

# THE UK ENDOMETRIOSIS SURVEY AN ENDOMETRIOSIS MEDICAL RESEARCH PLATFORM.

## PROJECT STATEMENT 21/5/2010

Across the UK there are thousands of women suffering silently with endometriosis, unable to work or enjoy a quality of life. This network of sufferers are an un-tapped source of endometriosis expertise and information with research value.

The UK Endo Survey is a trial for a new kind of medical research platform created by Waltham Media Ltd. It is designed and created specifically to aid and advance research into endometriosis and has been done so under a non-profit basis and is independent from pharmaceutical companies.

### The research platform was created with the following objectives:

- 1. Involve endometriosis sufferers in direct research**  
The partners and sufferers of endometriosis across the UK are currently an untapped group considered experts in endometriosis suffering. This audience provides a great deal of research value and this audience is more than willing to help advance endometriosis research. The platform's main objective is to allow sufferers to participate in real medical research.
- 2. Open-source, allowing anyone to access and contribute research data**  
All research undertaken by the platform is open-source, which means any sufferer, any research groups and any medical professional can use the platform to both pose their own ideas, request help and ultimately access all the raw data collected through the platform.
- 3. To create the biggest library of endometriosis sufferer medical records**  
The platform is setup to allow endometriosis sufferers to create a detailed account of their entire medical history as well as all other relevant information about themselves. These accounts, although anonymous can allow researchers to access the information they need quickly and to ultimately get more research out of their budgets.

### How is research undertaken?

- 1. Hypothesis submission.** The first step in beginning research into endometriosis is to create a hypothesis. This is a suggestion or guess to why endometriosis happens, how it can be managed or how it can be treated. Anyone can submit a hypothesis for testing on our research platform.
- 2. Testing & challenging the hypothesis.** The second step is to decide how we can test and challenge a hypothesis. For example if someone hypothesizes that dioxin exposure significantly increases the development of endometriosis, then we would use the open-survey part of our website to ask every endometriosis sufferer where they have lived and worked throughout their lives.
- 3. Support for unseen uses.** The answers to all questions asked is stored openly, which means every researcher, sufferer, member of the public or medical professional can view and access the raw data.
- 4. Pattern detection.** There is also a second approach to research on our platform, which is the automatic spotting of patterns or similarities amongst sufferers as they share more information about themselves with us. It is very easy for sufferers to share information about themselves as we use a survey-style approach to collecting research.

### Who is behind the project?

The company developing the research platform is Waltham Media Ltd, a software and website development company operated by the partner of an endometriosis sufferer. The project has been setup non-profit purely for the benefit of endometriosis sufferers; to aid advances in endometriosis research to help with prevention, treatment and long-term pain management. The operators of other endometriosis websites have been surprisingly hostile to our project and efforts. We feel the operators of these websites are not acting with sufferers interests in mind. For this reason we are relying on word-of-mouth amongst sufferers to help promote our goals. We are not selling or marketing any products or services and never will.

The research platform will open to the public September 2010. You can visit the website now to register your interest and receive an invitation when the project is launched.  
[www.theukendosurvey.org](http://www.theukendosurvey.org)