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Copy of Responding to the increased genetic risk associated with customary consanguineous marriage: developing an expert consensus statement and principles for service design and delivery- Delphi Study Round 2

Developing an expert consensus statement and principles for se

Delphi Study Round 2

* 1. Have you already read the participant information sheet?

- Yes - please proceed to the next section
- No - please continue



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Participant Information Sheet

You are invited to contribute to a project by answering an online survey, and, if you wish, by attending a face-to-face workshop in Sheffield on 3rd July 2018.

Before you decide it is important to understand why the project is being done and what it will involve. Please take time to read this information and ask us if anything is not clear.

What is the project's purpose?

In populations where it is common for people to marry close relatives there is a higher incidence of autosomal recessive genetic disorders than in those in which reproductive partners are usually unrelated. Research has shown that many affected individuals are poorly informed of these risks and that appropriate services are often not accessible. In recent years, a number of local level responses have developed across England but these are variable in form, content and longevity. A more coordinated, national response is needed to support more consistent practice and encourage the sharing of knowledge. This project has been initiated by a stakeholder group working across Sheffield, Manchester, Bradford and London, with the aim of developing an expert consensus statement and principles for service design and delivery in response to this area of unmet need

We aim to:

- (1) explore the extent to which it is possible to establish common inter-professional principles for the design and delivery of service responses in the area of consanguinity (close relative marriage) and genetic risk.
- (2) identify a set of principles upon which there is sufficient consensus to warrant the production of a national guidance document.
- (3) highlight areas/issues where inter-professional differences of opinion warrant further debate and dialogue.

The project will last 7 months from May to December 2018.

Why have I been chosen?

You are being invited to contribute to the project because we believe you have important insights to share. We are inviting a range of people who will offer different and complementary perspectives on the issues.

Do I have to take part?

Taking part is entirely up to you.

If you do not want to take part, you need do nothing more. If you do decide to contribute you will be emailed further information about how to contribute to the project via the online survey and workshop. You will be free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you choose to take part, you should indicate this by following the link to the google form to register your interest. You will then receive an email with further information and a link to the online survey.

The survey will involve 3 rounds and completion of each round should take between 15 and 45 minutes depending on how much information you wish to contribute.

In Round 1, you will be asked to provide suggestions in response to a series of open-ended questions. This round is designed to gather a wide range of statements on what the priorities are for the design and delivery of service responses to this issue.

In Round 2 and 3, you will be presented with the combined statements from the group and asked to score each of them according to how strongly you agree or disagree with them.

While we would like people to contribute to all 3 rounds if at all possible, this is not a requirement and you may decide to contribute to Round 1 but not to subsequent rounds, or to participate in Rounds 2 and 3, but not Round 1.

Following Round 3 of the online survey, we will convene a face-to-face workshop on July 3rd 2018. Participants who are able to will come together in Sheffield for a workshop in which we will discuss and debate the findings from the online survey and seek to produce a draft of a consensus statement and set of principles for this area of service design and delivery.

The workshops will be structured and last 3 to 4 hours with refreshments.

Individuals who are unable to attend the workshop but would like to contribute to the production of the consensus document will be given the opportunity to comment on the draft as it is produced.

Will I be recorded and how will the recording be used?

We do not plan to use audio recording in this project.

What are the possible disadvantages and risks of taking part?

We have not identified any significant risks in taking part in this study, although we recognise that participation will involve a significant time commitment.

We will ask all participants in the face-to-face workshop not to pass any of the information shared during group discussions to anyone outside of the group. However, we cannot guarantee that people outside of the research team will maintain this confidentiality.

It is possible that some of the discussions may become heated or that participants may become upset. Researchers will do their best to ensure that a respectful and supportive environment is maintained at all times.

What are the possible benefits of taking part?

By participating in the consensus exercise you will be making an important contribution to the development of a national-level guidance document. If you wish, your name can be included as a contributor on any products that are developed through this process. There are no other immediate benefits for people participating in the project but it is hoped that the process will be interesting and informative.

What if I'm not happy with things or have a question about the study or my data?

If you have any concern about this research or any complaint you should first contact the Principal Investigator:

Professor Sarah Salway, Department of Sociological Studies
Elmfield, Northumberland Road, Sheffield, S10 2TU. s.salway@sheffield.ac.uk
0114 222 6438

If you are not satisfied with the response, then you should contact:

Professor James Wilsdon, Faculty of Social Sciences
Director Impact and Engagement
ICOSS, 219 Portobello, Sheffield, S1 4DP
j.wilsdon@sheffield.ac.uk
0114 222 8343

For any concern or query relating to the storage and use of your personal data, please contact the University's Data Protection Officer:

Anne Cutler
University's Secretary's Office
University of Sheffield
Western Bank
Sheffield S10 2TN
A.Cutler@sheffield.ac.uk
0114 22 21117

What will happen to the results of the research project?

Early findings will be shared at the workshop in July. This workshop will determine the form and content of the consensus statement or set of principles to be produced and disseminated. We hope to finalise this document/product by December 2018. We also anticipate producing an academic paper for publication in a journal.

Who is organising and funding the research?

This research is funded by the University of Sheffield and the NIHR CLAHRC for Yorkshire & Humber.

Who has ethically reviewed the project?

This project has been ethically approved via the ethics review procedure of the Department of Sociological Studies at the University of Sheffield.

Contact for further information

Principal Investigator:
Professor Sarah Salway, Department of Sociological Studies
Elmfield, Northumberland Road, Sheffield, S10 2TU. s.salway@sheffield.ac.uk
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Consent Form

* 2. I confirm that I have read and understand the information sheet dated 12/04/2018 (version 3) for this study. I have had the opportunity to consider the information, ask questions and, if needed, have had these answered satisfactorily.

- Agree
 Disagree

* 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any of my legal rights being affected.

- Agree
 Disagree

* 4. I understand what personal data will be collected about me and how this will be stored. I am aware of how I can make a complaint or raise concerns about the handling of my personal data.

- Agree
 Disagree

* 5. By proceeding to the next section, you are agreeing to participate in this part of the study. Please check the box below to confirm that you are happy to take part

- I consent to taking part in this study
 I do not consent to taking part in this study



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Introductory and Guidance Notes

In Round 1 of this Delphi exercise we received responses from 37 individuals and a total of over 700 separate statements.

We have consolidated these into around 150 statements organised across 10 sub-sections.

- General principles
- National level leadership and coordination
- Local level leadership and coordination
- Training and competencies of different cadres of staff
- Service components:
 - Enhanced genetic services
 - Increasing genetic literacy
 - Primary Care
 - Referral pathways and other health services
- Monitoring and evaluation of service developments
- Research

The task in this round is to rate each statement to indicate the extent to which you agree with it from "Very strongly disagree" to "Very strongly agree" (a 7 point scale).

You may participate in this round even if you did not contribute statements in Round 1.

Note that some statements included below contradict others, and that you may agree with some but not others.

Please read and consider each statement in turn and add your ranking.

If you do not feel well enough informed to rank a particular statement, please tick 'do not know'.

If you do not feel well enough informed to rank any of the statements in a particular sub-section, then please tick the 'I wish to skip this section' box at the start of the section.

If you did not respond to Round 1, you will be asked to provide some background information before the ranking exercise so that we can describe the profile of the people who have contributed.

Thank you very much for your contribution to this exercise.



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Your Background Details

* 6. Did you participate in the first round of the study?

Yes

No



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Your Background Details

* 7. Your contact information

Name

* 8. How would you describe your ethnic group?

- Asian/Asian British: Bangladeshi
- Asian/Asian British: Pakistani
- Asian/Asian British: Indian
- Asian/Asian British: Chinese
- Asian/Asian British: Any other Asian background
- Black/Black British: African
- Black/Black British: Caribbean
- Black/Black British: Any other Black/African/Caribbean background
- White: English/Welsh/Scottish/Northern Irish/British
- White: Gypsy or Irish Traveller
- White: Irish
- White: Any other White background
- Mixed/multiple ethnic groups: White and Black Caribbean
- Mixed/multiple ethnic groups: White and Black African
- Mixed/multiple ethnic groups: White and Asian
- Any other Mixed/multiple ethnic background
- Arab
- Prefer not to say
- Other (please specify)

* 9. What is your age?

- <25
- 25-34
- 35-44
- 45-54
- 55-64
- 65+
- Prefer not to say

* 10. In what capacity are you responding?

- In your work/professional capacity
- As a member of the public

* 11. Region of residence (if general public) or region of employment

- London /Greater London
- South East
- South West
- North East
- North West
- East of England
- West Midlands
- East Midlands
- Yorkshire and the Humber
- Other (please specify)

* 12. If responding in your work capacity, what is your area of work (please choose one that best describes your focus)

- N/A - responding as a member of the public
- Clinical Genetics
- Health Visiting
- General Practice (medical)
- Nursing - primary care or community
- Other Primary Care
- Midwifery
- Paediatrics (medical)
- Other secondary care / hospital
- Social Care
- Community Development
- Equality and Diversity
- Public Health
- Health services / health systems

Other (please specify)

* 13. If responding in your work capacity, how would you describe your role (choose the best one)?

- N/A- responding as a member of the public
- Service or Programme Manager
- Commissioner (strategic purchaser)
- Administrator
- Practitioner (delivering services/input to patients or the public)
- Trainer / capacity development / consultant (delivering services/input to other professionals)
- Researcher/academic

Other (please specify)



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Your Background Details

* 14. Your Email Address

* 23. A9

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Sensitivities should be understood as arising from a dominant culture that regards close relative marriage as incestuous and places a value judgment on the practice, and not from consanguineous communities themselves.

* 24. A10

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Service developments should be framed as an equity issue and centrally concerned with addressing unmet need.

* 25. A11

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

There should be national standardization of service standards, approaches and materials wherever possible. Local variations should occur only within a clear framework.

* 26. A12

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

There should be active sharing of knowledge and resources nationally to support service development and sustainability.

27. Do you have any specific comments to make in relation to any of the statements above?



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Section B- National Level Leadership and Coordination

28. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section



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Section C- Local Level Leadership and Coordination

46. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 55. C9

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Genetics service staff should provide technical input to the development of instruments, resources and tools used by staff within other health services and at community level.

* 56. C10

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Dedicated staff working on this issue should do outreach work to increase staff awareness and coordination across public health, primary care and secondary care.

* 57. C11

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Mechanisms should ensure sharing of genetic risk information between relevant healthcare professionals to support timely service offers (e.g. GPs should share information about previous children affected by a genetic condition with Maternity Services early in pregnancy; Genetics Services should inform GPs when diagnosis is made).

58. Do you have any specific comments to make in relation to the statements above?



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Section D - Training and Competencies for Healthcare and Other Professionals

59. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 73. D14

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Staff training may be delivered by genetic outreach workers once they have achieved a set of competencies.

* 74. D15

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

All staff training, including for those working within genetics services, should include cultural sensitivity and inter-cultural communication skills.

* 75. D16

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Training of healthcare and community staff should include basic genetic information (including drawing a family tree) and clear guidance on referring to genetics services.

76. Do you have any specific comments to make in relation to any of the statements above?



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Section E- Enhanced Genetics Services

77. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

Genetic technologies

* 101. E24

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

There should be storage of DNA relating to all babies who die of probable genetic disorder as if nothing is stored the family is at huge disadvantage in future pregnancies.

* 102. E25

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Expanded carrier screening (ECS) may become available due to emerging genetic technologies and may provide genetic screening for consanguineous communities and the general population. ECS should be considered for implementation in the NHS in a responsible way.

* 103. E26

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

There should be investment to develop tests for rare conditions and to develop a panel of genes based on the most common conditions (identified through a national registry). Such tests should be readily available across genetic services without charge in a clinical setting.

* 104. E27

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Work in this area must look forward to the implications of large scale deployment of new genetic technology: e.g. one of the earliest effective applications of whole genome scanning is likely to be for risk assessment in relation to consanguineous marriage.

105. Do you have any specific comments to make in relation to the statements above?



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Section F - Raising Genetic Literacy

106. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 120. F14

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Information conveyed at community level should emphasise shared carrier status rather than consanguinity.

* 121. F15

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Community level information-giving should address assumptions held about genetics services and explain the options that may be available to couples.

* 122. F16

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Information conveyed at community level should include signposting to appropriately informed people who can provide moral or religious guidance.

* 123. F17

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Information conveyed at community level should include signposting to support for families living with genetic conditions.

* 124. F18

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Standardised leaflets should be made widely available via GP surgeries, pharmacies, community paediatrics, community centres and midwifery.

Wider, general audiences

* 130. F24

Very
strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Resources should be spent on high risk families who would be more willing to listen and understand the issue in hand rather than the wider community who have no knowledge or experience of a genetic condition.

* 131. F25

Very
strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree very strongly agree Don't know

Information should be made available to all. The general population should be educated about new developments in genomics in a general way and not focus on any particular community.

* 132. F26

Very
strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

There should be an inclusive message that genetics affects everyone, with consanguineous communities presented as an integral part of a diverse, multi-ethnic population.

133. Do you have any specific comments to make in relation to any of the statements above?



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Section G - Primary Care

134. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 143. G9

Very
strongly disagree Strongly disagree Disagree Neither
agree nor disagree Agree Strongly agree Very
strongly agree Don't
know

Innovative ways to engage GPs in this agenda should be developed.

* 144. G10

Very
strongly disagree Strongly disagree Disagree Neither
agree nor disagree Agree Strongly agree Very
strongly agree Don't
know

Primary Care should support and monitor information flow within extended families over time.

145. Do you have any specific comments to make in relation to any of the statements above?



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Section H - Referrals and Coordination Between Services

146. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 155. H9

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

General Practitioners, and other health professionals, should be able to refer any related couple directly to genetic services for counselling, including before marriage.

* 156. H10

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Recording of consanguinity at antenatal booking must be comprehensive and any concerns referred to a senior midwife who can then liaise with the genetics service (rather than first referring to an obstetrician which introduces a delay).

* 157. H11

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Clarification of referral criteria is needed to avoid inappropriate referrals and patient disappointment.

* 158. H12

Very strongly disagree Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree Very strongly agree Don't know

Approaches to referral should avoid the offer being perceived as judgemental, discriminatory or worrying.

159. Do you have any specific comments to make in relation to the statements above?



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Section I - Monitoring and Evaluation of Service Developments

160. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 196. I36

Very
strongly disagree Strongly disagree Disagree Neither
agree nor disagree Agree Strongly agree Very
strongly agree Don't
know

Incidence of births to women who report being in a consanguineous union (by ethnic group) (via Maternity Services Database)

197. Do you have any specific comments to make in relation to any of the statements above?



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Section J - Research

198. If you feel unable to complete this section, you may choose to skip it

- I would like to complete this section
- I would like to skip this section

* 224. J26

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Prevalence and experience of consanguineous marriage in the White majority community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 225. J27

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Factors affecting use of and satisfaction with available services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

226. Do you have any specific comments to make in relation to any of the statements above?



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Submission page

227. If you are ready to submit your responses please click below

Submit responses