What is the SDRN Research Register?
The SDRN Research Register gives all patients with diabetes living in Scotland an opportunity to be contacted about good quality research that is likely to suit their health profile.

What do you mean by "Research Register"?
Many people with diabetes living in Scotland would like to contribute to health research, but it is often difficult for them to find out what research is happening and which studies they may be suitable for. It is also difficult for researchers to identify suitable people to take part in research. The Research Register allows people with diabetes living in Scotland to submit their name and contact details so that they can be added to the Register. If you join, you are simply saying that you are willing to be contacted about possible participation in research studies.

Is the SDRN Research Register part of the NHS?
Yes, the SDRN was commissioned by the Chief Scientist Office (CSO) of the Scottish Government and is part of the Scottish National Health Service (NHS) and NHS Research Scotland. The SDRNs aim is to improve the quality and increase the quantity of diabetes research in Scotland, as part of the UK Clinical Research Collaboration.

Why is it important to have a Research Register for patients with diabetes?
It is important to have a register because it will help match interested people with diabetes to good quality research studies that are likely to suit them. This will greatly improve the time it takes to carry out research and to bring new treatments into routine use. Only with the help of people with diabetes, who take part in research, will we be able to improve the methods of diagnosis, care, treatment and prevention of this condition across Scotland.

Why was the SDRN Research Register set up?
The Research Register was set up to enhance patient participation in research. The Register achieves this by giving all people with diabetes living in Scotland the opportunity to be contacted about research that is likely to suit their health profile.

Why should I sign up to the SDRN Research Register?
More research is essential. Yet without volunteers who have diabetes, many of our health and medical studies simply won't happen. Only with your help will we be able to improve our understanding, methods of diagnosis, care, treatment and prevention of diabetes across Scotland.

What might research involve?
Research can vary. You may be asked to take a new or existing drug or a placebo (Placebo – contains no active drug) while another study could test new devices such as a blood glucose meters. However, it does not always involve drug or medical intervention. Some may instead be interested in lifestyle and environmental factors and are as simple as completing a questionnaire. In all cases, patients participating in research can be assured they will receive the best possible standard of clinical care and their safety and wellbeing will be protected at all times. If you are contacted, you will be provided with more information and you will be able to ask any questions you want. If you feel you'd rather not respond, that's still ok, you don't have to give any explanation whatsoever.

What can I expect to gain from taking part in a study?
It depends on the study. Some patients may find that they get a better understanding of diabetes by, for example, learning how to better control their condition. In some instances, a study may allow for more
regular checks such as blood pressure and blood sugar level. In any case, by participating in research you are making a significant contribution to helping progress our understanding of diabetes.

**What does randomization mean?**
This is the process by which patients are assigned, by computer, to different treatment schedules for a clinical study.

**How long will a study last?**
How long each study will last, will depend on the type of study in which you are involved. Again, you will be told before you decide you take part how long the average visit should last.

**How many visits will I need to make to the clinic?**
Some studies require a once only visit but most studies last from a few weeks to months or years. You will be informed about how long a study will last before you decide to take part.

**What time of the day will the clinic appointment be?**
Most visits will take place in the morning but staff aim to be flexible in order to accommodate changing lifestyles.

**Will I need to make any changes to my diet?**
Most studies do not require that you change your diet however it may be necessary to FAST overnight before a clinic visit. Breakfast will be provided at the end of your appointment.

**What happens if I wish to withdraw from a study?**
You can withdraw from a study at any time without having to give a reason. If you do decide to withdraw from a study it will not affect your ongoing clinical care.

**How The SDRN Research Register Works?**
The SDRN Research Register is part of an NHS computer-based record (called SCI-Diabetes), which helps to support the treatment of patients with diabetes living in Scotland.

When we receive your completed registration leaflet or you complete the online form, the information provided is used to search for and locate your name. From here, the SDRN simply marks you as having joined the Register before adding any additional contact information that you have provided.

When a suitable research study comes along, the SDRN looks carefully at the specific criteria that are required for potential participants. These requirements are entered into a search whereupon a list is produced of registered people who may be a good match. These people can then be contacted and asked if they would like to find out more.

**How do I join the SDRN Research Register?**
It's simple. If you have diabetes and you live in Scotland, you can join the Research Register. The only information we require is:
1. Your full name
2. Date of birth
3. And postcode (back)

**If I join, what happens next?**
If you decide to join the Research Register you are agreeing to allow us to use your NHS computer-based record for diabetes to check whether you might be suitable for research studies. If you are suitable, you will be contacted by letter, email or phone (whichever method you prefer) to let you know about a relevant study. Once you hear more about any study you will have the opportunity to decide whether to take part.

**How often will you contact me about potential studies?**
It depends on what studies come along and whether you might meet the required criteria. Some volunteers may be eligible for several studies per year, while others may remain on the register for some time without being invited to participate in a study.

**Does this mean I will have to take part in a future research study?**
No. Joining the Research Register does not mean that you have to take part in research; only that you are willing to be contacted, about research, that might be suitable for you.

**Do I have to take part in a study when invited?**
No. You can choose whether or not to take part in a study once all your questions have been fully answered. If you’d rather not take part you don’t have to give any explanation whatsoever.

**Will I have to travel long distances if I want to take part in research?**
The SDRN coordinates research at hospital clinics right across Scotland as well as at a number of General Practices. You will always be fully informed about where research is taking place and be able to decide in advance if you are willing to travel. It is your choice.

**Could there be any risk to my health in taking part in a clinical trial?**
Clinical trials and studies are highly regulated. In all cases, safety is paramount. Patients on trials are continuously monitored and studies would be modified or stopped if any risk was identified. The majority of studies use existing procedures and medicines and pose virtually no risk. If a treatment is novel and risk was less clear it would be clearly discussed with you before anything happened. You could of course choose not to proceed at any point.

**Will I get paid if I take part in a trial?**
Most studies do not pay patients to take part. You will be able to claim reasonable travel expenses or staff can arrange a taxi to collect you and take you home.

**How will I be contacted?**
You can choose to be contacted by mail, email or telephone. If you have chosen email or telephone and we are unable to reach you, we may choose to send you a letter instead.

**Am I going to be bombarded by information from the SDRN?**
Absolutely not. Some volunteers may be eligible for several studies per year, while others may remain on the register for some time without being invited to participate in a study.

**I’m worried about confidentiality?**
Your information will be held securely at all times. The process is simple, if a suitable piece of research comes along, the SDRN will carry out a computer search of your NHS electronic patient record for diabetes (see above: How does the SDRN Research Register Work). By conducting this search the SDRN are able to check if you are someone that may meet the requirements for the research study in question. If you are suitable, you may be contacted with more information on what the project involves. If you are interested you can find out more. If not then, you are completely free to decline.

**Will my taking part in a study be kept confidential?**
Yes. Strict laws of confidentiality safeguard your privacy.

**Who will have access to my records?**
The SDRN will have limited access to medical information which is relevant to your condition and commonly used by health care professionals to help manage diabetes. Your records will remain entirely confidential. Patient confidentiality is paramount within the NHS and the SDRN and we will only allow you to be contacted if your health profile matches a study.

**How long will my name stay on the Register?**
Your name will stay on the Register until you request its removal. You can withdraw at any time.
What happens if my contact details, name or address changes?
If you change your phone number, mobile number or email address you should let us know (but only if you have given us these details already).
If your name or address changes you don't have to do anything. This is because any change that your current health care provider, such as your GP, knows about will be reflected in your NHS records automatically.

What happens if I go on holiday or work away from home?
If you are going away on holiday or work away from home for long periods there is no need to let us know, you can still remain on the register.

What if I am too busy due to other commitments?
If you have no spare time at the moment due to other commitments, you can still remain on the register. Remember, if you are contacted, it is your choice whether or not to take part. You can simply explain that you are currently too busy.

How do I withdraw if I want to?
Remember, you have total control and can decline to respond to any invitation to take part in a health study at any time, without having to give any explanation whatsoever.

If you decide you want to withdraw all you need to do is contact the SDRN on the details provided below, providing your full name, date of birth and post code:
Email: withdraw@sdrn.org.uk Telephone: 01382 383 241
Address: Scottish Diabetes Research Network, Diabetes Support Unit, Level 8, Ninewells Hospital Dundee DD1 9SY.