

# Developing an app to support sensitive enquiry and discussion about female genital mutilation

## › Abstract

Health professionals working in community settings are increasingly using mobile technologies to access information and support clients. A Mary Seacole Leadership Award enabled the production of an app, Let's talk FGM, to assist health professionals to make sensitive inquiry about female genital mutilation (FGM). This article outlines the rationale for the project and the steps needed for successful app development. It illustrates how clinical practitioners can respond to service users' needs and, in collaboration with colleagues and community groups, create responsive, usable tools to harness digital technology. It also showcases the role of partnership working and networking to develop the skills needed to lead in digital health.

### Key words

› Female genital mutilation › Innovation › Digital health › Leadership  
› Public health › Engagement

**F**emale genital mutilation (FGM) is a sensitive subject to discuss (Royal College of Nursing (RCN), 2019). For many health professionals working in community and primary care, instantaneous access to information is crucial to initiate and develop such conversations, keeping in mind the safeguarding, legal and therapeutic aspects of care for those affected (RCN, 2019).

Health professionals require knowledge and confidence around the issue of FGM and, in community settings, access to high-quality, contemporary sources to support such discussions is key. This project aimed to address this need by harnessing digital technologies.

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A Mary Seacole Award (MSA) in Leadership was granted to produce the 'Let's talk FGM' app, to assist health professionals to make sensitive inquiry about FGM, identify girls at risk and direct survivors towards care and support.

MSAs are awarded following a competitive application process to nurses, midwives and health visitors working in England seeking to undertake a project that will have a positive impact on the lives of people from specific groups. MSAs incorporate academic and professional mentorship, and funding for project planning, implementation and conclusion within one calendar year. The awards take inspiration from the pioneering 19th-century Jamaican-British nurse, Mary Seacole and aim to build on her legacy (Anionwu, 2006).

The MSAs are funded by Health Education England and supported by NHS Employers, Unite CPHVA, RCN, Royal College of Midwives and Unison. Successful completion of a project requires professional leadership, collaborative working and academic rigour (McEwan and Bedford, 2017). MSA scholars undertaking a leadership award are required to submit an academic (Master's level) final project report to the MSA Steering Group on completion, and to fulfil a commitment to dissemination as a condition of the award.

This article outlines the process of collaboration in app production, including initial, substantive planning during the MSA project and its subsequent development to become a web-based app in 2018. Initially, the app was aimed at health professionals, primarily health visitors. It was designed to address a clinical need for health visitors who used iPads provided by their employing NHS Trust to access appropriate literature, policies and guidelines on FGM in people's homes.

App development was enabled by collaboration between an NHS Trust and a voluntary sector organisation run by and serving families affected by FGM. Let's talk FGM was the result of rich feedback from focus groups undertaken with health and social care professionals, community workers, NHS service users, young people and women from affected communities.

Following positive feedback, an enhanced version of the app and a web-based app (letstalkfgm.nhs.uk) were developed, which have enabled greater access for health professionals and the public. The app has value as a source of contemporary information and a conversational tool. It incorporates films and key information in six languages on the impact of FGM, why it occurs, the law, rights, religion, how to protect children and local support for survivors.

## Prevalence of FGM

Globally, FGM is estimated to affect 200 million women and girls from around 30 countries (Unicef, 2016). FGM is recognised by the UN as a form of violence against women and girls, a violation of human rights and a child protection issue. The World Health Organization (WHO) defines FGM as ‘all procedures that involve the partial or total removal of the external parts of the female genitalia or other injury to the female organs for non-medical reasons’ (WHO, 2008).

From census data of country of birth in 2011, it is estimated that FGM has affected 137 000 women and girls in England and Wales (MacFarlane and Dorkenoo, 2015). Estimated prevalence rates are around 4.7% in the London borough of Southwark, 1.2–1.6% in Birmingham, Bristol, Slough and Manchester, and 0.7% in Oxford (MacFarlane and Dorkenoo, 2015).

Discussing FGM is often met with communication barriers. In a synthesis of 57 papers (Evans et al, 2018), barriers were thematically divided into language barriers and interpretation challenges; can’t talk, not asked: double silence and cultural taboo; and cultural (in)sensitivity. There is evidence that health professionals’ knowledge, confidence and experience have been lacking (Zaidi et al, 2007; Relph et al, 2012; Gabrasadig et al, 2015), and that discussions are complex and potentially stressful (Dixon et al, 2020). All studies, including Simpson et al (2012), recommended specialised training on knowledge around FGM and how to communicate sensitively.

## Digital health technology

As the NHS promotes technology and innovation to improve the quality of patient care and outcomes, health professionals increasingly use digital technology to access information and support clients across a range of care settings. The *NHS People Plan 2020/21* (NHS England, 2020) addresses this by promoting new ways of working, and weaving technology into care. The strategic framework of Health Education England (2017)

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also identifies technology as one of the drivers for global change.

The National Information Board (2014) stated that service users should have more control over their health and healthcare choices. Furthermore, the Digital Nurse Network promotes nurses to engage in digital transformation, keep them connected and share learning in digital projects (NHS England and NHS Improvement, 2020).

Policy and professional research continue to support this stance by recognising and promoting the excellent digital tools that already exist (Department of Health and Social Care, 2018) and providing professionals with support and funding to develop digital technology-based care, including user engagement at the heart of the design (Queen’s Nursing Institute, 2018).

Using mobile technology can address patients’ and clients’ needs instantaneously, saving on resources to improve quality and innovate in the NHS. In his valuable round-up, Mistry (2020) reflects that, before the outbreak of coronavirus, adoption of digital technology at scale across the health and social care sector remained limited; however, the pandemic has necessitated the swift implementation of technology-based tools.

## App development in healthcare

Apps are software programmes that have been developed to run on a computer or mobile device to accomplish a specific purpose (Wallace et al, 2012). Health apps have the potential to improve patient care through communication and quick access to key information.

Apps can be categorised as a ‘medical device’ when they support diagnosis (Buijink, 2013). The Medicines and Healthcare products Regulatory Agency (MHRA) has published guidance on medical device software, including apps (MHRA, 2021). When non-diagnostic, but intended to promote behavioural change or offer therapeutic outcomes, apps can also be considered medical devices; however, they rarely require approval from the MHRA (2016). Under the Medical Devices Directive (93/42/EEC) regulations, such apps do not require the International Organization for Standardization (ISO) standard and individual

Table 1. Focus group questions	
Focus groups details: Stakeholders (and numbers of participants)	Questions posed
<p><b>Focus group: Health professionals (11)</b> Health visitors School health nurse Social workers Midwife Obstetrician GP Student of adult nursing Named nurse Digital agency designer</p>	<p>How do we identify FGM? How do we discuss FGM? What do we need to act? What are the barriers to discussing FGM? How will an app address these barriers? What content should the app contain?</p>
<p><b>Focus group: Community workers (7)</b> FGM survivors Women from FGM-affected communities Community workers experienced in FGM work</p>	
<p><b>Focus group: Young people (5)</b> Sixth-form girls from black, Asian and minority ethnic backgrounds</p>	<p>What do you know about FGM? How do you think FGM should be discussed with young people? What should the FGM app contain?</p>
<p><b>Interview: Service user (1)</b></p>	<p>What do you want in the app? How do you want the app to talk to you?</p>

NHS Trusts can self-certify for a CE mark. Now the UK has left the EU, CE marks will continue to be recognised in Great Britain until June 2023 (MHRA, 2021).

The number of mobile health app downloads has grown from 1.7 billion in 2013 to 3.7 billion in 2017 (Statistica, 2019), with 325 000 health apps available on iOS and Google Play (Research 2 Guidance, 2017). There is a debate on the efficacy of some apps, ranging from harmlessness to inducing undue anxiety, or being reductionist (Hussain and Spence, 2015). Other problems have been identified, including privacy issues (Huckvale et al, 2015), poor evidence base, lack of regulatory control and pharmaceutical companies influencing care through promoting their products (Buijink, 2013). Other authors comment that there is little evidence that health professionals have been consulted in the design, content and scrutiny of apps (Armstrong, 2015; Lee et al 2015; Macmillan et al, 2015).

Following these concerns, recommendations for health app development have been published to promote quality assurance. The National Institute for Health and Care Excellence (NICE), in collaboration with NHS England, Public Health England and MedCity, has produced guidance on behavioural change and digital health technologies aimed at technology developers and

commissioners. Its *Evidence Standards Framework for Digital Health Technologies* outlines a tier system of functionality, which it says should demonstrate system benefits, inform the public, promote healthy behaviours and monitor or analyse use (NICE, 2019).

### Let's talk FGM project

App development followed the phases and outputs of NHS Innovations South East (2014) as a project guide; namely, planning, developing app content, design and app development, beta-testing and evaluating user experience. An application was made to the Oxford Health NHS Foundation Trust research and ethics committee, which concluded that the project did not require ethical approval as it was considered a quality improvement project.

### Developing app content

To oversee the project to develop the app a working group was established, comprising a project lead and key staff from Oxford Health NHS Foundation Trust (a community focused trust), including the patient experience lead, head of public health, IT manager, and communications and media manager, as well as staff from the digital agency White October (app designers). The substantive content of the

app was informed by data collection with key stakeholders, who were women from FGM-affected communities, school sixth-form pupils from black, Asian and minority ethnic groups and health professionals.

Four focus groups and one interview (hereafter described as ‘focus groups’) were conducted as follows:

- ♦ **Focus group 1:** Women employees and volunteers from a local charity, Oxford Against Cutting. Some of the women were from FGM-affected communities. The group met in a community centre
- ♦ **Focus group 2:** Health professionals working in Oxford Health NHS Foundation Trust and Oxford University Hospitals NHS Foundation Trust, plus two social workers from Oxfordshire County Council. The group met in a local health centre
- ♦ **Focus group 3:** School sixth-form pupils (girls) from black, Asian and minority ethnic backgrounds at Oxford Academy. The group met in school at the end of the day. As they were over 16 years, they did not require parental consent
- ♦ **Interview** with an FGM survivor who was a service user. The interview was conducted in her home.

Written consent was sought and obtained from all participants before undertaking the focus groups, and confidentiality and anonymity were guaranteed. With consent, notes and recordings were taken during the discussions. All data were stored and handled in accordance with the Trust’s information governance policy. A schedule of questions was devised (see *Table 1*) and time was allowed for open discussion during the focus groups, which typically lasted 2 hours.

Information from the focus groups was summarised into short sentences and themed. The content and features of the app were determined by the focus groups’ feedback, and this informed discussions with the digital agency, White October. Initial overarching features of the app were articulated as technology, images, translation, key information, culture and religion, and communication.

Detail of the content included easy-to-read information; upbeat photographs with videos, maps, and infographics; the law, what FGM is, clinical care, contact information, safeguarding, services and support; stigma, why it happens, against religion; easing the conversation, respect and empathy.

The following quotes from focus group participants illustrate the development of the app’s content and features.

*‘We know as Muslims that it [FGM] is wrong and it shouldn’t happen – that needs to be said.’*  
[Young person]

*‘It is not telling them what to do, but them not allowing it to happen. Inclusive!’* [Health professional]

*‘I want to see it [on the app], and feel that this didn’t just happen to me.’* [FGM survivor]

*‘For a professional not particularly confident, it gives them the opportunity to say, “Let’s begin with that”, giving them a starting point.’* [Health professional]

*‘It should be something to draw the focus away from the woman or girl as it is an intense subject. Some cultures don’t always like to have direct eye contact.’*  
[FGM survivor]

The focus group participants asked that the app contain information on the law, government legislation, cultural practices, definitions of FGM, and survivors’ clinical and emotional support needs. They wanted the information to be delivered in a culturally sensitive manner, which incorporated positive images and was attractive to the eye. They wanted text translated into target languages and delivered through audio and visual means, such as videos and soundbites.

## Design and app development

To understand how the app would be used, a ‘process mapping session’ (which included storyboards) was held between the project lead and White October. Although intended for use by a range of professionals, the MSA project proposal had anticipated that primary users of the app would be health visitors; therefore, the process mapping explored a health visitor’s day.

The following questions helped shed light on the details to ensure maximum usability:

- ♦ How does the health visitor meet a client?
- ♦ Will they know the client has had FGM before the visit?
- ♦ How and why will they raise the subject of FGM?
- ♦ What are the processes for meeting the client next time?

Images for the app were sourced from photo libraries. To seek views on the appropriateness

**Table 2. User feedback from workshops**

Positive feedback	Suggested improvements
<ul style="list-style-type: none"> <li>• Information just right – not too much</li> <li>• Enjoyed videos and soundbites</li> <li>• To be available to the wider community</li> <li>• Available for use in their home country</li> <li>• Videos were of good length</li> <li>• App gave structure to discussions</li> <li>• Easy to navigate for young and old</li> </ul>	<ul style="list-style-type: none"> <li>• More videos, including young people and men</li> <li>• Would like a Christian preacher to be filmed</li> <li>• Correction to statistics</li> <li>• Have easy access to videos – a video listing page</li> <li>• Availability on other devices – not just iPad</li> <li>• Accessibility for anyone – not just health professionals</li> </ul>

of the images, the project lead consulted with women from FGM-affected communities while attending an FGM workshop held at the University of Oxford. The feedback indicated that the images were usable and positive.

Contributors to the focus groups indicated that Swahili, Mandinka, Tigrinya, Somali and Arabic (Egyptian and Sudanese dialects) would be the target languages for Kenya, The Gambia, Eritrea, Somalia, Egypt and Sudan, respectively. Text with five engaging facts about FGM in those countries was written from evidence-based sources.

Six women from the focus groups and the wider FGM-affected community agreed to translate the texts into their languages, and their voices were recorded for the country information soundbites. Participants gave written consent for their participation, which was anonymous, and were paid for their time from the MSA funding.

Focus group feedback had also indicated that short films on the app would aid sensitive and informative discussions, particularly to raise issues that participants found difficult to explain in written form or verbal explanations. Four films were made, featuring:

- ◆ A Muslim scholar on the Islamic view
- ◆ An obstetrician and director of the Oxford Rose Clinic (for women who have experienced FGM) talking through a consultation at the clinic
- ◆ Three young people originating from FGM-affected countries reflecting on their experiences
- ◆ An FGM survivor story of two Gambian women speaking about their role protecting young girls.

All text, videos, images and audio recordings were collected and incorporated into the app design by White October. The app was then launched for the beta-testing phase to determine user experience. Based on participants' suggestions during the focus groups, and in discussion with White October, a consensus agreement resulted in the app being called Let's talk FGM.

### Beta testing and evaluating the user experience

The app was beta-tested for 60 days. The working group suggested a mailing list of users from Trust staff, focus group participants, the MSA steering group and anti-FGM activists from the author's professional networks. Health visitors were asked to try out the app in emails from their operational managers. A total of 410 people were sent an email link with a notification request to download the app and complete a digital survey on whether they used the app, how often they used it, if they found it useful, for what purpose they used it, and if they would recommend it. At the end of the 60-day beta-testing, of the 410 who received request notifications, 81 had installed the app and completed the digital survey. The 81 users had undertaken a total of 326 successful trial sessions using the app and only one trial session had crashed.

Oxford Against Cutting ran four workshops to pilot the app, each with between four and 15 participants of a specific nationality to overcome language barriers. These were delivered by native speakers of languages of Nigeria, Sudan, The Gambia and Kenya. Three workshops were held in community centres and one in a participant's home. Paper questionnaires and/or the digital survey were used to capture user feedback according to what was most appropriate in each workshop setting.

At the close of the beta-testing period, 53 of 81 users who installed the app completed the digital survey. Use was predominantly 1–3 times at 86%. Over 70% used it to inform their own knowledge, 19% used it as a training tool and 10% to inform a conversation with a client.

All users said they found the app useful and would recommend it to others. In the question, 'What could be improved?' only 19 answered, with 31% suggesting better options for navigation, 26% for text to be improved, and 21% and 10.5% for video and soundbite improvements (although there were no comments on what exactly should be improved in audio and video). A total of 43

users who completed the digital survey stated their role. The largest group were health visitors (44%), followed by school health nurses (11.6%) and 25% other. Free text feedback from the workshops is shown in *Table 2*.

### Summary

This project fulfilled its intention to produce an app to enable and inform health professionals to engage with clients to discuss FGM in a sensitive manner, addressing needs and directing appropriate care and/or safeguarding. Following the positive feedback from beta-testing, the app was made available to iPad users on iTunes in December 2016. Dissemination of the app took place via the MSA network and articles in a range of media, including local news and healthcare titles. The app won a London Design Award 2016 and the project lead received a Trust award for Recognising Excellence and Innovation.

The project set out to create the app for iPad for health professionals, primarily health visitors, but achieved greater impact from the positive feedback from women from FGM-affected communities. One woman said she wanted to show it to her family in Kenya as it explained the issues so clearly, but that as her family and friends used Android phones, she would not be able to do so. Feedback from communities overwhelmingly indicated that they wanted to use the app. This led to further development, with the aim of improving the app's performance and accessibility for wider public use.

### Further development

The working group agreed that the app would be improved and a new, web-based app developed to be accessible from any browser. In November 2016, charitable funds from Oxford Health Charity were secured. Permission was obtained from NHS England to use the website domain name '.nhs.uk', to give credibility to the website, and the name agreed as 'letstalkfgm.nhs.uk'.

Further enhancements to the web app included creation of a video to include men's voices. This was a film organised and planned by Oxford Against Cutting, who invited men from FGM-affected communities to discuss how they saw their role in ending FGM. The aim was to have a broad discussion on FGM in their communities and make a 3-minute film to promote on the charity's website. All five films on letstalkfgm.nhs.uk were uploaded to YouTube.

Key information about FGM already on the app was translated into Arabic and French, targeting women and girls affected by FGM in Africa

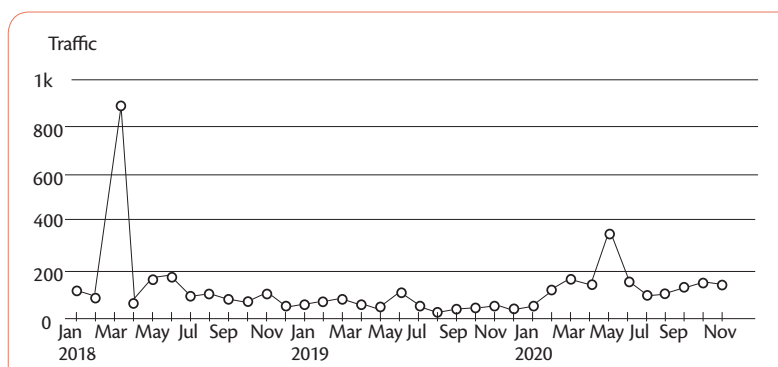


Figure 1. Website traffic for letstalkfgm.nhs.uk (January 2018–November 2020)

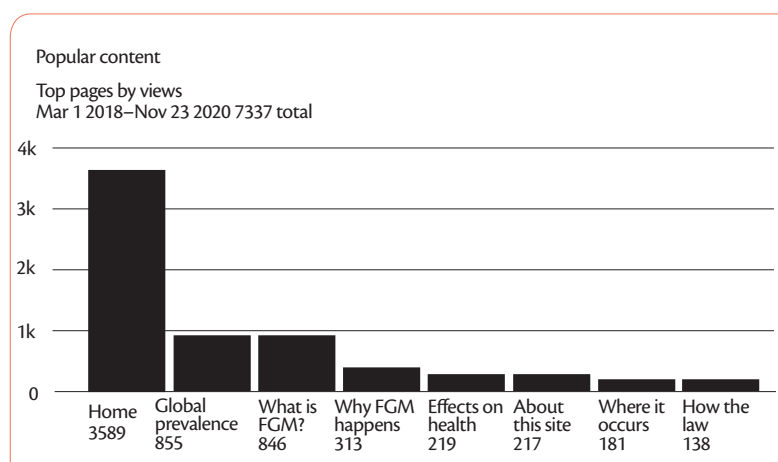


Figure 2. Most visited pages to letstalkfgm.nhs.uk (January 2018–November 2020)

and Asia. French and Arabic translations were embedded into the web app as audio recordings. The content references and external links were strengthened to comply with UK government legislation and national policy, and include information about access to care for women seeking asylum.

The web app was launched in December 2017 in collaboration with White October and the Oxford Health NHS Foundation Trust. Media announcements were made through Twitter, the Trust's Facebook page, the Oxford Against Cutting website, a Unite Live article (2018) and press releases to local and national media. An email was sent to all on the beta-testing launch list, prompting them to re-install the upgraded iPad app in April 2018 and/or use letstalkfgm.nhs.uk on their browser.

### Evaluating use of the app

User analytics from the web app showed that, between March 2018 and November 2020, there were over 3900 visits to the website. Website traffic in 2020 showed 1600 visits, with 1500 unique

## Key points

- ◆ Health professionals and service users are increasingly engaged in digital technologies to promote health
- ◆ Clinicians' roles in advancing digital health are key; leadership opportunities and expansion of digital skills are to be encouraged
- ◆ Insights and reflections from practice can fuel technological innovation to underpin high-quality care, as evidenced in the Let's talk FGM app and, later the letstalkfgm.nhs.uk web app
- ◆ Female genital mutilation remains a key public health issue, requiring sensitive, effective and evidence-based discussions to engage with service users, plan and provide care

users (Figure 1). In 2020, 1149 users went directly to the web app, while 323 found it through a search engine. The desktop was the most used device at 1408 visits, compared to 323 visits from a mobile. Web app traffic was predominantly from English-speaking countries; notably, the UK (1507), the USA (910), Canada (264) and Australia (82). India had 142 users and Egypt and Sudan had 9 and 2, respectively. The most visited pages were the home page, 'What is FGM?' and 'Global prevalence' (Figure 2).

The predominance of desktop use in 2020 may be explained by the Covid-19 pandemic, leading to more home working. Furthermore, the web app and the updated iPad app are included as resources in Oxford Health NHS Foundation Trust safeguarding training, and Oxfordshire Safeguarding Children's Board and Hertfordshire County Council learning resources for professionals.

## Discussion

The benefits of digital tools to improve care have never been more relevant than during the Covid-19 pandemic, with doctors and nurses in wards and intensive care units using digital apps and devices to communicate with patients and their loved ones. Similarly, health visitors have had to be inventive when unable to conduct face-to-face visits to clients' homes. While health visitors will welcome a return to communicating with clients without exclusively using digital devices, many are aware that these tools are beneficial and here to stay.

This project is an example of how practitioners can reflect on the needs of service users and feel confident to employ project planning, collaborative engagement and management skills so often used in clinical practice. Furthermore, the empathy and therapeutic relationships that form part of the health visitor repertoire are also vital skills required in a service improvement project or innovation.

To establish whether an idea will work requires listening to service users, acknowledging their views and having the flexibility to adapt to their needs. A responsive approach should lead to an adaptive project and, ultimately, as in this case, an agile app. This project is an example of how engaging with service users in a meaningful way can benefit both them and health professionals.

## Conclusion

What is evident from the published literature and the focus groups undertaken in this project is that discussing FGM in an informed and sensitive manner is imperative for health professionals to safeguard women and girls, and provide the needed support to FGM survivors. Let's talk FGM is a tool that informs and guides users around a complex subject, encouraging a collaborative discussion when shared. The app developed from listening to professionals, FGM survivors, and women and men from FGM-affected communities, and provides an opportunity to explore the use of audio and visual references around this sensitive topic. JHV

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