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Round 3 Delphi Study: 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 3

\* Please confirm whether you participated in Round 2 of this Delphi Study

- Yes, I completed Round 2
- No, I did not complete Round 2 (Please note that you should not complete this questionnaire but can attend the meeting in July if you wish)



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\* Would you like to re-read the participant information sheet?

- No, I do not need to re-read the information sheet - please proceed to the consent section
- Yes, I would like to read it again - 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  
0114 222 6438



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## Consent Form

\* 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

\* 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

\* 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

\* 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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### Introduction to Round 3

**In Round 2 of this Delphi exercise we received responses from 35 individuals .**

Respondents each ranked the 150 statements organised across the 10 sub-sections. Some respondents chose to skip some sections of the questionnaire.

**We have now summarised these Round 2 responses .** Beside each statement below, we present both the % of respondents who ranked each statement as 'agree' , 'strongly agree' or 'very strongly agree', and the weighted average of the rankings (where 'very strongly disagree' was ranked '0' and 'very strongly agree' was ranked '6'). For example; [65.5%; 3.9] would mean that 65.5% of respondents said that they agreed, strongly agreed or very strongly agreed with the statement; and the overall weighted average of the rankings that were given was 3.9.

[Note that the percentage figure is out of all respondents, even those that responded 'Don't Know', while the weighted average is the average among those that gave a ranking for the statement]

In addition, in response to open-ended comments from respondents, a small number of new statements have been added and a few statements have been slightly reworded for improved clarity. Other comments will be fed into our face-to-face meeting in July.

Further information about Round 2 responses - including your own rankings - has been provided in a pdf document sent to you via email.

**The task in this round is to re-rate each statement in light of the collective responses. You may decide to stick with your original ranking, or you may decide to adjust it.**

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.

Thank you very much for your contribution to this exercise.



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### Your Background Details

\* Please confirm your name

\* Your Email Address



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### Section A- General Guiding Principles

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

\* A1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Nationally coordinated action on this issue is a priority [86.5%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
It should be recognised that close relative marriage is widely practiced globally and confers benefits to individuals and families. [83.8%;4.5]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Close relative marriage should not be represented as an inherent problem, in any community, by any professional or within any service.[86.5;4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A4a [Reworded statement; original statement "Communicating levels of genetic risk associated with close relative marriage should always be accurate and non-alarmist (absolute rather than relative risks should be conveyed)" [89.2%; 5.0]

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Communicating levels of genetic risk associated with close relative marriage should always be accurate and non-alarmist.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A4b [Reworded statement; original statement "Communicating levels of genetic risk associated with close relative marriage should always be accurate and non-alarmist (absolute rather than relative risks should be conveyed)" [89.2%; 5.0]

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
In communicating levels of genetic risk associated with close relative marriage absolute rather than relative risks should be conveyed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A5

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Enhancing the accessibility and appropriateness of genetic information and counselling services are key priorities.[100%;5.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A6

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
This is not a professional issue, it's a community issue. Once we are at the point of professionals involvement, it is generally too late since the marriage has taken place.[18.9%; 2.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A7

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Integrated working is needed between genetics services, public health, primary care, secondary healthcare and community organisations.[97.3%; 5.2]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* A8

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

All activity should be culturally sensitive, non-stigmatising and empowering for affected individuals and communities. [100%; 5.7]

\* 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. [51.4%; 3.6]

\* 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. [89.2%; 4.9]

\* A11a *New Statement; Original Statement* "There should be national standardization of service standards, approaches and materials wherever possible. Local variations should occur only within a clear framework." [75.7%; 4.5]

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.

\* A11b *New Statement; Original Statement* "There should be national standardization of service standards, approaches and materials wherever possible. Local variations should occur only within a clear framework." [75.7%; 4.5]

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

Local variations in service standards, approaches and materials should occur only within a clear national framework.

\* 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.[100%; 5.2]

\* A13 *New Statement*

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

National standards and specifications must recognise variation in the relevance of this topic across local populations and provide guidance on how to prioritise and resource appropriate local action.

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

\* 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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**B - National Level Leadership and Coordination**

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

\* B1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Public Health England should lead and coordinate a national multi-professional working group on this topic. [61.8%; 4.0]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* B2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
NHS England should lead and coordinate a national multi-professional working group on this topic. [47.1%; 3.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* B2a *New Statement*

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Both NHSE and PHE have a national leadership role to play on this topic and there is a need to delineate responsibilities and ensure coordination.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* B3

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

A national multi-professional working group involving PHE, NHSE, National Clinical Reference Group, LAs, CCGs and other experts and stakeholders should clarify commissioning responsibilities and minimum expected levels of service provision.[88.2%; 5.0]

\* B4

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

Contracts and payments should incentivise genetics services to be innovative in tackling inequities in service access. [76.5%; 4.4]

\* B5

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

National commissioning guidance should be developed on best available knowledge to ensure more consistent local services and standards against which commissioners can measure provision and require improvements.[94.1%; 4.9]

\* B6

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

National guidance should establish professional responsibilities and boundaries for each healthcare role in conveying generic and individually-specific genetic risk information.[88.2%; 4.6]

\* B7

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

A national web-based hub for professionals should be funded housing standardised information and resources to support consistent and appropriate service design, delivery and evaluation.[79.4%; 4.5]

\* B8

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

Local commissioners and practitioners should be directed and supported to draw on resources and materials already developed.[88.2%; 4.7]

\* 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).[91.2%; 4.9]

\* 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.[79.4%; 4.4]

\* 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.[67.7%; 4.3]

\* B12

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

National leaders should combat the poor sustainability of investments in this service area.[70.6%; 4.5]

\* B13

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

Relevant national professional bodies should be engaged in this agenda and contribute to a national working group (e.g. RCGP, RCM, AGNC). [82.4%; 4.3]

\* 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.[97.1%; 4.8]

\* 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.[85.3%; 5.0]

\* 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).[76.5%; 4.4]

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

\* 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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**C- Local Level Leadership and Coordination**

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

\* C1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
A designated lead health professional should be responsible for overall coordination and monitoring of local service responses, including community engagement and care of affected families.[65.7%; 4.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* C2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Public health should lead and coordinate action at local level.[62.9%; 3.9]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* C3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Genetics services should lead and coordinate action at local level.[37.2%; 3.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* C4

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

A local multi-professional working group should meet regularly and include: public health; genetics; primary care; health visiting; midwifery; paediatrics; community/voluntary sector; and patient and public representatives.[85.7%; 4.6]

\* 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.[77.2%; 4.1]

\* C5a *New Statement*

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

Local commissioners should demonstrate compliance against a national service specification which allows for flexibility in responses appropriate to local need.

\* 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.[80.0%; 4.3]

\* C7

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

Local Authorities, CCGs and regional commissioners should work together to co-commission services and achieve adequate investments.[91.4%; 4.6]

\* 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.[94.3%; 4.7]

\* 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. [91.4%; 4.7]

\* 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.[91.4%; 4.5]

\* 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).[88.6%; 4.9]

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

\* 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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**D- Training and Competencies for Healthcare and Other Professionals**

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

\* D1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Training of healthcare professionals should be selective, with individuals then cascading information to others.[47.1%; 3.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
All healthcare professionals should be given regular training in order to ensure inaccurate and inappropriate messages are not conveyed and to increase referrals to genetics.[61.8%; 3.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Staff in all levels of the health service require regular training, given rapid developments in the field of genetics.[47.1%; 3.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D4

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Most healthcare professionals already have good awareness, so training may not be needed.[0%; 1.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D5

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Training of healthcare professionals does not lead to increased referrals to genetics services and so it should not be a priority for investment.[8.8%; 1.9]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D6

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Training of healthcare professionals must include clear direction on their responsibilities (and boundaries) in relation to improving genetic literacy and uptake of genetics services.[85.3%; 4.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D7

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Training should only be undertaken with community level workers if there is also support in place to ensure the quality of their work.[67.7%; 3.9]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D8

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Training of healthcare and other professionals should only occur alongside enhancements to the genetics service offer. Demand for services should not be generated unless it can be met.[50.0%; 3.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* D9

Very  
strongly  
disagree

Strongly  
disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly  
agree

Very  
strongly  
agree

Don't  
know

Standardized training materials and competencies should be developed nationally, drawing on existing materials, and employed consistently.[85.3%; 4.6]

\* D10

Very  
strongly  
disagree

Strongly  
disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly  
agree

Very  
strongly  
agree

Don't  
know

Medical and social care curricula should be updated to reflect developments in genetics and the associated knowledge and skills required to meet the needs of diverse populations, including those practising customary consanguineous unions.[94.1%; 4.7]

\* D11

Very  
strongly  
disagree

Strongly  
disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly  
agree

Very  
strongly  
agree

Don't  
know

Face-to-face training is important to ensure adequate levels of both genetic and cultural competence.[67.7%; 4.1]

\* D12

Very  
strongly  
disagree

Strongly  
disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly  
agree

Very  
strongly  
agree

Don't  
know

Web-based resources should supplement face-to-face training and include videos on how to draw family trees and convey information to patients/public.[88.2%; 4.3]

\* D13

Very  
strongly  
disagree

Strongly  
disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly  
agree

Very  
strongly  
agree

Don't  
know

Training should be delivered by people with both advanced genetics knowledge and significant understanding of community needs.[67.7%; 4.3]

\* 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.[67.6%; 3.8]

\* 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.[100%; 5.1]

\* 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.[88.2%; 4.6]

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

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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**E- Enhanced Genetic Services**

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

**General considerations**

\* E1

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

Enhancements to genetics services are an important element in addressing genetic risk associated with close relative unions.[76.0%; 4.5]

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

\* E2

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

Commissioners must recognise that the necessary enhancements to genetics services will require resources.[84.0%; 4.8]

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

\* E3

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

Enhancements to genetic services should be integral to the core service rather than a stand-alone project (so that knowledge is developed across staff members and sustainability is supported).[92.0%; 5.0]

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

\* E4

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

Enhancements to genetic services require specialist skills.[76.0%; 4.4]

**Cultural competence of services**

\* E5

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

All staff working in genetics services should understand the needs of the population and provide culturally and religiously competent, non-judgemental care.[100%; 5.4]

\* E6

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

Genetics services must effectively meet the needs of patients who wish to communicate in a language other than English via the provision of professional interpreters.[100%; 5.4]

\* E7

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

The ethnic diversity of genetics services staff should reflect that of the local population and efforts should be made to recruit and train people from minority ethnic backgrounds.[84.0%; 4.7]

\* E8

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

Bilingual practitioners should be recruited to work in genetics services and be able to use their language skills in consultations.[80.0%; 4.5]

\* E9

Very  
strongly disagree

Strongly disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly agree

Very  
strongly agree

Don't  
know

A range of informational resources should be available for patients in accessible formats and languages. [100%; 5.2]

\* E10

Very  
strongly disagree

Strongly disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly agree

Very  
strongly agree

Don't  
know

Service developments should be informed by diverse patient and public involvement e.g. via patient liaison groups. [96.0%; 5.2]

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

\* E11

Very  
strongly disagree

Strongly disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly agree

Very  
strongly agree

Don't  
know

Community-based genetic counsellor(s) working to support families through their journeys and linking primary care and specialist services with genetics services. [80.0%; 4.5]

\* E12

Very  
strongly disagree

Strongly disagree

Disagree

Neither  
agree  
nor  
disagree

Agree

Strongly agree

Very  
strongly agree

Don't  
know

Community-level outreach via satellite clinics e.g. at GP practices. [56.0%; 3.8]

\* 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. [44.0%; 3.7]

\* E14

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Self-referral into the service (particularly to a community-based outreach service as a first point of contact).[88.0%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* E15

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Provision for genetic counselling prior to marriage and prior to pregnancy for individuals in/considering a close relative marriage.[88.0%; 5.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* E16

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Telephone or face-to- face contact before first appointments to ensure understanding of purpose of, and what to expect at, the appointment.[64.0%; 4.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* E17

	Very strongly disagree	Strongly agree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Follow-up phone call or home visit, rather than automatic discharge, for patients who do not attend appointments. [92.0%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* E18

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Steps to ensure that the service only sees couples/patients who want to be referred as opposed to those being sent.[44.0%; 3.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Ensuring consistent practice once within the service**

\* E19

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

Families already known to the service should be given the contact details for a genetic counsellor in case of urgent prenatal enquiries. [92.0%; 5.0]

\* E20

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

When a child is diagnosed with a possible recessive disorder linked to consanguinity, an extended family genetic history should automatically be taken. [92.0%; 5.3]

\* E21

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

Where a condition has been identified in a family, adequate information about the health risks to offspring, benefits and limitations of testing, and the options after a positive result, should be clearly communicated to help couples make an informed decision about genetic testing. [100%; 5.4]

\* E22

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

A more proactive and supportive approach to cascading information and offering carrier testing among extended family members is needed. Provision of letters in English to pass on to family members is insufficient. [100%; 5.2]

\* E23

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

Continuity of contact with families must be ensured so that future pregnancies are fully supported with screening and sensitive presentation of the options. [100%; 5.0]

**Genetic technologies**

\* E24 Original statement slightly reworded to include "Subject to informed parental consent..."

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Subject to parental consent, 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. [72.0%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 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. [80.0%; 4.9]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 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. [80.0%; 5.0]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 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. [80.0%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



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### Section F - Raising Genetic Literacy

\* 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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**F - Raising Genetic Literacy**

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

**General approach within affected communities:**

\* F1

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

Action at community level should not be prioritised because it is costly and there is the possibility of stigmatisation and negative effects. [16.1%; 2.0]

\* F2

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

There should be well-designed community level activity to increase genetic literacy and awareness of genetic services and options among affected communities in a non-stigmatising way. [93.6%; 4.9]

\* F3

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

Community level information should not focus on consanguinity in isolation but rather include comprehensive information on pre-conception health. [93.6%; 4.8]

\* F4

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

Community level information-giving should include materials that are specific to the issue of consanguinity and genetic risk and address the concerns and questions raised by members of affected communities. [77.4%; 4.4]

\* F5

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

There should be nationwide consistency in communication tools, leaflets and patient information resources. [87.1%; 4.7]

\* F6

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

Activities and resources used at community level should be designed and delivered in partnership with voluntary groups, community organisations and local people (including those affected, and those not affected, by recessive disorders). [83.9%; 4.6]

\* F7

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

Patients with direct experience of genetic disorders should be involved in design and publicity of services as community champions. [90.3%; 4.6]

\* F8

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

Community leaders should be involved in the design of activities and resources to be delivered at community level. [71.0%; 4.0]

\* F9

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

Community leaders should be engaged in delivering consistent messages to community members. [61.3%; 3.6]

**Personnel**

\* F10

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

Dedicated community level workers should be recruited and trained to work on this issue within affected communities; they do not need to be qualified in genetic counselling but should attain competencies. [61.3%; 3.9]

\* F11

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

A wide range of generalist front-line workers should be trained to work on this issue within affected communities. [67.7%; 4.0]

**Content and media**

\* 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. [96.8%; 4.7]

\* F13

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

Opportunities for learning should recognise diversity within and between communities and be varied enough to meet the needs of different age, ethnic and socio-economic groups, and non-English speakers. [100%; 4.9]

\* 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. [74.2%; 4.5]

\* 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. [96.8%; 4.9]

\* 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. [64.5%; 4.1]

\* 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. [96.8%; 4.8]

\* 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. [77.4%; 4.3]	<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**

\* F19

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Schools-based work should be undertaken to increase general genetic literacy e.g. in PHSE lessons. [90.3%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* F20

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Wider networks should be harnessed to undertake nationally coordinated awareness raising initiatives. [74.2%; 4.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* F21

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Standardised web based resources for the general public should be available nationally. [77.4%; 4.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* F22

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Media coverage of the issue should be avoided due to high risk of negative representations and adverse consequences. [51.6%; 3.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* F23

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

Communications should involve wider audiences including schools and journalists to counter misconceptions and challenge unhelpful attitudes (e.g. that cousin marriage never occurs in White majority population). [80.7%; 4.2]

\* 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. [41.9%; 3.5]

\* F24a New Statement

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

Resources should be prioritised for genetic literacy work with at risk families who already have children with recessive disorders.

\* 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. [71.0%; 4.2]

\* 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. [93.6%; 4.8]

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



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### Section G - Primary Care

\* 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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**G - Primary Care**

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

\* G1

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

GPs already have a heavy workload and cannot be expected to contribute to this area of service delivery. [19.4%; 2.1]

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

\* G2

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

Primary care services including GPs and health visitors have a major role to play in improving genetic literacy and access to genetic services. [83.9%; 4.6]

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

\* G3

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

GP practices serving affected communities should host regular outreach sessions for genetic counselling. [51.6%; 3.7]

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

\* G4

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

General Practitioners should offer sensitive, non-judgmental information to related couples and those planning marriage to a relative. [93.6%; 4.7]

\* G5

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

General Practitioners should offer specific preconception care consultations. [54.8%; 3.9]

\* G6

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

General Practitioners should provide long-term family-based care to affected families to support the sharing of information and uptake of genetics services. [77.4%; 4.5]

\* G7

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

GPs should act as the coordinator of care for individuals living with recessive disorders and of support to their carers, ensuring signposting to relevant support agencies. [41.9%; 3.7]

\* G8

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

There should be an incentivised target for GPs to refer patients into genetics services. [35.5%; 3.1]

\* 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. [80.7%; 4.6]

\* 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. [54.8%; 3.9]

\* G11 *New Statement*

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

Within the existing GP contract, good practice in this area includes: basic genetic counselling, provision of accessible information resources and referral to genetic services.

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

\* 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



Round 3 Delphi Study: Responding to the increased genetic risk associated with customary consanguineous marriage: developing an expert consensus statement and principles for service design and delivery

**H- Referrals and Coordination Between Services**

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

\* H1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Significant effort is needed to address the large number of missed opportunities to refer people into genetics services from primary care, health visitors, secondary care and community contacts. [85.7%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* H2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
There is a need to develop and enforce simple, rapid, standardized pathways of referral, particularly across maternity; neonatology; paediatrics; and general practice. Flow charts should be developed for professionals and for patients. [92.9%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* H3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Formal referral to genetics services should be through GPs to ensure consistency and continuity of care. [17.9%; 2.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* H4

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

A range of healthcare professionals should be able to make referrals to genetics services to ensure good access and uptake. [92.9%; 4.6]

\* H5

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

Paediatricians should have a staff member who can take an extended family history and provide basic genetic counselling to family members. [67.9%; 4.3]

\* H5a *New Statement*

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

All specialties should have staff member(s) who can take an extended family history and provide basic genetic counselling to family members.

\* H6

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

Comprehensive provision of genetic information to families through Multi-Disciplinary Team clinics will improve health outcomes and provide a cost-effective genetic service. [60.7%; 4.3]

\* H7

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

Genetic counselling to individuals and families should be provided by qualified genetic counselling staff. Other healthcare professionals should refer patients to the genetics service rather than try to provide this information themselves. [60.7%; 4.0]

\* H8

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

There should be an intermediate genetic outreach counselling service to which GPs, health visitors and community level workers can refer (to assemble the information needed to support/reject a referral into the genetics service). [50.0%; 3.8]

\* 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. [71.4%; 4.3]

\* 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). [71.4%; 4.6]

\* 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. [89.3%; 5.0]

\* 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. [96.4%; 5.3]

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

\* 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



Round 3 Delphi Study: Responding to the increased genetic risk associated with customary consanguineous marriage: developing an expert consensus statement and principles for service design and delivery

**I - Monitoring and Evaluation of Service Developments**

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

General

\* I1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
A standard monitoring framework and set of measures should be developed and implemented routinely across all areas that are implementing service developments. [77.4%; 4.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I2 *Statement slightly reworded. Original wording "A local lead should be identified for monitoring and auditing work across all service developments in each area."*

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
There should be a designated local lead to coordinate monitoring and reporting across all service developments in each area. [80.6%; 4.2]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Monitoring and evaluation of services should be undertaken from an equity perspective, with measures routinely being examined by ethnicity. [74.2%; 4.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 14

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

Local audits should be carried out immediately to assess the current care of families already known to be living with recessive disorders linked to consanguinity and enhance support to these families within existing resources. [77.4%; 4.2]

\* 15

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

A consistent approach to maintaining local registers of cases with recessive genetic (or possibly genetic) disorders should be established. This should allow linkage across localities where other affected members of the same extended family may reside. [64.5%; 4.0]

\* 16

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

Work should be undertaken to ensure these local registers feed into a national database, and this may be achieved via the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). [67.7%; 4.1]

\* 17

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

Key indicators of success for this area of service development should relate to understandings of genetic risk and available options among affected families and communities. [96.8%; 4.7]

\* I8

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

Key indicators of success for service developments should relate to reductions in affected births (less genetic morbidity and mortality). [51.6; 3.5]

\* I9

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

Key indicators of success for service developments should relate to having an established enhanced genetics service with community outreach that is fully integrated into and supported by the core genetics offer. [74.2; 4.5]

\* I10

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

Monitoring and evaluation of service developments should include identification of harmful or unanticipated outcomes. [93.6%; 4.6]

\* I11

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

The sustainability of service investments over time should be monitored and reported on nationally. [80.6%; 4.5]

\* I12

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

All service developments should be evaluated. [87.1%; 4.8]

\* I13 *Slightly reworded. Original wording: 'All service developments should be monitored, but rigorous evaluative research can only be conducted with research grants and input from trained researchers.'* [61.3%; 3.9]

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
All service developments should be monitored, but rigorous evaluative research can only be conducted with input from trained researchers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I14

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Qualitative methods should routinely be used at community level to assess the acceptability of service developments. [83.9%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I15

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Qualitative methods should routinely be used at genetic services level to assess the experience of care and the acceptability of services to patients. [96.8%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I16

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
The degree of joined-up working across services and professionals should be monitored regularly and any lack of coordination identified and addressed. [80.6%; 4.4]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I17

	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). [61.3%; 4.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input 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:**

\* I18

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Number and sources of referrals to specialist genetic services (by ethnicity) [87.1%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I19

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Number and sources of consultations (take up of referral) with specialist genetic services (by ethnicity) [87.1%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Among patients accessing genetic services:**

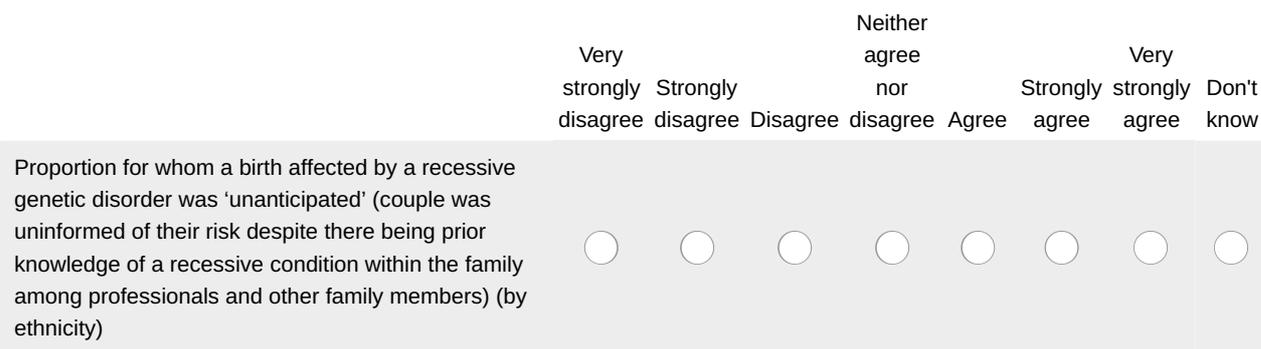
\* I20

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Proportion who report being able to make a well-informed reproductive decision (by ethnicity). [93.6%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I21

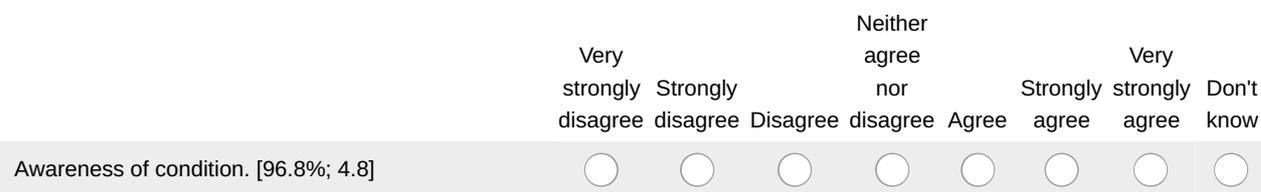
	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Proportion who report high satisfaction with service received (by ethnicity) [87.1%; 4.5]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I22 Statement slightly reworded. Original wording: 'Proportion for whom a birth affected by a recessive genetic disorder was 'unanticipated' (couple was uninformed despite prior knowledge existing)' [83.9%; 4.5]]

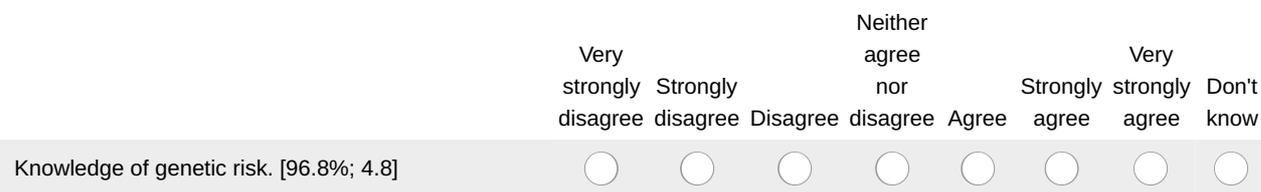


**Among extended family members where a recessive genetic (or probable genetic) condition identified in the family:**

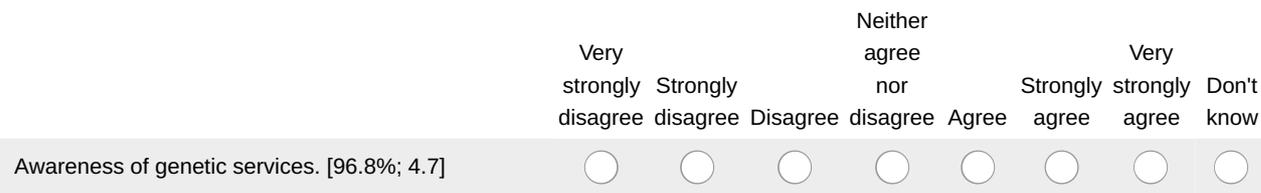
\* I23



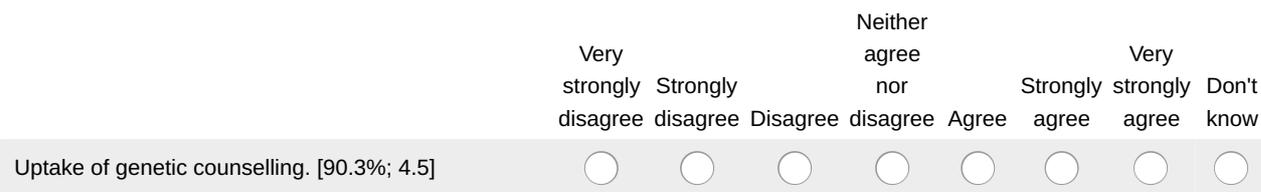
\* I24



\* I25



\* I26



\* I27

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Awareness of screening options available. [96.8%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I28

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Uptake of screening (where available). [80.6%; 4.5]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Within affected communities generally:**

\* I29

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Awareness of genetic services. [90.3%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I30

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Knowledge of genetic risks associated with consanguineous union. [90.3%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I31

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Confidence to discuss topic openly. [93.5%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**At the wider population level:**

\* I32

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Knowledge of genetic risks associated with consanguineous marriage. [74.2%; 4.2]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I33

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Incidence of births with congenital abnormality (by ethnic group). [67.7%; 4.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I34

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Infant mortality rate (by ethnic group) (should be available via Public Health England fingertips resource). [74.2%; 4.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I35

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Prevalence of children with complex disabilities (by ethnic group)(via Community Services Database). [67.7%; 4.1]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* 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). [71.0%; 4.2]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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



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## Section J - Research

\* 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



Round 3 Delphi Study: Responding to the increased genetic risk associated with customary consanguineous marriage: developing an expert consensus statement and principles for service design and delivery

J - Research

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

**General**

\* J1

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
There is a need for much more research in this area. [73.3%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J2

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
A review of current research evidence should be undertaken before any new studies are planned. [83.3%; 4.8]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J3

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Any future research should build on relevant work ongoing (e.g. Genetic Alliance toolkit on joined up working; Dor Yeshorim (Jewish Genetic Screening)). [80.0%; 4.7]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J4

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

Academics and practitioners working in this area in different parts of the country should collaborate in order to design a larger scale, more rigorous service evaluation. [86.7%; 4.9]

\* J5

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

Greater effort should be made to learn from other countries. [86.7%; 4.6]

\* J6

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

Research should re-focus away from consanguinity to endogamy-biraderi (in the case of the Kashmiri/Pakistani community) to understand genetic risk. [33.3%; 3.9]

\* J6a *New statement*

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

Research should include work to understand the genetic risk linked to endogamous marriage practices aside from close relative marriage (e.g. marrying within the biraderi - the extended kinship network - in the case of the Kashmiri/Pakistani community).

**Areas of research that should be prioritised are:**

\* 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. [90.0%; 4.6]

\* J8

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

Evaluation of healthcare professional training to assess impact on subsequent practice, including appropriate referrals into genetics services. [86.7%; 4.6]

\* J9

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

Relevance of the issue in different localities. [63.3%; 4.1]

\* J10

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

Evaluation of community genetic literacy initiatives to assess engagement of local people and impact on knowledge, behaviours and service access. [90.0%; 4.7]

\* J11

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

Experiences, acceptability and value of genetics services and the service journey from patient and family perspectives. [83.3%; 4.5]

\* J12

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

The process of genetic counselling. [63.3%; 4.2]

**(Continued) Areas for research that should be prioritised are:-**

\* J13

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Attitudes to and acceptability of preimplantation and prenatal diagnosis. [76.7%; 4.2]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J14

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Impact of incorporating consanguinity related genetic risk assessment into preconception health promotion. [86.7%; 4.3]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J15

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Social and emotional impact of genetic disorders in consanguineous families (across different ethnic groups). [83.3%; 4.5]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J16

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Barriers and facilitators to healthcare professionals discussing this topic with families and making appropriate referrals to genetics. [93.3%; 4.6]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J17

	Very strongly disagree	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Very strongly agree	Don't know
Assessment of the value of a standardized disease register as an audit tool. [60.0%; 4.0]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* J18

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

Development and evaluation of tools for family history taking in primary care and specialist services. [73.3%; 4.0]

\* J19

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

Development and evaluation of approaches/tools for assisting the sharing of genetic risk information within extended families. [86.7%; 4.5]

\* J20

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

Development and evaluation of tools for conveying genetic information in primary care and specialist services. [76.7%; 4.3]

\* J21

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

Evaluation of the community genetic counsellor role. [80.0%; 4.2]

\* J22

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

Evaluation of community-led initiatives and their impacts on families. [90.0%; 4.4]

\* J23

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

Development of measures and approaches to assessing informed choice in reproductive decision-making. [83.3%; 4.5]

\* J24

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

Economic analyses of costs of action versus inaction on this issue. [90.0%; 4.7]

\* J25

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

Social return on investment of the services provided. [66.7%; 4.3]

\* 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. [66.7%; 3.9]

\* 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. [80.0%; 4.5]

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



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### Submission page

Please confirm whether you are able to participate in the face-to-face meeting in Sheffield on 3rd July 2018, 11:00-15:00

- Yes, I am able to attend
- No, I am unable to attend

If you are ready to submit your responses please click below

- Submit responses