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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
ICOS, 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



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Section A- General Guiding Principles

Please rate the extent to which you agree with the statements below

* 15. A1

[illegible]

* 16. A2

[illegible]

* 17. A3

[illegible]

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



B - National Level Leadership and Coordination

* 29. B1

* 30. B2

* 31. B3

[illegible]

* 37. B9

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
National and regional documents on relevant issues should routinely include accurate information on this topic (e.g. Infant Mortality; Childhood Disability; Equality & Diversity)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 38. B10

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
There should be a coordinated bank of nationally recognised experts who can be approached for advice and information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 39. B11

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Public Health England should organise and support regular knowledge sharing events for professionals working in this field.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 40. B12

[illegible]

* 41. B13

[illegible]

* 42. B14

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Public Health England should ensure that relevant epidemiological information is available to inform local and national action.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 43. B15

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Consistency is needed on how the 'modifiable risk factor' designation is used by Child Death Overview Panels since this affects local action.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 44. B16

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
PHE and NHSE should mobilise resources and expertise elsewhere in the system to support service development in this area (e.g. Kings College London Genetic Risk and Counselling Course; National Sickle Cell & Thalassaemia Screening programme).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



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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



C- Local Level Leadership and Coordination

* 47. C1

* 48. C2

* 49. C3

[illegible]

* 50. C4

[illegible]

* 51. C5

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
A local service specification should describe each service element and their inter-connections and conform to national guidance/standards.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 52. C6

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Regular local knowledge sharing events should bring together professionals working at community, primary care and secondary care level, together with patients and public representatives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 53. C7

[illegible]

* 54. C8

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Genetics service staff and those working on community genetic literacy should mutually support one another to ensure good understanding of community needs and genetic competency.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



D- Training and Competencies for Healthcare and Other Professionals

* 60. D1

[illegible]

* 61. D2

[illegible]

* 62. D3

[illegible]

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



E- Enhanced Genetic Services

General considerations

* 81. E4

[illegible]

Cultural competence of services

* 82. E5

[illegible]

* 83. F6

[illegible]

* 84. E7

[illegible]

* 85. E8

[illegible]

* 86. E9

[illegible]

* 87. E10

[illegible]

To increase access to services the enhanced service offer should include:-

* 88. E11

[illegible]

* 89. E12

[illegible]

* 90. E13

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Home visits by genetic counsellors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



F - Raising Genetic Literacy

General approach within affected communities:

Community level information should not focus on consanguinity in isolation but rather include comprehensive information on pre-conception health.

* 115. F9

[illegible]

Personnel

* 116. F10

[illegible]

* 117. F11

[illegible]

Content and media

* 118. F12

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Genetic literacy interventions at community level must include opportunities for face-to-face, well-informed conversations to clarify understandings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 119. F13

[illegible]

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



G - Primary Care

* 135. G1

* 136. G2

* 137. G3

[illegible]

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



H- Referrals and Coordination Between Services

* 147. H1

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

* 148. H2

[illegible]

* 149. H3

Neither
agree nor disagree

Very strongly disagree Strongly disagree Disagree Agree Strongly agree Very strongly agree Don't know

☐ ☒ ☐ ☐ ☐ ☐ ☐

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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 <u>senior midwife</u> who can then liaise with the genetics service (rather than first referring to an obstetrician which introduces a delay).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 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.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



I - Monitoring and Evaluation of Service Developments

General

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

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

○ ○ ○ ○ ○ ○ ○ ○

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

* 174.114

[illegible]

* 175.115

[illegible]

* 176.116

[illegible]

* 177.117

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Information from local Child Death Overview Panels should be used to assess services (e.g. via patient journeys).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Performance measures that should be routinely collected and reported include:

At the genetics service level:

* 178.118

[illegible]

* 179.119

[illegible]

Among patients accessing genetic services:

* 180.120

[illegible]

* 181.121

[illegible]

* 182.122

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Proportion for whom a birth affected by a recessive genetic disorder was 'unanticipated' (couple was uninformed despite prior knowledge existing) (by ethnicity)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Among extended family members where a recessive genetic (or probable genetic) condition identified in the family:

* 183.123

[illegible]

* 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)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



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Please rate the extent to which you agree with the statements below

General

* 199. J1

[illegible]

* 200. J2

[illegible]

* 201. J3

[illegible]

* 202. J4

[illegible]

* 203. J5

[illegible]

* 204. J6

[illegible]

Priority areas for research are:

* 205. J7

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Community-level awareness and understandings around consanguinity and genetic risk, including among different age-groups and within consanguineous families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 206. J8

[illegible]

* 207. J9

Relevance of the issue in different localities

* 208. J10

Evaluation of community genetic literacy initiatives to assess engagement of local people and impact on knowledge, behaviours and service access.

* 209. J11

Experiences, acceptability and value of genetics services and the service journey from patient and family perspectives.

* 210. J12

The process of genetic counselling

(Further) Priority areas for research are:-

* 211. J13

Attitudes to and acceptability of preimplantation and prenatal diagnosis

* 212. J14

Impact of incorporating consanguinity related genetic risk assessment into preconception health promotion.

* 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