G.I.N. 2013

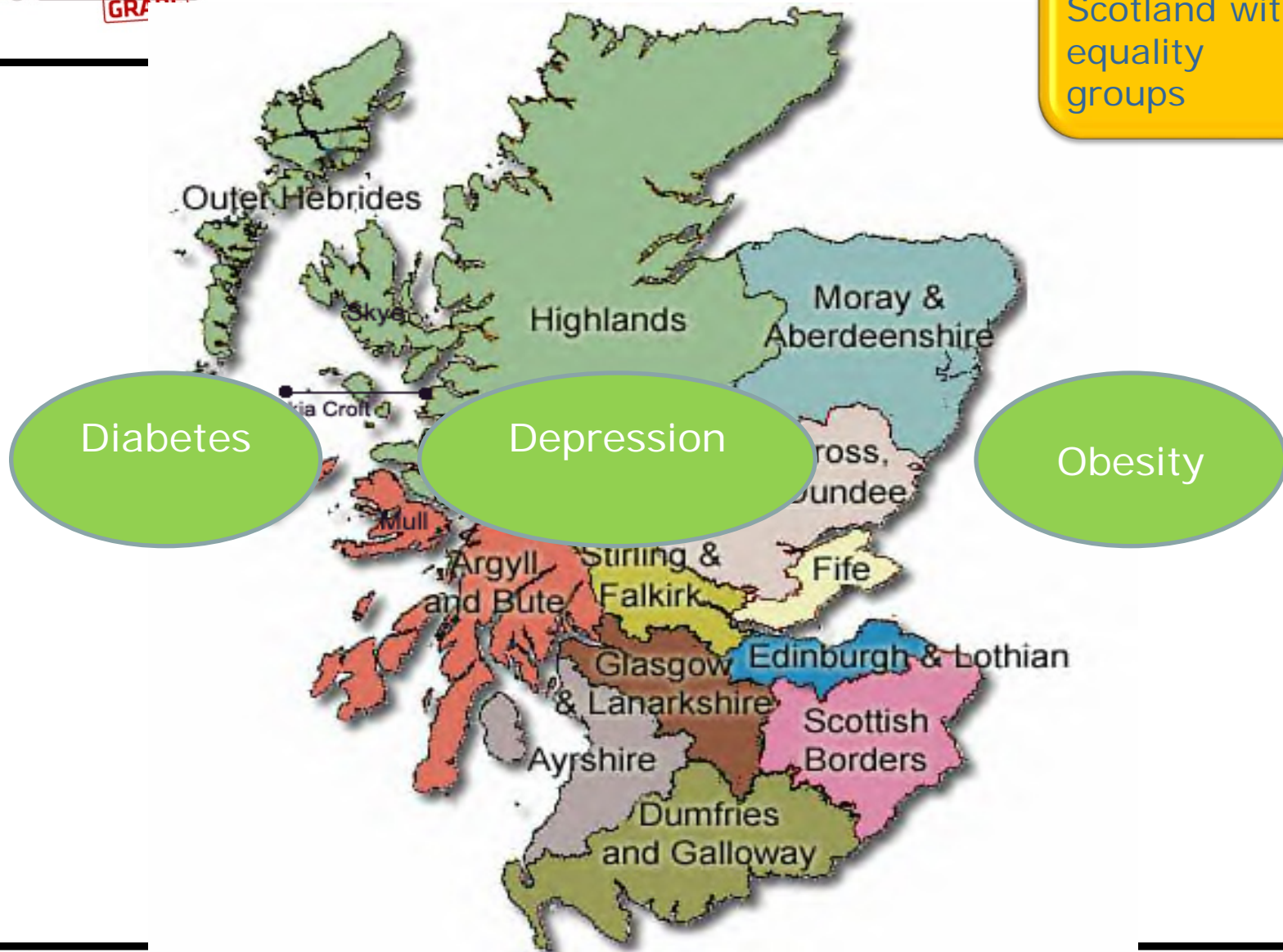
- Five year EU funded research project.
- Supporting the uptake of evidence-based recommendations to patients, their carers, and the general public.
- SIGN (Scottish Intercollegiate Guidelines Network) is the lead for user involvement in guideline development and dissemination.
- Early findings presented.



Methods

- Early user testing pilot: homeless people, those with mental health problems (12 people).
- 10 groups from geographical and equality areas (4-8 in each group).
- Framework analyses.
- Early stage of analyses.

User testing throughout Scotland with equality groups



ONGOING CHANGES

Obesity: We changed from 'obesity guideline' to 'weight management' and now users think we should use 'losing weight.'

Depression: We changed from formal language to informal language, users felt that the language was clear but should be made more personal, perhaps using stories and pictures.

Diabetes: We made this less formal but it was still felt to be complex. Users wanted more information on what they could do for themselves.

MAKING CHOICES

“So my understanding is if SIGN says that patients should have a choice then the GP would have to have a very good reason for refusing the patient’s choice?”

(Dundee, deprived areas group)

“Maybe to outline contraindications of any medicine you were taking. Stuff like that.” (Orkneys, Gaelic speakers)

TOO MUCH CHOICE IS STRESSFUL

"I like the idea of information being able to let people find out what to expect of them but at another level that's putting a lot of responsibility back on the patient and I still, might be an old fashioned attitude but I'm going to see the specialist, I don't want to be the one making decisions, because what do I know about the medical background of things?" (Orkneys, remote and rural areas).

“Well, direct you to the right option. I had a friend who said what if it was your wife? And the guy did give her an indication I know it’s a good thing patient choice but I think for a lot of people it’s a burden and I think the time constraint, you might struggle to take it in, especially with cancer or something like that, it’s very hard to take in information, just as you said, the time, you might have something else to ask but their body language you know if they’re bent over the computer, you might think that the time is up and you just think I better go.” (Arbroath, long term conditions).



STRENGTH OF EVIDENCE NOT WIDELY UNDERSTOOD

“Well if it’s in that leaflet and the leaflet is from the NHS then it must work. They wouldn’t put things in that didn’t work. So why do you need to discuss this?” (Glasgow, BME group)

“If you say that there is no evidence for self-help groups working [for depression] then you can’t be looking in the right places.” (Arbroath, Long term conditions)

“I’m not sure that you need to know that [evidence]. If you were depressed you couldn’t take that information in.” (Dunoon, patient representatives)

STILL TOO MUCH JARGON

“Why say ‘structured exercise programme’ when you could say ‘go for a walk’, why say ‘raise blood sugar’ when you could say ‘eat a mars bar’” (Falkirk, Young people)

“This is written for old people” [What age] “Oh about 30, yeah definitely 30. It’s like something from the eighties” (Edinburgh, Young people)

“SIGN, NICE what do these words mean? It’s off putting.” (Highlands, Patient representatives)

“It’s very hands off, like you’re a doctor talking to another doctor, if I was to be given this I’d be thinking ‘is this meant to be about me?’ ” (Aberdeen, People with disabilities)

Overall

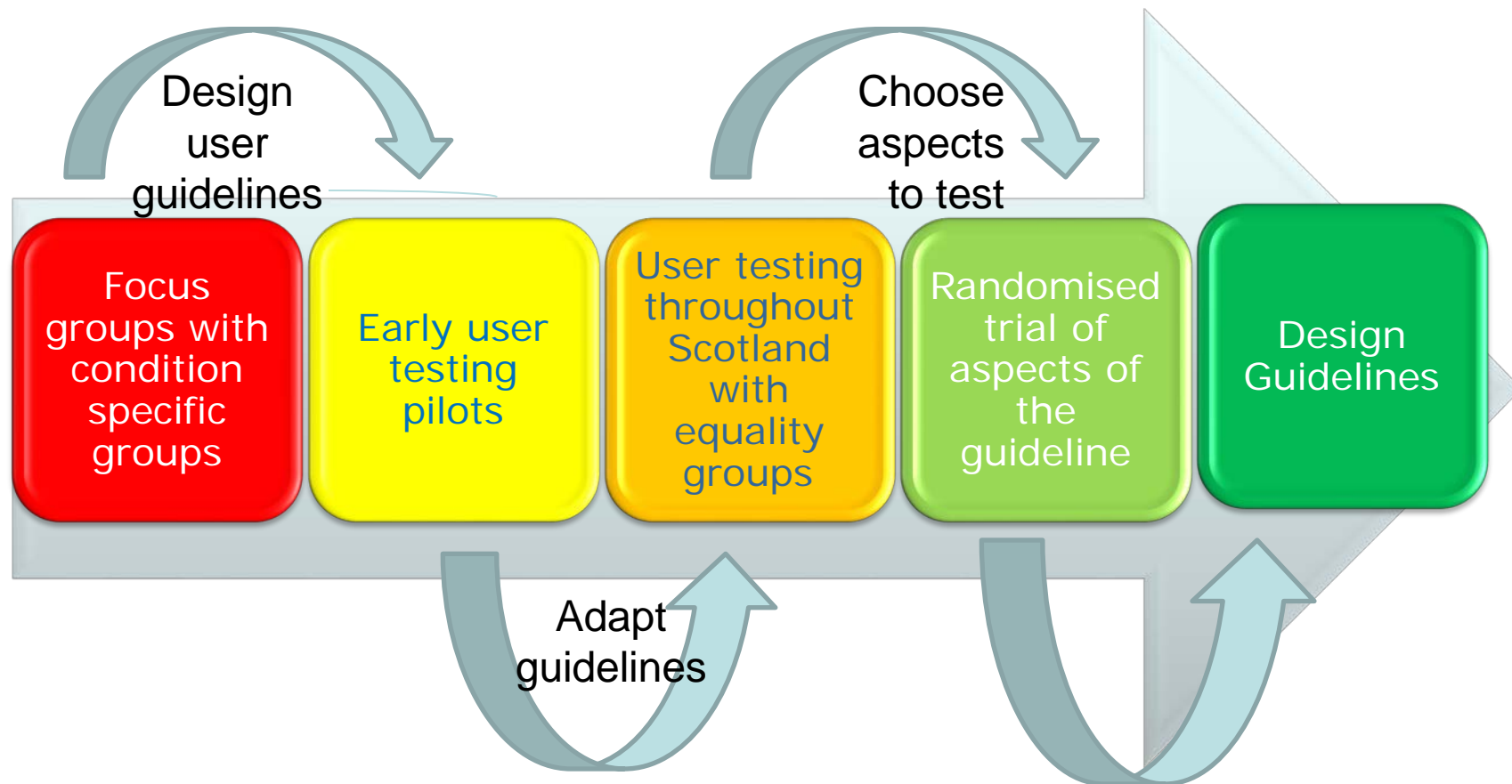
- Users wanted to know how they got an illness, what they could do for themselves and what would happen to them.
- We were better at explaining strength of evidence than in the previous stage, but whilst users now understood this well they were not convinced that they needed to know this.
- Users were not interested in hearing where guidelines came from or how much treatment cost.
- Users wanted to know where they could get further information.
- The tools needed more pictures and less formal language.
- Accessibility should be considered further.

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Next Steps

- Do we need to support people better to understand the strength of evidence?
- Should we be working with other health information providers so that they refer to our guidelines for patients as well as us referring to them?
- Do we need to consider further which guidelines are suitable for patient versions?
- We will be testing a patient version of a breast cancer guideline later in the year which will give us the opportunity to explore some themes further.



And finally

*"I felt like crying, it sounds ridiculous because I'm 60 but I felt like crying the way he was speaking to me. Some of the words he was using and I thought well I've worked in the health service and you don't speak to patients like that, use words they'll understand. It's a long training they've got and you think they should be able to communicate with patients, they should make sure that they understand."
(Woman, Inverness rural group)*