

# **Scottish Education Project**

Working to help preserve fertility, improve awareness and educate young people

### Independent evaluation October 2016





Wren and Greyhound

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#### **Executive summary**

Since 2012, the Scottish Education Project has worked with universities, health professionals, GPs and employers to raise awareness of fertility. People already affected by fertility problems are also engaged, through open sessions in health clinics and well-regarded regional information events.

#### Outcomes

The evaluation explored evidence of the extent to which five outcomes have been achieved:

### 1. Improved awareness among students of the factors affecting fertility and how to protect fertility.

This outcome was fully evidenced. The project typically exceeds its targets for engaging with students, universities and colleges. Its resources are viewed as relevant and have been shown to be effective at raising awareness of lifestyle fertility factors.

#### 2. Improved access to information and support for those affected.

Evidence from the evaluation shows that the project has made a practical difference to people affected by fertility problems, chiefly through its regional information days.

# 3. Improved partnership responses to fertility awareness and prevention

The project has raised student and professional clinicians' awareness of fertility issues, including the emotional impact. Partners in further and higher education rate the project's input particularly highly and are keen to help the project reach new audiences.

#### 4. Fertility issues are better understood and supported

Respondents, including people affected by fertility issues, report understanding fertility better. Professionals report an improved ability to identify and signpost people appropriately. However, awareness of Fertility Network Scotland support services could be increased.

# 5. Employers have better understanding fertility issues faced by employees

This outcome has chiefly been achieved and evidenced by the project's successful engagement with trade unions. This appears to have had an impact with local government employers. It remains to be seen how the project will work with other employers in future.

#### Learning

During the evaluation, some interesting learning points emerged:

#### • The value the project adds to partners

The Education Project benefits its partners by bringing up to date resources and expertise (including lived experience), making an important topic accessible.

#### • Developing partnerships

To continue to communicate its messages effectively the project would benefit from a more deliberate, planned approach to partnership work.

#### • Reach – how much is enough?

At present, the project follows demand, which is sensible given its limited resources. However it would benefit from mapping the areas it has and has not reached, and how well needs are identified and met.

#### • Linking education and support

Respondents suggested a clearer link be made between the education project and the organisation's support services.

#### • More structured volunteering

Like partnerships, volunteering is an area where the project is likely to benefit by having greater recognition, and making better use, of its supporters' goodwill.

#### Recommendations

The evaluation report makes seven recommendations:

- 1. Adopt the new outcome framework including the additionally recommended indicators to ensure the project continues to be able to understand and evidence its impact.
- 2. Consider providing a larger or dedicated activity budget for events.
- 3. Continue to provide information events for people affected by fertility issues, as there is good evidence of their effectiveness in achieving a number of goals.
- 4. Adopt a deliberate, planned approach to partnership work. Explore networks and alliances of support with other single-interest health promoting organisations.
- 5. Develop a process of reviewing the project's reach periodically to inform planning and evaluation (e.g. during annual work planning).
- 6. Ensure the education project is sufficiently integrated within and informed about the work of the wider organisation.
- 7. Continue the development of a structured and supported volunteering programme.

### 1. Introduction, aims and methodology

In June 2016, Fertility Network Scotland issued a brief for an independent external evaluation of the Education Project to:

- Ascertain if the project is having maximum impact
- Add value to self-evaluation reports
- Inform future project development

The evaluation took place between August and October 2016. It started with a review of the project's work plan, outcomes and Key Performance Indicators. This led to the development of a new outcome framework, used to structure and present the evidence that was gathered for this report.

The report aims to present a rounded assessment of the project by analysing evidence gathered and triangulated from a range of sources:

- Telephone interviews with eight project stakeholders
- Observation of project staff interactions at a full-day information event (Glasgow Fresher's Fair)
- Short interviews with 30 Fresher's Week students
- Meetings and interviews with five staff members
- Testimonials and feedback from project partners
- Data from three in-house surveys and four project reports
- Organisational literature (UK-wide survey on infertility, information leaflets etc.)



### **99**

Quotes used in the report are all verbatim, transcribed from interviews with project stakeholders. Unless otherwise stated, they are representative illustrations of the theme being discussed, rather than solitary views. Where more than one quote appears in a section, the quotes are from different people. Ellipses (...) indicate where quotes have been edited for brevity of clarity. Dashes (-) indicate a pause in speech. (Brackets) indicate where a word has been added, usually for clarity but occasionally for anonymity.

Note: The organisation's name changed in July 2016. Sometimes people quoted in the report refer to the 'Infertility Network UK' (or INUK) rather than 'Fertility Network Scotland' (or FNS). These were correct at the time they refer to, so have not been changed.

### 2. Education project background

In 2012 Fertility Network Scotland recognised the need for an education project to empower people to make informed lifestyle choices. A project plan was created, focusing on awareness raising, promotion and prevention. Funding was subsequently awarded by Scottish Government and work began in the same year.

Since then, the Scottish Education project has worked with universities, health professionals, GPs and employers across Scotland to introduce ways of ensuring people are better informed about how their fertility can be conserved.

The project visits colleges and universities, presenting students with information on fertility and infertility. As a way to educate the workforce of tomorrow, the project also gives talks as part of nursing and midwifery curricula. GPs and other health professionals are reached through presentations in practices, sexual health, family planning and other clinics.

People already affected by fertility problems are also engaged, with open sessions in health clinics and through well-regarded regional information events. The overall aim of these events is to provide accurate and up to date information on infertility for patients, raise awareness, and provide education about the support available.

The need for and legitimacy of fertility treatment appear to have become better understood over recent years, across the globe and in the UK. However there is a growing recognition of the need for fertility education, particularly about lifestyle factors that influence fertility<sup>1</sup>. Having said that, this evaluation takes place in the context of a service that is funded and supported in Scotland, but not currently in the rest of the UK. This report therefore identifies learning from the Scottish model, to inform the future development of this and other fertility education projects.

<sup>&</sup>lt;sup>1</sup> <u>http://www.bionews.org.uk/page 634715.asp</u>

### 3. Project outcomes

The project's outcomes have evolved in the five years since its inception. There are now seven outcomes in the project's work plan, each of which contains a number of Key Performance Indicators. The evaluation began by examining the outcomes in the light of the project's self-evaluation evidence. In some cases the project was measuring and achieving what look like appropriate outcomes. In others, the stated outcomes were being overshot by what the project was actually achieving. We therefore clustered some of the 'smaller' original outcomes together to create new overarching outcomes, and used these to structure the evaluation, see Table 1 below.

| Existing outcome   | Proposed new outcome  |
|--|---|
| Improved awareness among students of the factor<br>protect fertility   | ors affecting fertility and how to  |
| Improved access to information and support for t problems  | hose affected by fertility  |
| Closer working relationships with long-term<br>unemployed, young offenders and care leavers,<br><u>supporting the hardest to reach young people</u><br>Closer working relationships and improved<br>awareness of the emotional impact of fertility<br>problems among student Nurses and Midwives<br>Closer working relationships and improved<br>awareness of the emotional impact of fertility<br>problems among GPs<br>Closer working relationships and improved<br>awareness of the emotional impact of fertility<br>problems among health professionals within<br>Sexual and Reproductive Health clinics | Improved partnership<br>responses to fertility<br>awareness and prevention    |
| (Funding application outcome)<br>Health and wellbeing of people of reproductive<br>age in Scotland will be improved by <i>increased</i><br><i>knowledge of how their reproductive system</i><br><i>works and what can negatively impact on their</i><br><i>ability to have a child in the future.</i><br>(Funding application outcome)<br>Those affected by infertility would also be<br><i>better informed and empowered</i> through this<br>project, thus <i>better able to manage their</i><br><i>illness.</i>  | Fertility issues are better<br>understood and supported                       |
| Engage with HR departments of companies  | Employers have better<br>understanding fertility issues<br>faced by employees |

The report assesses these outcomes by presenting evidence systematically against a number of indicators. This table gives an overview of the indicators and the extent to which the outcomes were evidenced by the evaluation:

| Outcome                                  | Indicator   |
|--|---|
| 1. Improved                              | 1.1 Number of students reached and engaged with   |
| awareness among                          | 1.2 Level of awareness and consideration of lifestyle   |
| students of the factors                  | choices which could affect future fertility   |
| affecting fertility and                  |   |
| how to protect fertility                 |   |
| 2. Improved access                       | 2.1 Number of people with fertility issues engaged with   |
| to information and                       | and helped through information events   |
| support for those                        | 2.2: Effectiveness of information events  |
| affected                                 | 2.1 Number of young people reached and engaged with   |
| 3. Improved                              | 3.1 Number of young people reached and engaged with   |
| partnership responses                    | 3.2 Number of workers engaged with within the   |
| to fertility awareness<br>and prevention | organisations targeted  |
|  | 3.3 Number of student midwives and nurses engaged<br>3.4 Evaluation feedback indicates student nurses and |
|  | midwives feeling better informed about the infertility  |
|  | patient experience; the impact of infertility on mental   |
|  | health; the reality of infertility treatment.   |
|  | 3.5 Number of GPs engaged with  |
|  | 3.6 Number of evaluation forms indicating improved  |
|  | awareness and understanding of FNS and the emotional  |
|  | impact of fertility problems  |
|  | 3.7 Number of health professionals engaged with   |
|  | 3.8 Number and nature of mainstream education and   |
|  | health providers using or promoting FNS information and   |
|  | messages  |
| 4. Fertility issues are                  | 4.1 Extent to which people affected have knowledge of   |
| better understood                        | their reproductive system and factors that can impact on  |
| and supported                            | their ability to have a child in the future   |
|  | 4.2 Level of information, empowerment and ability to  |
|  | make informed decisions   |
|  | 4.3 Extent of professionals' awareness of fertility problems  |
|  | and their emotional impact  |
|  | 4.4 Extent to which professionals are able to provide   |
|  | information and signposting to appropriate fertility  |
|  | resources   |
| 5. Employers have                        | 5.1 Number of companies engaged with  |
| better understanding                     | 5.2 Level of trade union acceptance of and support for  |
| fertility issues faced                   | fertility as a workplace health issue   |
| by employees                             | 5.3 Number of companies adopting a policy on fertility  |
|  | issues within their workforce   |

Table 2: Summary of outcomes and the extent to which they were evidenced

Key:

Strong, consistent evidence of outcome being achieved Some good evidence

Mixed or partial evidence No or very limited evidence Outcome 1: Improved awareness among students of the factors affecting fertility and how to protect fertility

'The presentations at the Fresher's Fair have loads of information and are very well-attended. (The worker) has got such a wonderful personality, she pulls all these folk in and has great conversations with them.' (University lecturer)

This outcome was fully evidenced from project reports, stakeholder interviews and observed practice. The project typically exceeds its targets for engaging with students, universities and colleges. Its resources are viewed as relevant and have been shown to be effective at raising awareness of lifestyle fertility factors.

#### Indicator 1.1 Number of students reached and engaged with

The project primarily aims to reach students by attending Fresher's fairs and other events, with a KPI of reaching 20 universities and colleges every year. This is a relatively challenging target, given the density of fairs during September every year - and the liaison and preparation required beforehand. However, project reports show that the target has been met (2014: 19 fairs; 2015: 21).

The 2014 and 2015 project reports show that the project distributed 5000 'future fertility' leaflets, compared to a KPI target of 4000. As well as being given information, students at the fairs are invited to take part in surveys about their awareness of fertility. The project aims to get at least 500 respondents to the survey annually, another KPI it is has exceeded (2014: 542; 2015: 625).

Whenever a project exceeds its targets in this manner, it is fair to ask whether the targets are appropriately challenging. However, having shadowed the education team during a busy Fresher's event, our observation would be that exceeding the target is a result of skill, perseverance and a strong values base. The team engaged proactively and enthusiastically, despite the long hours and high volume (in both senses) of students and stallholders. The engagement was also noticeably inclusive, with very broad diversity in the ethnicity, gender, sexuality, age and disability of people approached by the team. In this and in separate one-to-one interviews, the team's commitment to fertility education for all was very evident.

'The core message is that you don't want anybody ending up in that position of being infertile. You want everyone to know that there's help out there.' (Project worker)

The project's final KPI in this area is to use at least two interactive tools to engage students in highlighting how lifestyle factors affect fertility. The four activities we observed were creative, and popular with students. They helped to lighten the tone and facilitate low-pressure conversations about lifestyle and fertility. However, the resources all relate to alcohol (unit measure glass, wheel and scratch card; 'beer goggles' and sperm-shaped stress balls) and rely on resources being available from other organisations (e.g. NHS health promotion).

The project's event/promotions budget allows it to book stalls and provide organisation-specific giveaways which help to attract people to their stall. But staff have also clearly made imaginative use of limited resources. It is worth considering whether a larger and/or dedicated *activity* budget for events would help to achieve a greater or wider educational impact.

### Indicator 1.2 Level of awareness and consideration of lifestyle choices which could affect future fertility

Almost all of the participants in the last two year's student surveys report an increase in awareness of lifestyle fertility factors (2014: 99.7%; 2015 98.9%)<sup>2</sup>.

Only 3 of the 30 people we spoke to at the Fresher Fare felt the lifestyle messages were not relevant to them. The predominant view was that the stall was a valuable addition to the event:

'It's not the sort of stall you'd expect to see here, but it's good that it is. It should be here.' (Female mature student)

'It's good, because students make unhealthy decisions that can affect them in later life, so it's important they have information so at least they can make informed decisions.' (Female student)

'If you think about it, these students are about to embark on years of self-abuse, with drinking, partying, smoking! All the things that affect fertility. They need to know this.' (Male mature student)

'I think it's the best stall here because it's about safety and responsibility. It's good to see a health stall.' (Female student)

'Good to know. You might be affected by these things later in life, especially in the aftermath of drinking alcohol, so it's good to know how to prevent it.' (Male student)

'This is the most important stall here. It's so unusual to see anything about it, no-one talks about fertility.' (Female student)

Another way the project reaches students is by giving talks in colleges and universities. These are greatly valued by these institutions for enhancing their own curricula and bringing the topic to life.

<sup>&</sup>lt;sup>2</sup> From 542 surveys in 2014, and 625 in 2015.

'(The project worker) has been able to bring along women who have been through that process of infertility, which is hugely beneficial for our students... It's been really integral to our programme and has always been very well evaluated'. (University lecturer.)

'It's relevant information, giving young people and students informed choice. Health and well-being is a big part of student studies.' (College partner)

A final observation would be that the surveys and information are well designed in that they are brief and focused, were judged as relevant by most participants, and appeared accessible (they did not take long to complete and staff were observed giving help where student literacy was an issue).

# Outcome 2: Improved access to information and support for those affected by fertility problems

'When I first went to go for fertility treatment, I just assumed that the fertility treatment was all that there was. It wasn't until I went on to the Fertility Network - they gave out advice leaflets as well as the professionals that are on there. The waiting felt like a long time before the appointment. To be able to say, if you focus on your diet, there are things you can change and try and improve the PCOS<sup>3</sup>, lifestyle changes that could help improve the outcome. This meant I had something else to focus on while I was waiting for the treatment. I was always going to need the treatment, but I didn't know up until that point how many other factors, things that I could have done to help improve the outcome.' (Project beneficiary and volunteer)

The quote above demonstrates that there is a need for information and support, even when fertility problems have been identified and when treatment is awaited. The education project's main focus is education and young people, but evidence from the evaluation shows that the project has made a difference to people affected by fertility problems, chiefly through its 'regional information days'. However evidence would be further strengthened by collecting data from a wider range of sources.

<sup>&</sup>lt;sup>3</sup> PCOS: Polycystic Ovary Syndrome

### Indicator 2.1 Number of people with fertility issues engaged with and helped through information events

The project's information events are designed to give people affected by fertility issues access to information and professionals, through a combination of speakers, presentations and displays.

The events have proved popular to date and are evidently achieving their stated aims. In 2015, 72 patients and 22 professionals took part (2014: 75 patients and 35 professionals). An event planned for October 2016 has been put back to February 2017, due to exhibitor availability, but the project's target is to increase participation by 25%.

#### Indicator 2.2: Effectiveness of information events

Participants rate the range of talks on a scale from 1-5, where 1='Poor' and 5='Excellent'. In 2015 the average score was 4.6 (2014: 4.7). Comments included:

'Very good, was put at ease from Infertility Network Scotland's presentation.' 'Patient experience talks were excellent.' 'Good variety, gave us more information on the process of IVF.'

The events include a 'Question Time' session, which also scores highly (2015: 4.4; 2014: 4.8).

'Just the right amount of time for questions.'

'Very open and informal, felt comfortable asking questions.'

'Very relaxed, thoroughly enjoyed it.'

From these comments and those below it is evident that the information events help people, by making good quality information accessible within a comfortable environment.

'Infertility Network Scotland staff so friendly and completely make you feel at ease.' 'Fantastic and really worthwhile.'

'Brilliant day and would recommend it to anyone.'

'Really informative and has helped a great deal.'

The education project also runs or takes part in other local events throughout Scotland. These include:

#### • Support groups

The project aims to assist groups either by developing new ones where there is local need, or maintaining existing ones. The project has learned that face to face contact isn't always straightforward for people at different stages in their journey, but it is important in ensuring people feel less isolated and better supported. 'To be able to honestly express my feelings anonymously was really important to be able to cope with the whole situation. It's such a long and stressful process so having other peers there to talk to, and then having all the specialists within the Infertility Network that had had counselling training, you could call if you got upset or had had a negative outcome, that was really, really important.' (Project beneficiary and volunteer)

#### • Attending clinics

The project has taken part in patient evenings/days at numerous clinics. In 2015 these included Aberdeen; Ayr; Biggar; Crosshouse; Dumfries; Dundee; Edinburgh; Fife; Girvan; and Perth.

#### • Other events

The project attends other events, sometimes with other voluntary organisations, including patient participation forums; family planning clinics; The Gathering; a 'Science Café'; a Midwifery Conference; and Sexual Health events.

These events, particularly its regional information days, provide the Education Project with an effective way to engage - and make a difference to - a relatively large number of people affected by fertility problems. Without this, the project's focus would be purely educational and preventive, which can give rise to a perceived gap between the organisation's information and support functions (see Part 4 below). The information events help to bridge these functions.

There are therefore several good reasons why this strand of the project's work should continue to be developed.

Other indicators that were not able to be measured in the evaluation, but which would strengthen this outcome in future reports include:

- Number of website hits, e.g. showing increased access over time
- Number of information enquiries
- Number of education and health providers using or promoting FNS information and messages
- Extent to which people affected know where to go for information and support.

# Outcome 3: Improved partnership responses to fertility awareness and prevention

'A friend...had a lot of different complications happen in her pregnancy and she was absolutely terrified all the way through. She didn't have much continuity of care with midwives and they were quite passive about the problems that she was having, so I felt really passionate...to try and educate midwives about the impact of fertility on pregnancy. I'm trying to raise awareness of the emotional and psychological impact of fertility treatment on pregnancy, which I think is the one thing that we don't have enough research and education on.' Project Volunteer

This new outcome demonstrates the *combined* impact of four separate but related current outcomes. All of these have the same focus - closer working relationships with a range of different target audiences:

- 1. Long-term unemployed, young offenders and care leavers, supporting the hardest to reach young people
- 2. Student Nurses and Midwives
- 3. GPs
- 4. Health professionals within Sexual and Reproductive Health clinics

For the last three groups, an additional objective is to raise awareness of the emotional impact of fertility problems.

Sub-outcome: Closer working relationships with long-term unemployed, young offenders and care leavers, supporting the hardest to reach young people

#### Indicator 3.1 Number of young people reached and engaged with Indicator 3.2 Number of workers engaged with within the organisations targeted

Previous project reports do not record the total number of young people or organisations the project reached. The KPI is to work with six organisations per year, which appears to have been met in 2014 and 2015, and to be on target in 2016.

It is particularly interesting that the project has worked with funders like the Hollywood Trust and Inspiring Scotland. These organisations typically have good evidence of need, and the ability to reach – and influence – large numbers of young people's organisations. Other third sector partners have included national organisations like Shelter and Quarriers as well as local ones such as Seascape, The Lighthouse and Impact Arts. [For more on partnership work, see Part 4 below.]

As to the *impact* on young people, one partner rated this highly, stating that FNS inputs can help young people to make informed choices about health:

'I definitely think it's giving them food for thought. It's maybe something they've never thought of before the fertility workshop is delivered. A lot of them do have chaotic lifestyles and do misuse drugs and alcohol, so it maybe makes them think about their future and how they take care of their bodies, how it can affect their future fertility.' (College partner)

Sub-outcome: Closer working relationships and improved awareness of the emotional impact of fertility problems among student Nurses and Midwives

Indicator 3.3 Number of student midwives and nurses engaged with The project's current KPI is to give presentations to a minimum of 150 student Nurses and Midwives every year, increasing 5% on the previous year. In 2015 160 feedback forms were received (2014: 150). It is rare to receive a 100% return rate, so it is likely that slightly more than 160 students were engaged.

# Indicator 3.4 Evaluation feedback indicates student nurses and midwives feeling better informed about the infertility patient experience; the impact of infertility on mental health; the reality of infertility treatment.

Of the 160 evaluation forms returned by student midwives and nurses in 2015,

- 100% rated the information provided as excellent (98%) or good (2%)
- 100% felt better informed about the patient experience
- 100% felt better informed about the impact of infertility on mental health
- 100% felt better informed about infertility treatments.

2014's results were consistent with this (the only difference being 95% rating the information as 'excellent', 5% as 'good'). Students clearly rate this input very highly, as their comments attest:

"The patient experience was fantastic (to hear)."

"Excellent presentation, amazing story."

"Found the whole presentation really informative."

"Patient story really helps us to be better nurses."

"Great. I never understood how traumatic it was for patients."

"Really enjoyed the personal story element."

"It is so good to have somewhere to direct patients to."

It is noticeable how much emphasis student clinicians place on the human story and *emotional* impact of fertility problems. This provides good evidence towards the overarching outcome.

University partners themselves see the value of this emphasis on patient wellbeing. In interviews, all of the education professionals we spoke to were enthusiastic about the role of the FNS input on their curricula. 'The standard midwifery textbooks all cover and make general comments about the physiological problems of infertility...but actually to hear it first-hand - Although there is lots of material available online, the unique difference is that they are able to ask questions. And they feel as if they can explore some of the points raised during the discussion. Because we've got access to these two individuals, which is an additional level of learning for them.' (University lecturer)

'It being from the client's or patient's perspective, it's not just the health service that provides services to people, there's all the emotional support, the specialised support that doesn't always come from within the health service... and we very much want the students at an early stage to recognise that, that not one agency can do it alone and they have to involve other sectors.' (University lecturer)

Sub-outcome: Closer working relationships and improved awareness of the emotional impact of fertility problems among GPs

#### Indicator 3.5 Number of GPs engaged with

The project aims to give at least five presentations to GPs every year, and to increase by 5% the number of GPs it reaches. In 2015, 73 GPs were present at presentations. The project works hard to reach GPs and meets its targets whether by presenting directly to GP surgeries (2014: 29 surgeries) or, where this is not possible, by making presentations to events and audiences that are likely to include GPs.

# Indicator 3.6 Number of evaluation forms indicating improved awareness and understanding of FNS and the emotional impact of fertility problems

As with student nurses and midwives, GPs rate the project's information very highly. In 2015, 100% rated it as excellent (95%) or good (2%) (2014: 99% excellent, 1% good).

- 100% felt better informed about infertility pathways (2014: 100%)
- 100% felt better informed about the impact of infertility on mental health (2014: 100%)
- 100% felt better informed of the services offered by Fertility Network Scotland (2014: 100%)

In addition, several of the evaluative comments (below) relate to being better informed about or able to signpost people to treatment. This is another useful indicator of the overall outcome of improved *responses* to fertility problems.

"Will definitely encourage patients to contact Infertility Network Scotland."

"I did not realise that patients could access treatment after age 38."

"I did not realise the BMI had been reduced or smoking would now be tested"

"I still believed Ayrshire and Arran offered 3 cycles of treatment" "Found this very informative and good knowledge when seeing anyone with fertility issues"

"It was good to hear a specialist in the fertility spectrum speak too"

Sub-outcome: Closer working relationships and improved awareness of the emotional impact of fertility problems among health professionals within Sexual and Reproductive Health clinics

#### Indicator 3.7 Number of health professionals engaged with

The project doesn't track the number of sexual health clinics attended, as some clinics serve more than one purpose. However the overall story appears to be that FNS, and fertility as an issue itself, has increased acceptance among sexual health practitioners. At first the education project found practitioners relatively reluctant to engage with the subject. This was perhaps because of a perception that the project would promote conception over contraception (whereas project staff describe these as 'two sides of the same coin'). However, there is increased recognition that the project, like the clinics, is about supporting informed choice. Also, STIs can affect fertility, and clinics therefore welcome FNS visits and literature.

Unlike the feedback from students and GPs, there was less evidence in the evaluation of raised awareness of the emotional impact of fertility problems. A sexual health practitioner we spoke to reported that the benefits of FNS input was increased awareness of the health, rather than emotional, impact:

'It broadens (sexual health practitioners') outlook in what they are already doing...It heightens their awareness... I think from our point of view it was more the health impact. It was an awareness-raising session from a health point of view.' (Sexual health practitioner)

### Indicator 3.8 Number and nature of mainstream education and health providers using or promoting FNS information and messages

This new indicator has been suggested by the evaluation partly because it is a common measure of influence (particularly in policy/advocacy arenas), and partly because a particularly interesting case study emerged during the process of gathering information for the evaluation:

"I was delighted to welcome (the staff) from Fertility Network Scotland to speak with our year 2 midwifery students on our Paisley Campus. This session formed part of our mental health module where we explore the emotional and psychological impact of both mental health difficulties and challenges that may arise during pregnancy and childbirth. The session was recorded so that it could be shared with our students on our Hamilton campus. The opportunity for my students to hear from two such passionate knowledgeable advocates for infertility care and support is not only inspiring but prepares these future midwives for the realities and complexities of clinical practice." Tom McEwan MSc, PgDip (ANNP), PgCert TLHE, BSc, RM, TCH, HEA (Fellow), Lecturer in Midwifery, University of West of Scotland

This example, of an education establishment making a lasting resource out of a one-off input, introduces the idea of FNS and its partners working together to create, share and save resources. In this example, UWS now has a resource that can be made available within the School of Midwifery and in other health programmes. Looking beyond that, the University also has the technology to broadcast presentations to the two other midwifery campuses (Robert Gorgon's University and Edinburgh Napier), allowing all midwifery students at the same level to access and interact with the same material at the same time.

**Other indicators** that were not able to be explored in the evaluation, but which could enhance this outcome for future reports were:

- The *impact* of FNS's involvement of the Association of Fertility Patient Organisations
- Number and nature of other partnerships, e.g. across single-interest boundaries with other Scottish health-promoting organisations

#### Outcome 4: Fertility issues are better understood and supported

'If women are able to focus on what they can do to improve their health and outcomes before their fertility treatment and before their pregnancy, they are reducing massive risk factors.' Project beneficiary and volunteer

For this new outcome to be achieved, both professionals and people affected by fertility problems need to be more aware of the issues and support available than they are now. For example, a recent survey<sup>4</sup> of 865 people found that only 52% fully understood the nature of their fertility problem, with just 26% reporting that their GP provided sufficient information.

Our evaluation found good evidence that the project has increased awareness of the majority of the health professionals and students that it has engaged with since 2012. There was less evidence of them having an increased ability to provide better support, though the respondents we interviewed agreed with the project's 'theory of change', that educating students would eventually lead to improved practice in their professional

<sup>&</sup>lt;sup>4</sup> Middlesex University London and Fertility Network UK: Survey on the Impact of Fertility Problems, Final Report, May 2016

careers – and across their professions. An education and awareness raising project can only do so much to influence *practice*.

There was also relatively limited evidence of people affected by fertility problems being more *empowered* to make informed decisions, though the Information Day feedback under Indicator 2.1 above, and the quotes below, contain some indications of this.

# Indicator 4.1 Extent to which people affected have knowledge of their reproductive system and factors that can impact on their ability to have a child in the future

### Indicator 4.2 Level of information, empowerment and ability to make informed decisions

These two indicators were in the original funding proposal before the project began in 2012, but they have been subsumed into other outcomes as the project has evolved. They have therefore not been systematically measured by the project, but are still evident in several quotes from information event participants and stakeholder interviews:

'While on the waiting list I know how to give ourselves the best chance of success.' (Information event feedback)

'Everyone was very clear and interesting. Wish we had something like this to attend before treatment.' (Information event feedback)

'If women are educated around their condition and how to improve their outcomes they are actually relieving pressure from the NHS because they are going to need less cycles to become pregnant, when they do become pregnant they're going to be healthier and have less complications.' (Project beneficiary and volunteer)

'(Information leaflets are important) to let them know that if their course of fertility treatment is unsuccessful, it's not the end of the world, there are other options available to them.' (Project beneficiary and volunteer)

# 4.3 Extent of professionals' awareness of fertility problems and their emotional impact

See Indicators 3.3-3.7 above, which also evidence this indicator very well.

# 4.4 Extent to which professionals are able to provide information and signposting to appropriate fertility resources

The education professionals and health practitioners interviewed generally agreed that although professionals would not be better able to support people affected by fertility problems, they would be better able to identify them and signpost them to appropriate support. '(The students) are actually more knowledgeable in the last couple of years that we've done this than a lot of their midwifery mentors. For our students to be aware of the organisations available to offer that support, even though there's a successful pregnancy, they are there and have got a unique understanding of what they've been through, then that's beneficial for the women that we care for.' (University lecturer)

'Made us aware of support that is available to people who are not conceiving as quickly as they would wish, and the role our service can play in helping people access this support'. (Team testimonial submitted to the evaluation by a health professional).

# Outcome 5: Employers have better understanding fertility issues faced by employees

'Every employer needs to have some kind of protocol in place and to encourage disclosure so people don't have to feel embarrassed or use annual leave or sickness absence.' Project beneficiary and volunteer

To date, this outcome has chiefly been achieved and evidenced by the project's successful engagement with trade unions. This appears to have had an impact with local government employers, but it remains to be seen how the project can work directly with other employers in future.

#### Indicator 5.1 Number of companies engaged with

The project's KPI for this outcomes is to give at least two presentations to companies on the benefits of their staff's health and wellbeing of understanding fertility issues. Although such sessions and inputs have been offered to employers, the main progress is being made through a partnership with Trade Unions that came about through a project beneficiary and volunteer, see below.

### Indicator 5.2 Level of trade union acceptance of and support for fertility as a workplace health issue

In 2013/14, FNS was asked to write a motion to present at Glasgow Unison's AGM for a patient whose employer did not recognise fertility issues as a medical condition. This was an issue for the individual and the union, as it was found that staff were using their holiday entitlement to attend fertility appointments and treatment. In March 2014 the motion was passed unanimously by the Glasgow Unison Branch.

All Unison branches in Scotland have now accepted this policy. It has also reportedly been adopted through COSLA and the Scottish local government agencies, again through the links with the trade unions: 'In co-operation with UNISON, Unite and the various trade union bodies and these local authorities we've got a draft protocol in place. It may have been something that they hadn't had to deal with before. (What helped was) the assistance that we got from FNS and the statistics that we were able to give them, (that) as many as one in six people suffer from fertility problems. We were able to say that it was an ongoing issue which wasn't going to go away.' Project beneficiary and volunteer.

### Indicator 5.3 Number of companies adopting a policy on fertility issues within their workforce

From the statement above, it can be inferred that each of Scotland's 32 local authorities has adopted or will adopt such a policy. Although this has inevitably taken some time to come about, it is sign of reach and impact that many advocacy organisations would be envious of.

### **4.** Learning

During the evaluation, some interesting learning points and questions emerged. The main themes are:

- The value the project adds to partners
- Developing partnerships
- Reach how much is enough?
- Linking education and support
- More structured volunteering

These are now explored in full below.

#### Value added to partners

Respondents spoke very highly of the education project as an organisational partner. Partly this was to do with the staff involved and their ability to build productive relationships:

'(The worker) that comes in has got a lovely personality, she's great at engaging with the young people. It's always very positive...She's got a really down-to-earth personality which the young people like. You can tell she loves doing her job.' (College partner)

Partners also view the project as a source of credible up-to-date information. Perhaps contrary to expectations, clinicians and educators particularly value the project's *non-clinical* expertise and role.

'We would expect...that they would update their presentation in terms of what was the latest (research) and what would contribute more...I've been relying on them to tell us what the changes were and how we should change or what we should do to support that session.' (University lecturer)

'Having a gynaecologist or an infertility specialist come in and speak to the students would have much less relevance for our group than actually speaking to someone who supports women, but is also engaged with the clinicians that provide the infertility care, so has got an awareness of the entire journey of women through infertility.' (University lecturer)

The Education Project's role in longer term prevention and cost-effectiveness was also highlighted by one respondent:

'If we have charities and support networks it takes a massive amount of work away from the NHS. If we're educating women, then they're going to have better outcomes. If we're supporting women, we don't need to have as much medical psychological

#### **Developing partnerships**

The Education Project benefits its partners by bringing additional resources and expertise, and by making an important topic accessible to young people.

In the immediate future, resources will be more constrained than ever. The number of issues competing for target recipients' attention is also growing. To continue to communicate its messages effectively the project would therefore benefit from a more deliberate, planned approach to partnership work.

#### ...with existing partners

Firstly, this would help it to build on the already high levels of goodwill with existing partners. In the examples below, one of Scotland's midwifery schools offers a means for the project's resources to reach into other university programmes. A college also indicated that it would willingly promote fertility messages, and that its students would be motivated to support the project, for example through project work or volunteering:

'If they wanted to work in partnership and do a project together, that could be an option...We're always looking for opportunities. The students develop lots of different skills when they do voluntary work, they are developing all their soft skills. It would be good to promote a small organisation at the same time.' (College staff)

'Looking to the future I would certainly want to be able to continue to work with (the project) and look at developing other resources. And helping them as well, even working on resources together, putting something together that would then allow Fertility Network Scotland to gain access more easily into other programmes.' (University lecturer)

The education project has a lot of stakeholder goodwill behind it, if it can find ways to capitalise on this. Inevitably this would require development time, perhaps taking some time away from project delivery. But for the work to be sustained and grown, networks and alliances of support are crucial.

#### ...with new partners

One obvious alliance that could be made is with other single-interest healthpromoting organisations in Scotland. With the inclusion of topics like alcohol, tobacco, drugs, and eating disorders in its materials, the project already shares messages that other organisations promote (e.g. ASH Scotland, Drink Aware Scotland, Scottish Drugs Forum and many others). Potential partners may not be aware of how much work FNS already does in their field of interest, so it would be in the project's interest to let them know.

At present, project staff are aware of these areas of crossover, but opportunities to discuss collaboration tend to be sporadic and untargeted, for example approaching other organisations' stalls at events. A more purposeful approach is recommended in the future.

This shouldn't be a difficult case for the project to make. With shared messages and limited resources, organisations like these increasingly rely on partnership work to reach target populations, attract funding and make a lasting difference. To progress this, the education project could identify a list of potential partners with shared interests and arrange exploratory meetings, singly or in groups to:

- Investigate the potential of creating formal or informal healthpromoting alliances<sup>5</sup>
- Make strategic agreements or form strategic partnerships to allow the flow of information, evidence and ideas
- Develop joint funding applications, which are often more effective when they have more than a single-issue approach to health
- Develop operational relationships, for example each organisation distributing the other's materials at conferences or events, taking shared stalls etc.

Another area for exploration in the short to medium term could be any potential health inequality aspects of fertility, as this topic is currently high on the health policy agenda.

#### Reach – how much is enough?

As with partnerships, the project could take a more structured approach to developing its reach. Should it target the greatest number of people, or the best geographical coverage? Do technologies and social media offer new ways to reach people? Can the partnership approaches above help extend the project's reach?

At present, the project follows demand, to 'go anywhere...go where the need is', as one project member put it. With only 1.5 full-time equivalent staff to cover the whole of Scotland, this makes a lot of sense. And it is likely that by following the need, the project is already working in the most densely-populated areas, reaching the greatest number of people it can.

However at this stage in its development, the project would benefit from taking a step back and mapping

• The areas it has reached

<sup>&</sup>lt;sup>5</sup> If it is not already, the organisation may benefit from being a member of Voluntary Health Scotland and/or The Health and Social Care Alliance.

- The areas it has most impact
- Significant gaps
- Areas of unmet need

This isn't so much a question of where the project works, or how many people it reaches, but *how it makes these decisions*. There does not appear to be a plan or process in place that would allow the project to review its reach and put its achievements – and ambitions - in context. There is no easy answer to the question 'How much reach is enough?', but there is benefit in asking it.

**Better links between education and support – or more awareness of these** In interviews, when asked what would improve the project, three respondents suggested needing support services to complement the awareness raising that it does.

'Maybe a greater presence, if someone could come along and complement our menopause clients, or if I knew that people were coming in for fertility awareness, (the project could) come along and meet with them and discuss everything around fertility awareness. I think if they were more visible at consultation to take part of it...sitting down with that person and discussing it in more depth, what they do and how they can take it forward. Separating the clinical part from the human part. And maybe even after they've left the consultation, somebody to talk it through with, because that's when you really start thinking about things.' A1

'You could wait three months for an appointment (for counselling). I think the charity are missing a big opportunity there to set up a support group, groups led by people like me, where people can come and have a coffee and a chat and get that personal contact if they require it. I feel as though the charity haven't facilitated that and it's a big area where they could give a lot of support and do great work. They've not got us together to discuss what we think we needed and didn't get when we were going through this.' N1

'I'd very much like to make that link between the support. People think it's nice to have someone empathetic to talk to sometimes and hand out information...It's to make them aware of what help is out there and what other people have experienced. The main thing is to show them that they're not alone.' N2

The organisation does offer the kinds of support suggested. Yet people who know the education project well did not know this. So, part of the learning here is about the need for the education project to promote the organisation's support services better. As the first point of contact for many hundreds of people, the project cannot be a standalone or add-on, it must be well integrated in the organisation, with good awareness of the developments taking place around it. This is particularly critical as the organisation transitions to its new corporate identity, branding and website, all of which are designed to promote a more inclusive approach to fertility and infertility. The education project needs to be flexible enough to understand and promote a range of messages to a range of audiences.

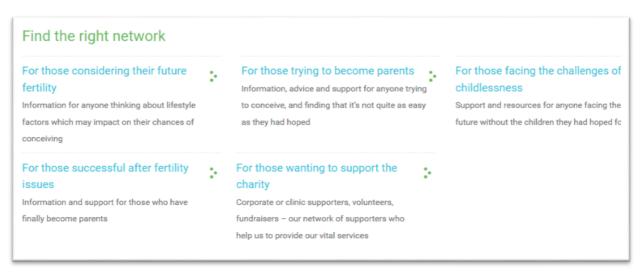


Figure 1: Screenshot from website in development, showing inclusivity for different target audiences

Regarding the need for support services, education project workers do aspire to be able to set up and support new groups, though they acknowledge that it is not easy. Sometimes sustaining existing groups is also hard, because of people's changing circumstances. (For example, group members can find it hard when another member's fertility treatment is successful, even though that person is likely to find the pregnancy stressful and need ongoing support.)

However, as suggested by one of the quotes above, volunteers offer a way to help improve the range and number of support services available across the country.

#### More structured volunteering

Like partnerships, volunteering is an area where the project is likely to benefit by having greater recognition, and making better use, of its supporters' goodwill.

To some extent this recommendation has been anticipated by the organisation, as it appointed a national volunteer coordinator very recently<sup>6</sup>. The rationale for this was based on the same need that the evaluation identified: to make better use of, and rethink the organisation's relationship with, volunteering.

<sup>&</sup>lt;sup>6</sup> August 2016

One reason for recommending this is that it was noticeable that some evaluation respondents had several roles or relationships with the project. For example, volunteers were likely to have been previous recipients of support. In some cases they also became professional supporters in their work roles.

Another reason is that some of the project's successes (e.g. gaining trade union support) weren't planned, but were the result of chance conversations or encounters with project beneficiaries. In the words of one volunteer, 'It just so happened...'. Similarly, the project's ability to provide speakers with lived experience is affected by chance, with factors such as geography and volunteers' availability playing a part.

Chance will always be part of any project' success, but it is best not to rely on it. The project's impact – and reach - will be increased when it has a more structured and supported volunteering programme.

An important part of this will be the project's ability to create a volunteering 'community'. Volunteers need to understand their role as part of the bigger picture and be able to communicate the project's messages consistently:

'If they are wanting their volunteers to be strong and be getting across the right message that they want to promote, they should be getting their volunteers together maybe once every three months to touch base, tell them what their vision is, where they are going, what's happening, opportunities they've got for you to go out and speak. I think that would work really well for them.' (Volunteer)

### One valuable suggestion in the evaluation was to support students to become peer educators:

'Instead of coming in just as a one-off for an hour and a half workshop, the young people could be peer mentors, we could go into different schools and work in partnership with various organisations where we could be promoting their organisation with young people speaking to other young people.' (College partner)

The project should therefore feel confident that it has something to offer volunteers, both in terms of having a message many people understand and support, and in the types and levels of involvement it can offer. A mature student at a Fresher's Fair noted that the project's opportunities were more interesting than they are used to seeing:

'It's good to see volunteering opportunities for something substantial, it's unusual to see opportunities like this.' (Fresher's Week student) One of the key indicators of sustainability for projects and their impact lies in the answer to the question 'Who does your project belong to?'. A volunteering programme that enlists stakeholder support has the potential to be strategically significant not just for the education project but for the organisation as a whole.

To conclude this section, it is clear that the education project has a number of very committed supporters. If this support can be harnessed, the project will benefit from the involvement, ideas and influence that they bring.

### 5. Recommendations

- 1. Adopt the new outcome framework including the additionally recommended indicators to ensure the project continues to be able to understand and evidence its impact.
- 2. Consider providing a larger or dedicated activity budget for events.
- 3. Continue to provide information events for people affected by fertility issues, as there is good evidence of their effectiveness in achieving a number of goals.
- 4. Adopt a deliberate, planned approach to partnership work. Explore networks and alliances of support with other single-interest health promoting organisations.
- 5. Develop a process of reviewing the project's reach periodically to inform planning and evaluation (e.g. during annual work planning).
- 6. Ensure the education project is sufficiently integrated within and informed about the work of the wider organisation.
- 7. Continue the development of a structured and supported volunteering programme.