

Views of female genital mutilation survivors, men and health-care professionals on timing of deinfibulation surgery and NHS service provision: qualitative FGM Sister Study

Laura Jones^{1*}, Emma Danks¹, Benjamin Costello¹,
Kate Jolly¹, Fiona Cross-Sudworth¹, Pallavi Latthe²,
Meg Fassam-Wright³, Joanne Clarke¹, Alison Byrne⁴ and
Julie Taylor⁵

¹Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK

²Birmingham Women's and Children's NHS Foundation Trust, Birmingham, UK

³National FGM Centre, Barnardo's, Barnardo House, Ilford, UK

⁴University Hospitals Birmingham NHS Foundation Trust, Heartlands Hospital, Birmingham, UK

⁵School of Nursing, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK

*Corresponding author L.L.Jones@bham.ac.uk

Declared competing interests of authors: Kate Jolly is part funded by National Institute for Health and Care Research (NIHR) Applied Research Collaboration West Midlands and is a subpanel chairperson of the NIHR Programme Grants for Applied Health Research programme.

Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published March 2023

DOI: 10.3310/JHWE4771

Plain language summary

Views of female genital mutilation survivors

Health Technology Assessment 2023; Vol. 27: No. 3

DOI: 10.3310/JHWE4771

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain language summary

Female genital mutilation (or cutting) involves changing or removing parts of a girl's or woman's genitalia when there is no medical reason to do so. Many women and girls who have been cut live in the United Kingdom, where female genital mutilation is illegal. Some girls and women who have been cut experience problems in getting pregnant and having their baby. There are four types of cutting. Type 3 involves cutting and sewing together the genitalia, leaving only a small hole. Women and girls with type 3 mutilation can have a small operation to open their vagina. We do not know when the best time is to have this operation. We would also like to know more about how NHS female genital mutilation services can best help women.

To answer these questions, we talked to 141 people, who were women who have been cut, men and health-care professionals. They told us that there is no ideal time to have the operation. Women who have been cut would like the operation before they get pregnant, but health-care professionals would like women to have it during their pregnancy. Men were not sure when it should happen. They all agreed that the operation should take place in a hospital and be carried out by a skilled professional.

The way that we support women and men could be better and we need to improve the help that is offered. Sometimes women and men did not know where to go for help or how to ask for help. Women, men and health-care professionals sometimes found it hard to talk about cutting. Some health professionals did not have the right skills to undertake the operation. They told us that they need more training and clearer guidance to ensure that women feel cared for and safe.

Health Technology Assessment

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 4.014

Launched in 1997, *Health Technology Assessment* (HTA) has an impact factor of 4.014 and is ranked 27th (out of 108 titles) in the 'Health Care Sciences & Services' category of the Clarivate 2021 Journal Citation Reports (Science Edition). It is also indexed by MEDLINE, CINAHL (EBSCO Information Services, Ipswich, MA, USA), Embase (Elsevier, Amsterdam, the Netherlands), NCBI Bookshelf, DOAJ, Europe PMC, the Cochrane Library (John Wiley & Sons, Inc., Hoboken, NJ, USA), INAHTA, the British Nursing Index (ProQuest LLC, Ann Arbor, MI, USA), Ulrichsweb (ProQuest LLC, Ann Arbor, MI, USA) and the Science Citation Index Expanded (Clarivate, Philadelphia, PA, USA).

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full HTA archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hta.

Criteria for inclusion in the *Health Technology Assessment* journal

Reports are published in *Health Technology Assessment* (HTA) if (1) they have resulted from work for the HTA programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

HTA programme

Health Technology Assessment (HTA) research is undertaken where some evidence already exists to show that a technology can be effective and this needs to be compared to the current standard intervention to see which works best. Research can evaluate any intervention used in the treatment, prevention or diagnosis of disease, provided the study outcomes lead to findings that have the potential to be of direct benefit to NHS patients. Technologies in this context mean any method used to promote health; prevent and treat disease; and improve rehabilitation or long-term care. They are not confined to new drugs and include any intervention used in the treatment, prevention or diagnosis of disease.

The journal is indexed in NHS Evidence via its abstracts included in MEDLINE and its Technology Assessment Reports inform National Institute for Health and Care Excellence (NICE) guidance. HTA research is also an important source of evidence for National Screening Committee (NSC) policy decisions.

This report

The research reported in this issue of the journal was funded by the HTA programme as project number 16/78/04. The contractual start date was in May 2018. The draft report began editorial review in November 2020 and was accepted for publication in May 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HTA programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HTA programme or the Department of Health and Social Care.

Copyright © 2023 Jones *et al.* This work was produced by Jones *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaptation in any medium and for any purpose provided that it is properly attributed. See: <https://creativecommons.org/licenses/by/4.0/>. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress, final files produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).

NIHR Journals Library Editor-in-Chief

Dr Cat Chatfield Director of Health Services Research UK

NIHR Journals Library Editors

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Professor Matthias Beck Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Dr Peter Davidson Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Ms Tara Lamont Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk