



Equality Impact Assessment Template

Before carrying out EqIA, you should familiarise yourself with the University's EqIA Policy Statement and Guidance and Checklist Notes, and undertake our online training on Equality and Diversity and EqIA. These, along with further information and resources, are available at www.ed.ac.uk/schools-departments/equality-diversity/impact-assessment

EqIA covers policies, provisions, criteria, functions, practices and activities, including decisions and the delivery of services, but will be referred to as 'policy/practice' hereinafter.

A. Policy/Practice (name or brief description): The Fragile X online registry research project

This is a research project which aims to gather cross sectional and longitudinal data on individuals with fragile x syndrome and associated conditions, along with a control groups of individuals who are unaffected by either. In order to further our knowledge of these conditions and provide information that could potentially be used to improve understanding and care provision in the future.

The registry has been running for 7 years, initially it only used face to face assessments, to overcome recruitment barriers (travel and time) it expanded to include online surveys using survey monkey as a platform. Though this was successful, it had limitations including not being able to integrate standardised questions. We therefore moved to deciding to create a custom build website to increase accessibility to the study, collect research data more securely and to feel more engaging for participants.

The website is being developed so individuals 16 years of age or over can register to join the website via email confirmation. Once they set up a password to protect their account, they then need to read a participant information sheet and complete an online consent form before they can enter the site. Individuals can complete surveys about themselves or for a care dependent who they are legally responsible for.

The website then contains surveys which individuals can complete about themselves or someone they are legally responsible for. They can choose not to complete all the questionnaires if wished.

B. Reason for Equality Impact Assessment (Mark **yes against the applicable reason):**

- ~~Proposed new policy/practice~~
- Proposed change to an existing policy/practice
- ~~Undertaking a review of an existing policy/practice~~
- ~~Other (please state):~~

C. Person responsible for the policy area or practice:

Name: Dr Sonya Campbell

Job title: Research Fellow in Clinical Psychology

School/service/unit: Clinical Brain Science, The Patrick Wild Centre

D. An Impact Assessment should be carried out if any of the following apply to the policy/practice, if it:

- affects primary or high level functions of the University **NO**
- is relevant to the promotion of equality (in terms of the Public Sector Equality Duty 'needs' as set out in the Policy and Guidance)? **YES**
- It is one which interested parties could reasonably expect the University to have carried out an EqlA? **YES**

E. Equality Groups

To which equality groups is the policy/practice relevant and why? (add notes against the following applicable equality group/s)

At the beginning of building this online site for our research project we have created a stakeholder working advisory group, consisting of members of the public representative of the population who are likely to be users of the research site in the future. They have been working with us to review and advise on the wording of items and usability of the website.

Participants will come from members of the public, many will be a member of the fragile x society. To access the site they need to register an email address and set up a password. All individuals joining are given an information sheet and need to provide consent online. The information gathered is pseudo anonymised for research purposes and at no point provides or restricts access to service provision or treatment.

Additionally, a few of researchers from within the Patrick Wild Centre will have access to the data as admin users. Only researchers approved by the PI will be given the necessary permissions to access the data. They will access the data via a secure university of Edinburgh login in. Fully anonymised data may be shared with research partners (this is made clear within our information and consent forms).

The data collected will be stored on a university of Edinburgh secure system called Maria which has encryption in motion.

- Age. The Individual adds their month and year of birth or that of their care dependent. This is gathered as user have to be over 16 years of age to use research site. It also is important to researchers as genetic conditions being researched can be associated to age related difficulties. For those over the age of 16 there is not age bias to how the site is accessed or used.
- Disability. The web design team have been building the site to be meet accessibility regulations, in particular to comply as far as possible with the Web Content Accessibility Guidelines 2.1 AA standards, including computability with assistive technology. Accessibility testing has been conducted on the website and an accessibility statement added in line with The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018. Where a disabled user is unable to complete the survey but wishes to reasonable adjustments will be put in place such as providing assistance to complete the form.

Some of the research questions asks individuals about health and disability within the survey section. All users have to read detailed information sheet and complete consent forms to ensure they know how this information will be used. They also have the option of not completing these questions if they do not wish to.

- race (including ethnicity and nationality). The website is in the English language as this is the main teaching language of the UK. We will not gather data on whether online browsers are used to translate the text within the website. We do not ask any questions about an individual's race
- religion or belief. The website will be accessible 24 hours a day 7 days a week to ensure individuals can access the site when suitable and so it does not clash with times of religious observance, caring responsibilities etc. We do not anticipate that any of the questions we ask would require a participant to discuss their religion or beliefs.
- sex. Once users have read the information sheet and completed the consent form they are asked to self-identify their gender. We have included 4 options namely: male, female, prefer to self- describe (they are not asked to provide a description) and prefer not to say. The 4 options were added to be inclusive, and to allow for the individual to make a personal choice about how much they want to disclose.
- sexual orientation. We do not anticipate collecting this data for our research purpose. In some cases it may be evident as the participant may choose to link another person of any gender to their profile and classify that individual as their partner. They however, can choice not to add their partner, or to classify their partner as "unrelated", or as a partner but not disclose their partner's gender. If information on sexual orientation was disclosed in this manner it would not be used for any purpose or have any impact on the research or the individual.
- gender reassignment. Individuals can self-identify their gender and they can update the gender on their profile within their own line profile settings any time they are logged in.
- pregnancy and maternity. We do not anticipate that any of our questions would elicit information about this. As mentioned the site is available 24/7 so users can choose to complete the survey at a time that suits them and taking account of child care/caring responsibilities.
- marriage or civil partnership. We have designed the site so someone can choice to indicate or not they have a partner. For those who choose to say they have a partner they are not asked any other relationship status questions.

Add notes against the following applicable statements:

On any available information about the needs of relevant equality groups: We have consulted with our stake holder group this was included within our ethics application. The group consists of adults who carry the premutation for the genetic condition or have family member who have fragile x syndrome. We have also met with the Information Services Disability Information Officer to discuss potential impacts on disabled users and she has tested the website for accessibility and assisted us in drafting the accessibility statement in line with The Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018

- Any gaps in evidence/insufficient information to properly assess the policy, and how this be will be addressed:

At this stage we feel we have sufficient evidence to proceed

- If application of this policy/practice leads to discrimination (direct or indirect), harassment, victimisation, less favourable treatment for particular equality groups: We do not believe that this research will lead to any form of prohibited conduct, for the reasons stated above and below. Where a disabled individual was unable to participate for any reason in the research for a reason related to a disability, reasonable adjustments would be put in place to ensure the individual experienced no disadvantage. The information gathered will be anonymised and kept on secure servers, with admin access rights only given a small number of trained member of the research team, therefore safeguarding its confidentiality.
- If the policy/practice contributes to advancing equality of opportunity¹ By making the survey online and available 24/7 we hope to reduce any barriers and therefore make it as easy as possible for all to take part in the research. Previous users had to attend in person to take part in the research but this will allow them to take part at any time of day and night that suits them. This should have a positive impact on some disabled users who may have found travelling difficult, those with parental/caring responsibilities, those who wish to observe times of religious observance. This should hopefully ensure individuals across all protected characteristics can easily participate and may increase responses from those with certain protected characteristics.
- If there is an opportunity in applying this policy/practice to foster good relations: It is hoped that the research may help further create good relations with the Fragile X community and by conducting this EqIA and considering the impact of the research on all protected characteristics we will demonstrate the Universities commitment to Equality and Diversity.
- If the policy/practice create any barriers for any other groups?

We do not envision this research will create any barriers for any other groups such as those on low incomes. To take part in the research is free but does require IT facilities and an internet connection. In the UK free access to IT facilities can be found in public libraries and similar arrangements exist in other countries.

- How the communication of the policy/practice is made accessible to all groups, if relevant?
The study will be advertised by a combination of online notices and newsletters from the Patrick wild centre and the fragile x society, and by word of mouth from those taking part. All communication will be made available in alternative formats free of charge upon request for disabled users.
- How equality groups or communities are involved in the development, review and/or monitoring of the policy or practice? We have an active stake holder working group which includes 5 members, who were initially contacted through the fragile x society. They all either have FXS or carry premutation for the gene and or have close family member who does. The group communicates by email and by Skype and includes members from around the UK. They have been sent copies of the questions we are asking and have comment on these, and will be testing the site. They sent comment through our skype meeting and by email, this group will continue to be active until August 2020.

We will continue to review all feedback positive and negative for any comments related to any of the nine protected characteristics and act accordingly whether this be from the working group or users of the site. The site will contain our contact details so if a user has concerns can contact us directly.

¹ This question does not apply to the protected characteristic of marriage or civil partnership

- Any potential or actual impact of applying the policy or practice, with regard to the need to eliminate discrimination, advance equality and promote good relations: Nothing other than that stated above and below.

F. Equality Impact Assessment Outcome

Select one of the four options below to indicate how the development/review of the policy/practice will be progressed and state the rationale for the decision

Option 1: No change required – the assessment is that the policy/practice is/will be robust. For the reasons stated above and below

~~**Option 2:** Adjust the policy or practice – this involves taking steps to remove any barriers, to better advance equality and/or to foster good relations.~~

~~**Option 3:** Continue the policy or practice despite the potential for adverse impact, and which can be mitigated/or justified~~

~~**Option 4:** Stop the policy or practice as there are adverse effects cannot be prevented/mitigated/or justified.~~

G. Action and Monitoring

1. Specify the actions required for implementing findings of this EqIA and how the policy or practice will be monitored in relation to its equality impact (or note where this is specified above).
 - ensure research staff are aware of the need to make reasonable adjustments and to make information available in alternative formats upon request
 - to monitor all feedback for any comments positive or negative related to any of the 9 protected characteristics .
2. When will the policy/practice next be reviewed? Sept 2020

H. Publication of EqIA

Can this EqIA be published in full, now? Yes

If No – please specify when it may be published or indicate restrictions that apply:

I. Sign-off

EqIA undertaken by (name(s) and job title(s)): Dr Sonya Campbell, Research Fellow in Clinical Psychology

Accepted by (name):

[This will normally be the person responsible for the policy/practice named above. If not, specify job-title/role.] Dr Andrew Stanfield, Senior research fellow.

Date: 19.11.2019

Retain a copy of this form for your own records and send a copy to equalitydiversity@ed.ac.uk